

**The relationship between art and wellbeing
in individuals living with dementia**

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Julie Gross McAdam MA

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Abstract

This thesis brings together existing and new research relating to the relationship between art, dementia and wellbeing. The thesis outlines the history of the rise of the non-pharmacological intervention movement over the last twenty years and profiles the work of influential figures who have promoted a person-centred approach to dementia care.

This thesis documents current literature on the relationship between art and dementia, details the observations of leading experts in the medical and recreation activity field, and then identifies the components that make up a dementia-specific art activity. Based on Tom Kitwood's (1937-1998) person-centred care and 'positive person' work tenets, the components of an art activity are separated and analysed and given a value. This process has resulted in an original holon of an art activity which identified eight wellbeing areas that the author believes can best be assessed during the art activity.

The other wellbeing data component of this research was conducted using one of the few dementia-specific assessment tools available - the Creative Expressive Ability Assessment (CEAA) tool - designed by Dr Dalia Gottlieb-Tanaka and Professor Peter Graf, of the University of British Columbia, and Hilary Lee, Western Australia.

The thesis research was conducted at a dementia-specific aged care facility in Melbourne Australia, where twelve participants living with dementia were observed working one-on-one with an art facilitator, on an art activity, that culminated in a communal permanent artwork. The research data was gathered in two parts: firstly, the results of the CEAA tool, independently scored by three different people, is juxtaposed with the holon research data; and secondly, a heuristic study in which the author observes the skills of participants and comments on her own approach, drawing on her professional

experience and practice. Finally, the heuristic study, combined with the other outcomes, is brought together and recommendations are advanced in order to assist art and recreation facilitators to plan future program design.

Student declaration

“I, Julie Gross McAdam, declare that the PhD thesis entitled, The relationship between art and wellbeing in individuals living with dementia is no more than 100,000 words in length including quotes and exclusive of tables, figures appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or part, for the award of any other degree or diploma. Except where otherwise indicated, this thesis is my own work”.

Julie Gross McAdam

05 April 2012

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In addition, the author wishes to extend special thanks to Anthony McAdam, Andrew McAdam, Luise Stewart, Dalia Gottlieb-Tanaka, Susannah Taylor, Colette Baya, Margaret Thorpe and the staff members at Nixon Hostel, and the professional librarians at Alzheimer's Australia, Victoria, and Melbourne and Victoria universities.

A note to the reader

A certain distance is important when writing a thesis in an area that has long been the sole domain of a particular healthcare approach and philosophy. As a consequence, this thesis is written in the third person. I have not ignored the personal and subjective considerations of an author, but I have restricted them to Chapter Ten, the heuristic study and parts of Chapter Eleven, the conclusion. Chapter Ten explores my lived experience of the art activity phenomenon and thus is written in the first person, as the subjective approach is, by definition, singularly appropriate.

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PART ONE

CHAPTER ONE

The Introduction

This research project is a phenomenological exploration of the lived experiences of a group of twelve individuals living with dementia in an aged care facility in Melbourne, Australia as they participate in an art activity. The overarching aim of this project is to examine and document ‘what’ each individual experienced during the art activity, and then assess ‘how’ each individual experienced that phenomenon.

What is phenomenology and why choose it as the methodological framework for this thesis?

There are many definitions of phenomenology in the literature - some seemingly inconsistent with others, and some rather obscure (Kockelmans, 1995).

The author has chosen to take the most straight forward and the most widely understood meaning of the term as the basis for proceeding, and by a process of distillation settle on a working definition that is both credible (by reference to its core meaning) and useful as the underlying methodological approach to this thesis.

The *Shorter Oxford Dictionary* (Oxford, 1973, p. 1569) calls it “the science of phenomena as distinct from that of being (ontology)”. An internet search provided the following definitions: *Merriam Webster* (2011) informs us that phenomenology is “the study of the development of human consciousness and self-awareness”. The *Free Dictionary* (2011) goes further: “A philosophy or method of enquiry based on the premise that reality consists of objects and events as they are perceived or understood in human consciousness”. Even

more useful for the purpose of this thesis is the definition provided by the *Stanford Encyclopaedia of Philosophy* (2011):

The discipline of phenomenology may be defined initially as the study of structures of experience, or consciousness. Literally, phenomenology is the study of 'phenomena'; the experience of things, or meanings as they appear in our experience, or the ways we experience things, thus the meanings things have in our experience. Phenomenology studies conscious experience as experienced from the subjective or first person point of view.

Creswell's *Qualitative Inquiry and Research Design: Five Qualitative Approaches to Inquiry* (2007) provides a clear guide as to how phenomenology can be applied in a research project. Drawing on the scholarship of van Manen (1990) and Moustakas (1994), Creswell sets out the following useful clarification:

Whereas a narrative study reports the life of a single individual, a phenomenological study describes the meaning for several individuals of their lived experience of a concept or phenomenon. Phenomenologists focus on describing what all participants have in common as they experience a phenomenon... The basic purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence... To this end, qualitative researchers identify a phenomenon... The enquirer then collects data from persons who have experienced the phenomenon, and develops a composite description of the essence of the experience for all of the individuals. This description consists of 'what' they experienced and 'how' they experienced it... (Creswell, 2007, pp. 57-58)

And, the 'experience' of phenomenon we are focussed on in this thesis is the art activity.

One interpretation of phenomenology, supplementary to the above definition, emphasises a distinctive human dimension of relevance to this thesis:

The aim is to study how human phenomena are experienced in consciousness, in cognitive and perceptual acts, as well as how they may be valued or appreciated aesthetically. Phenomenology seeks to understand how persons construct meaning and a key concept is intersubjectivity. Our experience of our world, upon which our thoughts about the world are based, is intersubjective because we experience the world through others. Whatever meaning we create has its roots in human actions and the totality of social artefacts and cultural objects grounded in human activity (Wilson, 2002, p. 1).

Any form of research into dementia presents a unique set of challenges and cultural considerations. One basic challenge involves a clear understanding of the terminology commonly used in healthcare workplaces. Schaef (1992, p. 205) believes the often specialized and inaccessible “language of science” has been one of “the traditional ways” by which an illusion of power and control has been maintained in the past. The author of this thesis believes that the progression over time of the concept of dementia, its evolution from being a “no hope incurable disease” to a treatable disability, might well benefit from the introduction of a new terminology beginning with the rehabilitation of some old words and the introduction of new ones into the best practice standards of what Goffman (1961) refers to as ‘total institutions’.

The approach of this research project, therefore, is to try to avoid being defined by institutional roles or relationships, or constrained by biomedical terminology or the design parameters set by an “old culture of care”. It is thus important to clearly define at the start the use of biomedical and other dementia-related terminology in the development of this thesis.

This introduction begins with an explanation of Weber’s “ideal types”, and is followed by a glossary of keywords accompanied by working definitions. This is

provided for the reader to better understand the terminology that is used throughout the text of this thesis so as to clarify the meaning of what is being discussed.

Weberian “ideal types”

Terms such as an “old culture of care”, coined by Tom Kitwood (1997), the umbrella term “dementia”, the generic term “biomedical model”, and biomedical terms such as “art therapy” and “art therapist”, and many others, are used throughout this thesis. Such terms often appear in the quotes from various authors, and each author speaks from his or her own unique experience. In this thesis, each author’s view is respected and understood in a “Weberian” sense, a reference to the work of the classical sociologist Max Weber (1864-1920), meaning that each author uses terms differently, but coherence is provided by the concept of “ideal types” (Weber 1968; Wilson 2002). In reality, institutions and individuals, including the authors quoted, often have different views and perspectives on the same phenomenon. It is the case that no use of a generic term has exactly the same meaning in all situations, given the multiple variables that pertain in any specific situation, or as applied by a particular scholar.

With reference to the specific focus of this thesis, the term ‘non-pharmacological’, as in ‘non-pharmacological intervention, shortened in the anagram ‘NPI’, refers immediately to what the words signify, the absence of drugs, but more generally it speaks to an approach in contra-distinction to the approach(es) favoured by the biomedical school of thought. In this thesis, primarily for the sake of clarity, continuity and consistency, I have chosen to use the term ‘non-pharmacological’, but I am persuaded by Susan McFadden in her examiner’s report (18 February, 2012) that a more even-handed and intellectually more logical term would be ‘psychosocial’. She also suggests that one could more reasonably call the pharmacological approach as ‘non-

psychosocial’. She argues: ‘I realise this would be a radical departure from convention but our continuing reference to engaging people with dementia with the arts as “non-pharmacological interventions” (NPI) implies that they are of lesser importance than giving people pills. I realise it’s become standard practice to refer to NPI, but to me, that privileges the biomedical approach...’

Glossary of keywords

Alzheimer’s disease: The most common form of dementia ‘discovered’ by Alois Alzheimer in 1908.

Art facilitator: The individual facilitating this research project’s art activity.

Art as therapy: The use of art in a general and non-specific therapeutic sense.

Arts and crafts: An arts movement inspired by William Morris in the 19th century (MacCarthy, 1994). In aged care, a term sometimes disparagingly used, by some aged care specialists, to describe art activities that fill resident’s time with ‘busy work’ (Patterson and Perlstein, 2011).

Biomedical model: A mechanical/reductionist approach to healthcare that tends to place the treatment of the disease, rather than the person, at the centre of the care equation.

Care partner/s: A dementia/disability term increasingly used to replace the term ‘caregivers’. They are individuals who share the care responsibilities of individuals living with dementia in, it is assumed, a reciprocal and equal way.

Clinification syndrome: A term coined by Pat Allen (1995) in the 1990s to describe the medicalization of art therapy.

Creative expressive arts therapies: A term used to describe a group of therapies that may include art, music, dance and movement, and poetry and reminiscence.

Creative Expressive Ability Assessment tool (CEAA): The quantitative research methodology used in this research project. (A detailed description is provided in Part Three).

Dementia: An umbrella term to describe the eighty or more diseases or syndromes that result in progressive cognitive impairment.

Holon: A term coined by Arthur Koestler (1969) to describe the joining of matrices to form a whole that results in a new concept.

Kitwoodian theory: The theoretical/philosophical ideas that underpin this research project, based on the dementia-specific writings and model of care designed by Thomas Kitwood (1937-1998).

Lived experience: What a person experiences during a phenomenon and how they experience that phenomenon.

Living with dementia: A dementia/disability term that has since the 1990s increasingly replaced the biomedical term “suffering from dementia”.

Matrix: A “scientific discipline, profession or craft, skill, or any activity governed by a recognised pattern of behaviour or thought” (Beveridge, 1980, p.2). Also a term used by Max van Manen in phenomenological research to describe the individual parts that make up a whole.

Matrices: More than one matrix, or individual part or element, that comprise this research project’s assessment tools and methodology.

Modern folk art: Community and communal artworks that visually record the lived experiences and stories of individual participants.

Non-pharmacological interventions: A term to describe a group of psychosocial non-drug interventions, such as art, music, dance, pet and horticultural therapy used in aged care to advance the quality of the lived experience of residents (the reader might be persuaded that this term is less accurate and intellectually logical than the term ‘non-psychosocial’, as suggested by Professor Susan McFadden (see above)).

Old culture of care: A term coined by Kitwood to describe a biomedical worldview and approach to dementia care.

Person-centred care and model: A model of care designed by Kitwood that places the person and their needs at the centre of the care equation.

Phenomenological study: “Describes the meaning for several individuals of their lived experience of a concept or a phenomenon” (Creswell, 2007, p. 57).

The scientific method: An empirical approach to research that is philosophically and operationally open to all avenues of investigation to achieve an objective.

Symbolic immortality: A term coined by Robert Jay Lifton (1971) to describe each human being's quest for eternal survival that is symbolically realised through artistic and other cultural works.

The Standards: The Australian Accreditation Grant Principles regulatory legislation (Commonwealth of Australia, 1999).

The introduction

In 1897, eight years before Alzheimer's disease was identified, Alois Alzheimer wrote, "excessive reservations and paralysing despondency have not helped the sciences to advance nor are they helping them to advance". At the very end of the 19th century Alzheimer put forward the proposition that any researcher with a positive and optimistic outlook is capable of "cheerfully searching for new ways to understand". He believed that research problems can best be understood when the researcher is "convinced that it will be possible" to find new ways to conquer them (Graeber, 2010, p. 7).

Speaking at a symposium on the advancement of understanding of dementia in July 2011, the Baroness Greenfield, Professor of Pharmacology at Oxford and one of the world's leading scientific experts in Alzheimer's disease research, made two simple but seminal recommendations. She said, "We must abandon the traditional dogma that there is only one approach [to dementia research]"; she then counselled delegates that "when at a crossroad, and you can take many paths, take them all" (Greenfield, 2011). The idea that Alzheimer's disease and other dementias can and should be understood in new and different ways is true to both traditional ideals of care and the spirit of the scientific method; it is also a very appropriate 21st century approach, and it is

this open-ended and arguably unconventional path that the author of this research project has chosen to take.

Dementia and the future of Australia

In the Intergenerational Report 2010, *Australia to 2050: Future challenges* (Commonwealth of Australia, 2010a), the Australian Government recognizes the importance of quality of life and individual wellbeing in the sustainability of the Australian nation's future.

Australians, particularly the baby boomers, generally defined as the generation born between 1946 and 1961, have a predicted life expectancy that is among the highest in the world (Australian Bureau of Statistics, 2009, p. 7). Many individuals in this cohort will live longer than any other generation in history, and one in nine is expected to live to be a centenarian. Within the next two decades, it is predicted that one in four baby boomers over eighty will develop some form of dementia, and half of the baby boomers, in their ninth and tenth decade of life, will end life living with dementia. The cost of maintaining the quality of life and individual wellbeing of this cohort will have a dramatic impact on the economy and the sustainability of Australia. And immigration will play an increasingly central role in the way this demographic conundrum is managed.

What is dementia?

In the *Clinical Descriptions and Diagnostic Guidelines* published in 1992, the World Health Organization (WHO) (1992) describes dementia as:

A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Consciousness is not clouded. Impairments of cognitive function are commonly

accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain (WHO, 1992, p. 45)

When determining a diagnosis of dementia, WHO (1992) suggests:

The primary requirement for diagnosis is evidence of decline in both memory and thinking which is sufficient to impair personal activities of daily living, as described above. The impairment to memory typically affects the registration, storage and retrieval of new information, but previously learned and familiar material may also be lost, particularly in the later stages. Dementia is more than dysamnesia: there is also impairment of thinking and reasoning capacity, and a reduction in the flow of ideas. The processing of incoming information is impaired, in that the individual finds it increasingly difficult to attend to more than one stimulus at a time, such as taking part in a conversation with several persons, and to shift the focus of attention from one topic to another. If dementia is the sole diagnosis, evidence of clear consciousness is required. However, a double diagnosis of delirium superimposed upon dementia is common. The above symptoms and impairments should have been evident *for at least 6 months* for a confident clinical diagnosis to be made (WHO, 1992, p. 46)

Dementia has many different forms and whilst a single cause is still unknown, and there are many similarities, the experience and progression of dementia is unique to each person. The most common and most well known dementia is Alzheimer's disease, which was first identified by Alois Alzheimer (1864-1915) in 1908. The second most common dementia is vascular dementia, which is usually caused by small strokes. Alzheimer's research assistant, Frederic Lewy (1885-1950), discovered the third most common form of dementia, known as "Lewy body dementia", in 1912. This dementia is not dissimilar to that experienced by some individuals living with Parkinson's disease. The Russian neuropathologist, Sergei Korsakov (1854-1900), identified another form of dementia caused by alcoholism and malnutrition, known as "Korsakov's syndrome", which may affect much younger individuals. Another relatively rare type of dementia, once known as "Pick's disease", but also now known as

either frontotemporal dementia or semantic dementia, has a special relevance to this research project. This form of dementia mainly affects the frontal and temporal lobes of the brain and is sometimes associated with an unexpected flowering of artistic talent in some individuals.

The importance of the development of dementia-specific stock resources

To return to the Intergenerational Report 2010 (Commonwealth of Australia, 2010a, p. 84), the authors write that “the wellbeing of a generation is determined by the ‘stock’ of resources that is inherited from previous generations and the choices that generation makes”. Given the projected future cost of dementia care in Australia, and the economies of developed nations, it stands to reason that the continuing improvement in the wellbeing and quality of life of the citizens cannot and should not be easily separated from the development of new and more humane approaches to dementia-specific aged care delivery. It has long been recognized that such developments have significant world health implications (Allen-Burge *et al.* 1998). It is also logical to suggest that the creation of a ‘stock’ of dementia-specific resources is in the long-term interests of the developed nations. Yet, the paucity of dementia-specific creative arts development and research means, that there are few if any ‘stock’ resources to call on. This circumstance presents fundamental challenges that regrettably continue to be largely ignored.

Dementia is set to become the biggest disability burden in Australia’s history by 2016 (Commonwealth of Australia, 2010b), and even though Alzheimer’s Australia has worked tirelessly to see dementia become recognized as a “national health priority”, the predicted impact of dementia is not mentioned once in the Intergenerational Report 2010, a report that purports to plan for the future health expenditure of the nation. Shortly after the publication of the report in May 2010, the Australian Government launched a major healthcare initiative. With no cure for dementia in sight, diabetes has instead,

it seems, become the Australian government's primary focus. This is presumably because, with appropriate treatment and lifestyle changes, most of those living with diabetes are able to manage their condition and, as a result, continue to be productive members of the workforce with benefits for the economy. In addition, federal funding for the dementia "national health priority" was scrapped in the 2011 budget. This evidence of the official avoidance of the huge impact of dementia in the near to medium term demonstrates that the creation and collection of a worthwhile dementia-specific stock resource, to encompass all aspects and approaches to dementia, is more critical than ever. When the big surge hits, and the now familiar term 'tsunami' has been used in this context, we will need all the resources we can muster.

The effects of the Australian aged care reforms of the late 1990s

More than a decade ago the architects of Australian aged care legislative reform made new laws to open the way for a more modern and up-to-date approach to aged care. They envisaged a qualitative move away from an institutional "old culture of care", i.e. the reality before the Cunningham Dax mental health reforms of the 1950s and 60s (at least in Victoria), which saw individuals living with dementia subjected to the full nightmare: variously housed with the criminally insane, treated as psychiatric patients, in pitiful conditions in locked wards of "lunatic" asylums, and/or subjected to harsh physical and chemical restraint and electroshock therapy.

The main tenet of the late 1990s aged care reforms was to provide equally for every elderly individual or person with a disability in Australia. It is based on the premise that those who require care can and will be assisted by the Commonwealth to make the transition from the community at large, irrespective of advanced age or personal circumstance, to a dignified life in government funded aged care.

2011 marks the year the first of the baby boomer generation turned sixty-five. This generation has a particularly significant role to play in Australia and in the world's future. Collectively, the baby boomers will consume more resources, demand more choice and will expect society to have a greater understanding and acceptance of what contributes to the quality of life of those living with dementia (Vann, 2010). And, if dementia is not adequately addressed, the baby boomer generation is likely to ensure that their plight will become a significant human rights issue (Zeisel, 2010). Although it may not yet be fully recognized, both the identification and the creation of choice in care options - including the use of creative arts to enhance the wellbeing and the quality of life for the baby boomer generation - will become increasingly obvious and even expected.

The purpose of this research project then is to begin to build a "stock" of resources for the nation by way of a modest study, based on extensive empirical evidence, into the relationship between art and wellbeing and dementia. There are many obstacles to overcome when tackling these issues, not least the way that the creative arts have traditionally been contrasted, and not always respectfully, with scientific inquiry.

The role and use of art in human history

Ellen Dissanayake (1988, p. ix) writes on the origins and the role and use of art in human history. In the preface of her influential book, *What Is Art For?*, Dissanayake sets out to untangle what she refers to as the "behaviour of art" to see what makes art "special". Her book examines what she describes as the "filaments and skeins" that she believes are "interlaced in different combinations to make cables and braids that then combine into more complex behaviour such as those that make up the arts" (Dissanayake, 1988, pp. 111-112). She believes that human survival in the past depended on the distinct combinations of different filaments. Further, she believes these combinations

of filaments had a way of “making special” the songs and poems and paintings created by humans. Dissanayake puts forward the premise that literacy, and the urbanization of people in today’s modern world, has led us to “forget” the primary significance of art and its role in our evolution and survival as a species.

In relation to art and how scientists evaluate art-based research today, Dissanayake (1998) makes the following observation:

Writers on the subject of the relationship of art to life, of its value to human beings, are usually literary persons not scientists. There seems to be something about art - its indefiniteness, its multiformity, its intimations of transcendence - that makes the scientist feel that his methods and tools are inadequate for understanding it, just as there is something in science -its rigor, its tendency for mechanical reductionism - that makes the artist or lover of art suspicious of its pronouncements concerning anything in the realms of the ‘spirit’. Art is usually contrasted with science; the twain are most often considered intrinsically incompatible (Dissanayake, 1988, p. ix).

Building a bridge between art-based research and scientific enquiry

McNiff (2009) persuasively argues that a bridge between art and scientific enquiry exists and that one of the purposes of any art-based research project is to produce an outcome that draws a closer connection between the two. Drawing on the guidance and recommendation of Cambridge Professor of Zoology, W.I.B Beveridge (1908-2006), and his books, *The Art of Scientific Investigation* (1957) and *The Seeds of Discovery* (1980), McNiff (2009) agrees with Beveridge’s recommendations that the best way to achieve a closer connection, when contemplating any research topic, is to adopt the traditional “scientific method” and then apply it to each particular and unique set of circumstances, in this case using art as an approach. This particular research project has its own challenges, not least because it examines a traditional biomedical research area, namely those individuals living with dementia.

The inherent difficulty of conducting dementia-specific research

It is acknowledged that until the recent introduction of specifically designed research instruments and assessment tools it has been extremely difficult to conduct creative expression research with individuals living with dementia (Zwarenstein et al. 2007; Boutron et al. 2008). In 2004, Dalia Gottlieb-Tanaka, co-author of one of the first dementia-specific creative expressive research tools, wrote:

Exploring the connection between creativity and dementia is a difficult task, especially in the absence of much current literature . . . To some, creativity represents wellness, potential, innovation, and motivation, while dementia represents illness and a decline in all functions over time. As a result, creativity or creative expression has not been encouraged among the elderly especially among seniors with dementia . . . [and] the environment is crucial in stimulating creativity. (Gottlieb-Tanaka, 2004, p. 10).

It can be argued, acknowledging that creative expression has not been encouraged among the elderly in the past, that this is largely due to a biomedical, mechanical and reductionist approach to aged care. Shaef (1992, p. 207) writes that “dualism [the body mind split] is at the very core of the modernist worldview” and a reductionist approach to research and science presupposes that, “the analysis of the parts is sufficient for understanding and understanding is all that is necessary for healing”. This approach leaves out the impact that psychological wellbeing has on health. Shaef (1992, p. 217) points out that “the science of psychology has clearly accepted the concept of reductionism” and has tried very hard to be “accepted among the sciences”. As a result, the approach to science favoured by the biomedical establishment “will only accept a reality that can be proven empirically” and, like Engel (1977 & 1997) before her, Shaef (1992, p. 214) believes that some psychologists “deny and ignore any information that does not match that scientific paradigm”. More generally, she believes from this “mechanist science has

spawned a political and economic system that is based on the illusion of control”.

It is reasonable to argue that a mechanical-reductionist approach to aged care has failed in the past to present creative opportunities to those living with dementia, and an inappropriate economic rationalism has too often been used as an excuse to limit funding for such projects. Two other main obstacles exist and have limited the progression of the creative arts in dementia-specific care. These obstacles are, firstly, the issue of obtaining informed consent and, secondly, the difficulty of eliciting responses from individuals who live with progressive memory loss. But, just because such obstacles exist does not alter the fact that the serious question of how society is to humanely care for the millions of individuals globally who will develop dementia over the next four decades still has to be addressed. The challenge is all the greater given that there is no cure and the cost of each individual’s care is considerable.

Gottlieb-Tanaka (2004, p. 11) has asserted, the benefits of a proactive response: “an understanding of the interplay between the cognitive and physical abilities of a person with dementia, and the need for creative expression activities and a therapeutic environment, can make a difference in [wellbeing and] quality of life”.

The Australian government, to its credit, has drawn a link between quality of life and wellbeing and economic sustainability by indicating that the development of a ‘stock’ of resources is essential to address the issue of Australia’s future disability burden.

How art is usually contrasted with science

To return to Dissanayake’s point - the way in which art is usually contrasted with science. A Dutch study (Verkaik *et al.* 2005) perfectly illustrates that, in

the lucrative world of pharmacological medical research, with its emphasis on finding a “cure”, many scientific reviewers continue to undervalue the findings of studies which focus on creative art and other non-pharmacological interventions (NPI), as they relate to dementia. The most common criticism of art-based research is its performance criteria and reviewers tend to take issue with the research methodology used claiming it does not “measure up” scientifically. As a result, reviewers tend to favour studies that they consider (often erroneously) to be more in line with the “core principles” of scientific research; this usually means studies that contain randomized controlled trials and apply Cochrane’s “gold standard” research performance criteria. Richard Bentall, Professor of Clinical Psychology at the University of Bangor in Wales, comments on this tendency, some would say orthodoxy, when he suggests that oftentimes the “way that evidence has been interpreted has been affected by psychiatrist’s [and some biomedical researcher’s] adherence to an outdated way of thinking about the problems of their patients” (Bentall, 2009, p. 189).

By applying outdated thinking and/or inappropriate criteria, some biomedical researchers are in danger of losing sight of what constitutes the essence of traditional scientific research. The “core principles” of the much-hallowed “scientific method” are, after all, to remain open to the truth no matter from which quarter it comes. A “core principle” of scientific research is the related injunction not to close off avenues to new discovery and knowledge. If one applies this tried and true research precept, widely also considered the core value of the Enlightenment tradition, it stands to reason, on the cusp of one of the biggest healthcare challenge the world has ever seen, that the *a priori* dismissal of research into the arts and other NPI in this context is in itself “unscientific”. And, if ever a true understanding of the concept and principles of the “scientific method” were needed it is now, and particularly in response to the challenge posed by the growing dementia epidemic.

What is the “scientific method”?

Beveridge (1957) devotes chapter four of *The Art of Scientific Investigation* to a detailed explanation of the “scientific method”. He describes it simply as “the procedures and mental processes used by scientists to advance knowledge” (Beveridge, 1957, p. 55). Further, he explains that researchers following the “scientific method” should begin the process with a considered recognition and formulation of a problem. This is followed by the collection of relevant data until the researchers arrive, through induction, at a hypothesis that indicates causal relationships or significant data patterns. *The Concise Oxford Dictionary* (1976, p. 550) defines induction, in its mathematical sense, as meaning: proving truth of the theorem by (1). If true of any particular case, it is true of the next case in the series. Beveridge recommends that researchers then test the correctness of the hypothesis and only then make deductions about the hypothesis by collecting more data. Finally, it is advisable, Beveridge states, to check to see if the results from the data are consistent with the deductions and, if this strengthens the hypothesis all well and good, but it does not necessarily prove it.

Beveridge (1980) contends that good researchers require several attributes. He says research begins with “intellectual curiosity”. As for ambition, he prefers it be driven by a “desire to serve mankind”. Researchers, he maintains, if they are to perform at optimum level must develop a strong and independent mind, have tremendous enthusiasm and emotional commitment and, not least, a considerable capacity for hard work (Beveridge, 1980, pp. 103-105).

These traits are particularly necessary when embarking on a subject of investigation that traditionally has been the hallowed domain of a limited and self-referential healthcare culture. The theoretical base of this research project is person-centred and Kitwoodian (i.e. inspired by the intellectual

contribution of Tom Kitwood 1937-1998). This thesis is necessarily written from an Australian healthcare perspective, the research having been conducted in Australia and within the regulations and guidelines of Australian aged care legislation. Reference is made to international practices and perspectives, and their application to Australia where relevant, because certain individuals, particularly from North America and Britain, have been the most effective drivers of the worldwide movement for the introduction of NPI and for a more humane and person-centred approach to dementia care.

An outline of the author's distinctive perspective

As previously stated, this thesis is written from a Kitwoodian, person-centred, theoretical viewpoint that encompasses the author's long-held philosophical beliefs. The author advocates the "deconstruction of dementia as a medical problem" (Bernfeld & Fitsch, 2006, p. 8), and the movement toward an appreciation of the concept of dementia as a treatable disability, including the implementation of basic human rights that allows every individual living with dementia to live a creative, full and productive life. This philosophical approach promotes the humanistic notion that it is indeed possible, particularly in western liberal democracies, to provide humane, person-centred care for all in need. On the assumption that a more equitable and efficacious balance between pharmacological and other non-pharmacological treatments and therapies can best serve the interests of those living in care, the author, over the past decade, worked to foster the introduction of creative arts programming in conjunction with traditional 'best practice' nursing care. This approach is still in its infancy in many parts of the developed world, including Australia, but it is gaining momentum. The author offers the following dementia/disability framework to further the effort to deconstruct dementia as solely a medical problem.

A framework to deconstruct a medical “problem”: A dementia/disability model pointing toward a new direction

One of John Zeisel’s most important contributions to dementia care was when he began the process of reshaping societal attitudes to dementia in the 1990s. More recently, Zeisel (2010), like others who share this view (Basting, 2009), have moved toward positioning dementia within a new disability framework. The concept of viewing dementia as a disability is something that Tom Kitwood was passionate about. As Kitwood (1997, p. 136) wrote, dementia “should be seen primarily, as a [form] of disability” and that concept is now finally, gaining greater recognition. To progress this concept even further, it may be useful to begin by examining the World Health Organization (WHO) model. This will be followed by an outline of the traditional biomedical model of dementia, that can be compared with the Zeisel dementia/disability model. At that point we can proceed towards the construction of a new and more progressive dementia/disability approach that incorporates best practice across all areas of healthcare.

The World Health Organization disability model

WHO (2011) describes disability as an:

Umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives (WHO, 2011)

A disability can be physical, intellectual, emotional or sensory impairment involving sight or hearing. A disability results from impairment and the functional limitations and consequences that the impairment presents.

Impairment is a medical condition and is an abnormality or loss of function that occurs when there is something wrong with a person’s body and how it works. It is the way in which impairment affects what a person can do that determines each person’s level of disability.

In the past, community attitudes toward the disabled were largely based on fear, ignorance and misconception. Until recently, society or societies used “senile” to label individuals living with dementia, and the terms “handicapped” or “spastic” were commonly used to describe the physically disabled. The WHO disability model below defines “handicap” as a result of a social consequence. A handicap occurs when social or environmental barriers are created that prevent individuals reaching their full potential, and when disadvantages are experienced as a result of these impairments and disabilities.

In the following tables the term primary, secondary and tertiary are used to describe the progression of dementia according to the WHO and biomedical dementia models. In a new dementia as disability model, as set out by John Zeisel below, his use of these terms is different. Primary relates to the “symptoms” of Alzheimer’s disease, secondary relates to behaviour, and tertiary relates to “symptoms” that are not so much side effects as reactions when an individual finds he or she is not able to handle what is happening.

THE WHO DISABILITY MODEL

PRIMARY	SECONDARY	TERTIARY
<p>A disability may be physical or intellectual or emotional or sensory</p> <p>An individual may experience a combination of one or more disabilities</p>	<p>A disability is a medical condition that affects the way an individual functions. This results in functional loss and impairment</p>	<p>The individual is not held responsible for the impairment because society accepts its responsibility to adjust conditions to include the individual and his or her disability</p>

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THE BIOMEDICAL DEMENTIA MODEL

PRIMARY	SECONDARY	TERTIARY
Dementia is an incurable medical condition that is best treated with medication	Brain damage causes functional loss that may affect an individual in many ways Psychological “symptoms” such as agitation, anger, anxiety and aggression may be present. These “symptoms” create behaviour that is of “concern” to staff and carers	The general implication is the individual is somehow responsible for the “behaviour” associated with dementia To help society and the individual handle the psychological “symptoms”, the individual is best treated with pharmacological interventions including psychotropic medications

The Zeisel dementia/disability model

As mentioned, since the 1990s Zeisel (Raia & Zeisel, 2000) has campaigned for the redefinition of dementia and for new terminology that steers away from viewing dementia in strict biomedical terms, i.e. the idea that the “patient’s suffering” stems from an “incurable and hopeless” terminal disease that manifests itself in a set of so called “behavioural symptoms”. In his book *I’m Still Here*, Zeisel (2009) comments that “in recent decades, mental illness, schizophrenia, manic depression [sic], multiple sclerosis and many cancers have made the shift to being treatable even though still incurable”. He argues that limited thinking has condemned “tens of millions” of people with dementia

around the world to a “limbo in which they are merely waiting to die”. Zeisel thinks a new paradigm that places dementia “squarely in the realm of an understandable and manageable condition” will see dementia evolve into what might be seen as a treatable disability (Zeisel, 2009, pp. 41-42).

The chapter, “The Alzheimer’s journey” (Zeisel, 2009, pp. 23-48), makes it possible to draw links between dementia and the WHO disability model. These links lay the foundation stones on which to build a new and workable dementia/disability framework.

Zeisel (2009) points out the primary “symptoms” of Alzheimer’s disease are caused by “damage to the orbitofrontal cortex and to the thalamus and hippocampus”. This results in some individuals having “difficulty dealing with complex environmental conditions and controlling their impulses”. In short, “damage to the brain is the physical manifestation of the disease. Loss of control is a primary symptom”. Secondary “behaviours” result from “difficulty accessing memory” and “organizing complex sequences of activities”. These are followed by so-called “symptoms that are not symptoms at all”, but tertiary side effects and reactions when individuals are “not able to handle what is happening” to him or her (Zeisel, 2009, p. 35).

Zeisel (2009) is convinced that “correctly defining and distinguishing” between the primary, secondary and tertiary “symptoms” of dementia will enable care partners “to treat the disease and the actual symptoms more appropriately”. He thinks a “coordinated treatment approach” that includes recognizing, reducing and alleviating “symptoms” and improving conditions “plays a major part in treatment in both dictionary and common parlance”, and that treatment for those living with dementia must “always include more than drugs” (Zeisel, 2009, p. 36). He believes “changes in behaviour and lifestyle that reduce symptoms are also treatments... [and] a mix of NPI along with

pharmacological treatments seems to be the most effective in treating Alzheimer’s disease” (Zeisel, 2009, p. 46).

THE ZEISEL DEMENTIA/DISABILTY MODEL

PRIMARY	SECONDARY	TERTIARY
Dementia is a disability caused by brain damage.	<p>The disability results in functional loss of control of impulses and difficulty dealing with complex emotional conditions</p> <p>When individuals cannot access memory or organize complex sequences of activities properly, psychological responses may occur</p>	Society can recognize, reduce and alleviate the psychological responses associated with this disability by implementing a coordinated treatment approach that includes both medical and non-pharmacological treatments.

The Gross McAdam dementia/disability model

Positioning dementia within a disability model is one way of creating a person-centred dementia/disability model that extends the boundary of humane care. If an individual’s needs are seen in a new and different perspective, i.e. as the tertiary side effects of a treatable disability called dementia, and the individual is placed at the centre of the care equation, then a shift in emphasis away from safely treating the “symptoms” of the physical body toward finding ways to meet the psychosocial needs of a whole albeit disabled person is possible. Such a shift would at least begin the change of traditional attitudes and thinking. And, although evolutionary change will be slow, and continue to be hindered by the legacy of an entrenched “old culture of care”, this shift has

the real potential to lead to an enhanced quality of life for individuals living with dementia.

THE GROSS MCADAM DEMENTIA/DISABILITY MODEL

PRIMARY	SECONDARY	TERTARY
Dementia is a treatable if incurable disability	The disability causes brain damage and a loss of access to memory and functional control. The ability to organize activity in sequence is lost	Society can respond by recognizing that individuals living with dementia progressively lose access to their memory and the ability to organize activity in sequence Society can reduce and/or alleviate the side effects of the disability by implementing a coordinated treatment approach that includes both medical and non-pharmacological treatments

Research terminology

There are some terms where a more specific explanation is required that is more than can be supplied in a glossary of keywords. The terms therapy and therapist are two of them.

What is therapy and what is a therapist?

Downs, Clare and Mackenzie’s (2006) essay illustrates the differences between different models of healthcare. The authors make the argument that the

biomedical approach to dementia represents only one approach to care. Interestingly, and somewhat curiously, alternate models of care appear to continue to be defined by biomedical terminology. The words “therapy” and “therapist”, for example, are both biomedical terms. *The Shorter Oxford Dictionary* (1973, p. 2281) describes therapy as: “the medical treatment of a disease; curative medical treatment”. Therapeutic is described as “1. That branch of medicine, which is concerned with the remedial treatment of disease; the art of healing. 2. A curative agent”, and the therapist is described as “one skilled in therapeutics; a physician”.

Unfortunately, some members of a multidisciplinary team will continue to see the role of the “therapist”, and the use of art, merely as a “clinical instrument” and little more than an optional adjunct to medical treatments (Woodhams, 1995). Woodhams (1995) explains this in context, by outlining the role and position of art in healthcare settings in 1990s. She writes that art as therapy

Is almost invariably understood instrumentally i.e. as an adjunct to a medical curing process. Thus art is understood as ‘art therapy’ and the artist who works in such settings are therefore ‘art therapists’ whose function is to elicit and interpret works produced by patients to accord with a treatment or a therapy program. Another common misunderstanding is that art is ‘a diversion to alleviate boredom and to keep people occupied’. The artist is then termed a ‘diversional therapist’ and their work is another form of therapy - diversional therapy. While there are many approaches to both art therapy and diversional therapy, both are grounded in a professional relationship between a therapist and a person who is defined in relation to that medical relationship as a patient or client [or aged care resident](Woodhams, 1995, p. 5).

Mary Rockwood Lane has been a long-time advocate for nursing care and art programming in healthcare settings (Rockwood Lane & Graham-Poole, 1994). Speaking from her vast experience she outlines the valuable role that nurses often play as “agents of creative change” in healthcare settings. Rockwood Lane (2005) writes that nurses often act as “the essential doorway, the guide

who, even more than the artist, invites the patient to make art”, and that is why “the creative arts have been so successful in hospitals” that embrace a holistic approach to healing (Rockwood Lane, 2005, p. 125).

In order to further Kitwoodian theory, and contribute to new knowledge, this research project has been linked to the “Lifestyle” regulations of Australian accreditation legislation (Commonwealth of Australia 1998).

The legislators implicitly recognize that human beings, at any age, are social beings who require meaningful activities to maintain wellbeing; the regulations, however, particularly Lifestyle Standard 3.4-3.9, do not require lifestyle recreation activities, such as art, to show evidence of ongoing improvement to health and wellbeing. The only legislative requirement is that a variety of activities must exist and be made available to residents in residential aged care, and each resident has the right to exercise choice and self-determination in deciding whether to participate. The legislators recognize that many elderly individuals, particularly in dementia-specific aged care, may need to be assisted and helped in this endeavour by a facilitator.

The author of this thesis believes dementia should be addressed from a ‘dementia as treatable disability’ perspective. The introduction of terminology that moves away from labels such as “diversional therapist”, for example, toward a more person-centred term such as “art facilitator” is arguably the key to the introduction of an important shift in cultural thinking.

On the subject of terminology, Basting (2009) reports that Luther Manor in Milwaukee has taken a person-centred initiative by choosing to reject terms such as “nursing assistant”, in favour of broader definitions that more clearly define healthcare workers and their jobs to reflect the “befriending” nature of the facility’s care goals. To institute positive change, Luther Manor has rewritten its job descriptions and titles, using new terms such as “person-

centred care specialist” to recognize and value the work of healthcare workers designated for such tasks. This is a move away from seeing therapy and therapists and healthcare workers merely as an adjunct to nursing and the “medical curing process”; a process that Woodhams (1995) convincingly argues can be shown to subsume groups of healthcare professionals who arguably have a role just as important, albeit a different one, to that of nurses.

What is facilitation in the context of this research project?

According to *The Shorter Oxford Dictionary* (Oxford, 1973, p. 717), the word “facilitation” is defined as “the action, process or result of facilitating” and “facilitate” means “to render easier, to promote, help forward. To lessen the labour of, [and] assist (a person)”. The term “art facilitator” is used in this research project, as it is the most appropriate term to use in a research project that aims to reflect a ‘dementia as treatable disability’ perspective, in line with the principles of a Kitwoodian person-centred approach and those informing Australian legislation.

This project is not a biomedical research project. Peter Whitehouse, Professor of Neuroscience at Case Western University in the United States, speaking at the *Creative Expression and Dementia Care: Moving Forward in Research* conference in Wisconsin in 2006, is quoted as saying we “need to deconstruct dementia as a medical problem... [and] as of today, [NPI] are the only thing that we know to be effective in meeting the needs of people with Alzheimer’s disease” (Bernfeld & Fristch, 2006, pp, 8-9). The opinion of the conference delegates was unanimous in support of the conference declaration on the core principles of dementia-specific person-centred care.

The principles (as set out in the conference summary) are: firstly, “the specific and individual needs of the person with dementia [should] guide care”. And, secondly, the “ease and efficiency of the care providers or institutions” must

always be secondary to the first and primary principle. The delegates agreed that the structure of creative expressive programs must view the person with dementia as “having a singular dignity” and to achieve a person-centred approach the dignity of the individual above all must be respected. They draw the conclusion that creative expression and a person-centred approach to care naturally go hand in hand because “each concept complements the other”. Together, the conference delegates concluded the declaration by adding the sentence, “person-centred care is at the heart of the cultural change movement” (Bernfeld & Fristch, 2006, p. 12). The delegates acknowledged there are many obstacles that stand in the way of “deconstructing dementia as a medical problem” and that reviewer’s insistence on randomised controlled trials (RCT), as the only way to validate the effectiveness of the creative arts in dementia care, is one of them.

Obstacles that stand in the way of the effective application of a “gold standard” RCT methodology in disability/dementia-specific research

Boutron *et al.* (2008) list the obstacles, what they describe as “specific issues”, that stand in the way of the effective application of RCT to NPI. The list is impressive, but the research projects they cite mostly explore research conducted with able-bodied participants. In late March 2011, John Zeisel, and a group of the some of the world’s leading exponents of a person-centred approach to dementia care, prepared an open letter to US policymakers. The group spoke of the huge cache of evidence-based knowledge demonstrating how the creative arts improve the quality of life of individuals living with dementia and their care partners. They pointed out that policymakers and researchers discount much of the existing research into NPI, primarily because it does not fit a particular research model. Alas, many researchers are convinced that the only evidence worth considering is generated by the Cochrane “gold standard” of research and found only in double-blind RCTs.

There is no doubt that RCTs have an important place in healthcare research, but they represent only one way to generate knowledge. Other methodologies can and do contribute substantially to our knowledge of the effectiveness of the creative arts in dementia-specific care, and it makes little sense for policymakers to continue to discount, or even discredit, such a large body of knowledge. After all, this knowledge, when combined with a person-centred approach, has the potential to significantly alter healthcare priorities and budget projections and, in the process, bring about cultural change for the betterment of millions of individuals worldwide.

There are, of course, many ways to approach healthcare research methodology and it is important to assess all the resulting data in order to calculate the impact that such findings have on the quality of life of individuals living in care. Zeisel and his colleagues put forward the following suggestions that begin by outlining some of the RCT “gold standard” assumptions.

RCT assumptions

The group contends that journal article reviewers and grant application administrators and the like apply the RCT “gold standard” to NPI because they assume that, no matter what the research question, RCT offers the highest level of proof. The group believe that many reviewers rely on statistical significance as a measure of the efficacy of any findings, because RCT are at the top of a hierarchy of methods and that other methodologies are logically “lower” on the continuum. Reviewers often fail to take into consideration the appropriateness of the research methods, and automatically assume the outcomes are less reliable when researchers use methods other than RCT.

An alternative “gold standard” for research into NPI calls for the application of no single continuum of methodology and no absolute hierarchy to determine the best research methodology. Rather, the methodology that best fits the research question should be logically recognized as the most appropriate

methodology. Further, an important addition to any statistically significant finding should be an appreciation of the “meaningful” effect the intervention has on the participant.

An explanation of the phenomenological approach to this research project.

This research study has been conducted employing a phenomenological methodological approach.

As stated Creswell (2007 pp. 57-58) is another authority who describes a phenomenological study as something that documents the “meaning for several individuals of their lived experience of a concept or a phenomenon” and one they all have in common. He says that after identifying the phenomenon, a qualitative researcher “collects data from persons who have experienced the phenomenon and develops a composite description of the essence of the experience for all the individuals”. This description consists of ‘what’ the individual has experienced and ‘how’ they have experienced it; the researcher then is in a position to reduce the individual experiences into what phenomenological researchers describe as a “universal essence”.

In academic research circles, the Canadian Max van Manen is widely recognised as a leader in the area of phenomenological research. In his writings van Manen places an emphasis on practical applications or the ‘doing’ of the research, and encourages researchers to use clear everyday language and straight-forward logic when discussing approaches to phenomenology. He refers to the researcher’s role when questioning lived experiences as having a ‘phenomenological conversation’ in an effort to see and gain deeper understanding. He regards such conversations and interpretations of the lived experience as “interpreting the texts of life” (1990, p. 177). He writes that exploring and grasping for “the very nature of the thing” results in a “universal essence” of each person’s experience (van Manen, 1990, p.4).

Writing in his seminal work, *Researching lived experiences: Human science for an action sensitive pedagogy* (1990), van Manen lays out six research activities that together form a basic methodological research structure. He recommends that each researcher begin by choosing a subject that interests and inspires. The researcher is then instructed not to conceptualise the subject but instead he or she is encouraged to investigate and consider the many parts that form the whole of the participant's lived experience. A strong relationship to the research material is achieved when the researcher writes, then considers and questions each part, and then, rewrites the lived phenomenon by taking in all parts of the whole.

In the book, van Manen demonstrates this method when he describes how he questions his own relationship with a wide range of subjects including the use of modern technology. He does this by separating and grouping information and experiences into what he calls individual 'matrices'. For van Manen the term matrix represents a useful way of grouping and balancing information making it easier to perceive a connection or an analogy between different fields of experience. W.I.B Beveridge (1980) defines a 'matrix' as a "scientific discipline, profession or craft, skill, or any activity governed by a recognised pattern of behaviour or thought". Like van Manen, Beveridge writes that when researchers perceive a connection between different matrices, and integrate previously separate pieces of information together, one opens the possibility to a "harmonious juxtaposition or a scientific insight", and when applied to a phenomenological research problem can result in a significantly greater understanding of the phenomenon under investigation (Beveridge, 1980, p. 2).

Following van Manen's lead, this thesis is written in plain everyday language and is the result of a practical examination and exploration of the experiences of individuals living with dementia in an aged care facility as they participate in an art activity. For simplicity's sake, and for want of a better term, the term 'matrix' is used throughout this phenomenological study to describe the

research tools and different elements of the art activity that make up the research methodology. The marriage of more than one matrix results in the creation of a 'holon', a research term that originated in the late 1960s.

The 'holon'

In the *Principles and Practice of Expressive Arts Therapies: Toward a Therapeutic Aesthetic*, Levine maintains that "phenomenology originated as a proposed solution to the problems created by Cartesian dualism" (Knill, Levine & Levine, 2005 p. 21). Beveridge (1980) explains that in 1969 Arthur Koestler (1905-1983) - the distinguished novelist, autobiographer and, in his later years, a daring if controversial philosopher of science - published the proceedings of a symposium to explore the problems of Cartesian dualism held the year before in Austria. The symposium, attended by a group of distinguished scientists and writers, addressed the challenge of creating harmony between reductionism and holism (Koestler, 1969). Beveridge (1980) further explains that Koestler, a keen student of the philosophy of the scientific method, came to the conclusion that joining individual and independent units together, using a traditional scientific approach to form matrices, each having different and individual parts, could result in a harmonizing "holon" of all the parts.

The origin of the term 'holon' can be traced back to the 1920s, and springs from political ideas of the South African statesman/philosopher Jan Christian Smuts in his book *Holism and Evolution* (Smuts, 1925). De Stefano (2006) details the influence that Smuts had on both political thought and healthcare and it is he who informs us that Smuts coined the term "holism". De Stefano goes on to describe how Smuts developed this term "through his exploration of 'wholes'". De Stefano believes that "Smuts offered a broader and more comprehensive perspective on the nature of reality than that provided by reductionist science" (De Stefano, 2006, p. xvii). Over the past century and after many digressions, the concept of holism is now applied and used liberally by the healthcare industry, and a clear line can be drawn between Smut's ideas

to phenomenological research methodology and to both Koestler and Maslow. This progression of the concept of holism into healthcare is perfectly illustrated in Maslow's multi-tiered 'holon' - "man's hierarchy of needs"- and is one of the antecedent key theoretical structures that underpin this research project.



Maslow's hierarchy of needs.

Maslow's multi-tiered 'holon' demonstrates how both the individual and independent matrix, i.e. safety and security, and the layering transformation of all of the collected matrices in the pyramid, can ultimately unite to form what results in a better understanding of the basic psychosocial needs of human beings. Once we understand this structure and see how each matrix can contribute to and influence the whole, then we can better understand each individual's lived experience. Maslow's 'holon' is prime example of how a phenomenological approach, utilising matrices and 'holons', can facilitate the

researcher's detailed examination of the whole and its many parts and thus enable a more accurate interpretation of the lived experience.

When considering the question of data collection, Creswell (2007, p. 59) adds that a researcher may strive for a fresh perspective of a concept or problem by setting aside, or "bracketing out", his or her views of the phenomenon in order to develop a deeper understanding of the experience. Magee (2010, p. 211) encourages researchers to "simply put to one side (in brackets) the unanswerable questions, and make progress with what we are so well equipped to investigate". When making a start Creswell (2007, p. 79) recommends that researchers begin with "interviews with individuals", but he adds that, "documents, observations and art may also be considered".

Stephen Levine (Knill, Levine & Levine, 2005, p. 31) writes, "within the framework of phenomenological analysis of human existence the arts occupy a central role". The use of the arts in phenomenological research is based on ideas explored by the philosopher Heidegger in an essay titled *The Origins of a Work of Art* (1971). Heidegger argues that the arts create connections across all phases of creative experience and these everyday connections to art set forth fundamental truths about "*dasein*" (our existence) that encompass our lived experience in the world.

Levine writes that it was Heidegger's hope that human beings, through the world of art, would "learn to dwell on earth within a world full of significance". Levine sees the shaping of a work of art as a 'gift' that confers meaning. Drawing on his own life experience he promotes the argument that art has a unique way of 'showing' and 'manifesting' the 'lived experience' (Knill, Levine & Levine, 2005, p. 31). Levine believes because the creation of a work of art can never be predicted, each work contains "a mystery that keeps it from being an object of knowledge; it will always be more than what we can say about it in our interpretations". He makes the point that, like memory,

something that is shaped and formed after an event, it is only later, as a witness to the phenomenon, that the artist and/or the observer and researcher, using reflective awareness, may perceive and make sense of what has emerged out of the finished work and the process (Levine, 2005, pp. 39-41). Perception, observation and the ability to make sense of a lived experience within the world of those living with dementia is particularly pertinent, especially for some research participants who may have lost the ability to articulate their feelings or communicate with speech.

Expanding on Merleau-Ponty's theory of *le corps vecu* (the body as we live it), Levine puts forward the notion that such awareness and perceptions are creative acts within themselves. He argues that all individuals who live in the world can create art. He maintains that Merleau-Ponty's notion that the "flesh" of art, with all of its incumbent textures and tones and density, has the ability to create and manifest the "world of an historical community". As a result, it is possible that there can be much more to the perception of art as a lived experience for those living with dementia than just a "passive reception to stimuli". (Knill, Levine & Levine, 2005, p. 72).

Levine believes that works of art open up each individual to different experiences in the world. This above all is the primary reason why phenomenology and the use of an art activity as a research tool are uniquely suitable and compatible when investigating the diminished and often times secret and misunderstood world of those living with dementia.

Writing in *Art-based Research*, Shaun McNiff (1998, p. 113) defines the role of a researcher conducting phenomenological research as the process of striving "to understand the objects of inquiry and experiences as they are lived while minimizing *a priori* assumptions and theories about these things".

A phenomenological framework and approach to art research is particularly appropriate when embarking on a study with individuals living with dementia. Such a study is designed to focus on the lived experience of those living with dementia as opposed to hypothetical theories or a series of myths and/or *a priori* assumptions. The use of an art activity opens up the possibility for researchers to obtain worthwhile and new information about not only the nature of creativity and the manifestation of creative skills, but also the lived experience of this cohort to counter the many negative assumptions associated with this cohort. McNiff (2011, pp. 12-13) writes that the act of ‘witnessing’ a phenomenon when engaged in a creative relationship with someone living with dementia “might be considered other-centred contemplative practice, in which dementia becomes an opening to an expansion of experience”. McNiff adds, by becoming involved in the arts within communities and organizations, practitioners have an opportunity to further the quality of life of those in care. He is further convinced that to counter *a priori* assumptions about dementia and “to increase creative energy in different sectors of society, we need to expand our assumptions about health and the values of artistic expression”, particularly in relation to those living in dementia-specific care.

The identification of a research subject that interests and inspires. The author’s personal reason d’etre.

Both van Manen (1990) and Creswell (2007) stress that any researcher undertaking a phenomenological study must be inspired and interested in his or her research topic and must begin by clearly identifying the phenomenon under examination.

The author of this thesis has held a long-standing commitment to the world of dementia-specific programming and has advocated for individuals living with dementia for more than a decade. The author authored and introduced the MAC.ART program into Australian aged care in 2001 because, at the time, there was a paucity of programs to address the emotional health and wellbeing needs

of those in care. This project was initiated because even after more than a decade of professional practice facilitating and demonstrating the MAC.ART program, involving more than three thousand participants, there still remains many unhelpful assumptions in the wider community about the ability of those living with dementia to engage in creative expressive activities. The author has frequently encountered both therapeutic pessimism and nihilism in aged care facilities and, she believes, these attitudes contribute greatly to two of the most common *a priori* assumptions about individuals living with dementia. The first assumption is that such individuals do not have the ability to concentrate on tasks for longer than a moment and therefore art activities are not worth the time, effort and resources involved. The second common assumption is that art activities are messy and, given the opportunity, those living with dementia will eat and drink the art materials during their participation (Wald, 1983).

In the author's wide experience in this area of activity neither of these assumptions has any basis in reality, but evidence to counter such assumptions is scarce, and the challenge is compounded by the fact that existing research into dementia-specific arts programming is too often criticised for lacking credibility. This no doubt is a consequence of researchers hardly ever revealing detailed descriptions of the processes they employ in any of their art activities. As a result, few comparisons can be made between different art programs and almost none have been attempted. Also, too often behavioural scientists are overly critical and dismissive of qualitative research methodologies, particularly those that do not conform to the Cochrane "gold standard" - the standard universally applied to drug trials and medical research. Most researchers and reviewers that apply the Cochrane gold standard insist on a burden of proof that is almost always impossible to attain from individuals who often cannot remember their participation in an activity and therefore cannot provide reliable follow-up research data.

This research project is undertaken because little is known, or has been published, about dementia-specific art activities and almost nothing is known about the ‘what’ and ‘how’ of the art activity phenomenon for this cohort.

The art activity research terms of reference

The aim of this research project is to explore the lived experience of individuals with dementia by examining the relationship between art, dementia and wellbeing. This has been achieved by applying a Kitwoodian theoretical approach and the scientific method, and a phenomenological methodology utilising both quantitative and qualitative information. The multiple reasons why a traditional biomedical research approach may not be appropriate when exploring this topic have already been outlined in this chapter and will be further elaborated in the subsequent chapters of this thesis.

This research project is conducted within the context of the Australian aged care legislation. The research data have been collected during the course of an art activity that culminated in the creation of a permanent communal artwork. The research outcomes are based on the lived experience data of the art activity participants gathered from both quantitative and qualitative sources. These sources include both live and videotaped observations of the lived experiences of individuals with dementia as they participate in, and work through, identified stages and steps of the art activity (Note: visual evidence of each participant’s participation in the art activity is contained in Appendix I - the USB memory stick - that is attached to the spin of this thesis).

The art activity research terms of reference are as follows:

- The research study focuses on the lived experience of individuals living with dementia. It follows a phenomenological research methodology.

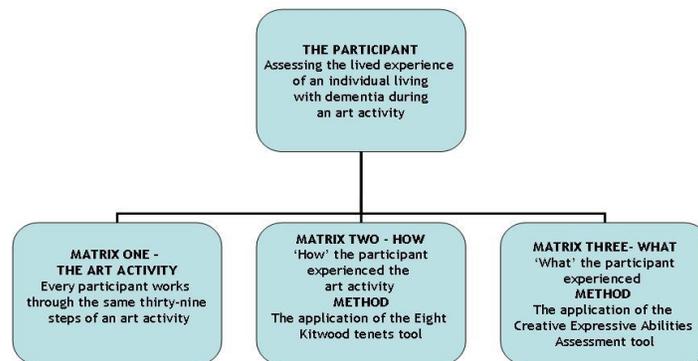
- The research project is conducted in a residential aged care facility. It is primarily the participants' home, not a hospital or clinical setting.
- The facilitator and observers tick score the predetermined wellbeing domains, inherent in the design and construction of the wellbeing assessment tools.
- This research project is an assessment of each individual participant's lived experience and his or her skill during an art activity and is not designed to be a critical analysis of his or her artistic output or psychiatric health.
- The art facilitator is not administering a curative or medical therapy.
- The art activity facilitator is not an art therapist. The facilitator's role is primarily to help and make it easier for each resident to participate and work through the stages and steps of an art activity.
- The research project is not an assessment of an established art program or of art therapy in general.
- The research project is not an evaluation of the ongoing or lasting wellbeing effects of an art activity.
- This is not a biomedical research project and does not have a biomedical controlled study performance criteria or emphasis.

In light of recent relevant research, particularly that of Susan and John McFadden (2011), the author acknowledges the important role that spirituality can play in the wellbeing of the lives of those living with dementia and their care partners. MacKinlay (2011, p. 213) writes, "the essence of facilitating wellbeing and providing effective care [to those living with dementia] includes the spiritual dimension". The spiritual realm is obviously encompassed in many responses to the psychosocial challenges of life, not least it provides solace to many when they are faced with the prospect of coming to terms with dementia - undeniably one of life's greatest challenges. Whilst spirituality is sometimes canvassed during the case study interviews, the author's experience is that it is rarely discussed during an art activity, and it has therefore not been explored

in any depth in this thesis. The subject of spirituality and dementia is amply addressed, most recently by Susan and John McFadden (2011) and Jewell (2011), and useful discussion of the subject can be found in Ai and Mackenzie (2006) and Elizabeth MacKinlay (2008 & 2010 & 2011). And, the specific involvement of the arts in spirituality and wellbeing in older people was the subject of a research study conducted by McFadden and Lunsman (2009) in Eastern Wisconsin.

The phenomenological research methodology

Three central matrices form the tools that make up the phenomenological research methodology of this study. The three matrices are illustrated in the following diagram.



Each of the three matrices above are designed to assess different aspects of the lived experience of individuals living with dementia whilst they participate in a particular phenomenon, in this case an art activity.

Firstly, Matrix One - the Art Activity - represents an empirical set of clearly defined stages and thirty-nine steps. The facilitator presents each step of the art activity to the participant in the same order. Matrix One is explained more fully on page 264 of this thesis. Briefly, Matrix One is the framework by which the facilitator and the observers are able to document the 'how' and the 'what' of the lived experience as each participant works through the art activity.

Secondly, Matrix Two - the eight Kitwood tenets - relates to 'how' the participant physically experiences his or her engagement in the art activity. Matrix Two is explained more fully on page 268 of this thesis. Primarily, Matrix Two is a wellbeing observational tool and is designed to document not only each participant's physical engagement, but also any emotional responses and/or comments that the participant may proffer relating to how he or she experiences the art activity.

The final matrix, Matrix Three - the Creative Expressive Abilities Assessment tool - is as its name suggests, used to assess the creative expressive ability of each participant to determine 'what' he or she experiences during the art activity. Matrix Three is explained more fully on page 270 of this thesis. Briefly, Matrix Three is divided into seven predetermined domains or parts. An observer tick scoring this tool is able to document, for example, such things as the length of time the participant remains engaged in the activity. It also records various psychosocial aspects of the participant's lived experience during the art activity.

Understanding dementia-specific wellbeing

The following paragraphs present a brief summary of the Australian aged care legislation (Commonwealth of Australia, 1999) and how psychosocial wellbeing research fits within the parameters of the Australian regulations. The summary

outlines the perceived importance of maintaining the emotional wellbeing of individuals through the mandatory introduction and monitoring of psychosocial interventions in residential aged care in Australia. An understanding of what constitutes wellbeing for the aged, and more specifically what the concept of wellbeing means from a dementia-specific perspective, is included in the research project discussion chapter in Part Three of this thesis.

The concept of psychosocial wellbeing in dementia-specific care and its relationship to Australian legislation

More than a decade ago, the architects of the Accreditation Grant Principles 1999 (Commonwealth of Australia, 1999), more commonly known as “The Standards”, recognized the importance of choice and self-determination and the central position of both resident’s rights and the concept of psychosocial wellbeing in aged care. The infamous Riverside “kerosene bath” affair in 1999, where frail elderly residents of a Melbourne nursing home were bathed in kerosene during a scabies outbreak, prompted the Australia-wide introduction and adoption of The Guide to Ethical Conduct for Providers of Residential Aged Care: Guide for employed and contracted staff (Commonwealth of Australia, 2001).

The legislators also understood the role of purposeful lifestyle activities in the lives of those living in care and regulated for their inclusion in The Standards. These and other mandatory aged care health reforms of the late 1990s (Commonwealth of Australia, 1997a, 1997b, 1998, 1999) have seen the progressive introduction of lifestyle activities, including the limited use of the creative arts, into residential aged and dementia-specific care. A driving motivation for the legislators was to open the way for a new, more up-to-date and modern approach to aged care to protect those living with dementia in care and for the betterment of the wellbeing of society in general.

A brief overview of The Standards - (Accreditation Grant Principles 1999)

There are forty-four Standards that make up the regulations that govern the accreditation of every aged care facility in Australia. Once every three years the Aged Care Standards and Accreditation Agency assesses every facility in Australia, against a total of forty-four Standards. Every facility must pass every one of the forty-four Standards to gain accreditation to provide aged care for the following three-year period. If a facility does not meet every criterion of every one of The Standards it may be sanctioned by the Agency and ordered to meet them, or it may have its operating license revoked and ordered to cease operations.

The Standards are divided into four major “umbrella” categories that cover every aspects of aged care service delivery. Each Standard has to comply with specific regulations, provide staff education and development and show evidence of continuous improvement. In brief, the four main areas are:

Standard 1: Management systems, staff and organizational development

Standard 1 comprises nine of The Standards and is responsible for regulatory compliance, human resource management, professional development and the provision of external services and information.

Standard 2: Health and personal care

Standard 2 comprises seventeen of the forty-four Standards and is primarily designed to meet the ‘physical and mental health needs of residents’. This Standard includes both clinical and specialized nursing care as well as medication, pain management and palliative care. Nutrition, hydration and skin care, and continence and sleep management complete this Standard’s remaining responsibilities.

Standard 3: Resident lifestyle

Standard 3 comprises ten of the forty-four Standards and is primarily designed to provide emotional support to residents. It recognizes every individual's need for independence, and protects each individual's right to privacy and dignity. This Standard requires that a service provide assistance to residents to enable them to understand their security of tenure responsibilities and to help each individual to make choices and decisions. This Standard, above all others, regulates to maintain the psychosocial wellbeing of those in care. This Standard also includes provisions to maintain the diverse cultural and spiritual life of all Australians living in residential aged care, and is of central importance to this research project because it encompasses leisure interests and activities. This Standard recognizes that every individual is unique and encourages the active participation of every resident in lifestyle support programs that meet the identified needs and preferences of that individual.

Standard 4: Physical environment and safe systems

Standard 4 comprises eight of the forty-four Standards and is responsible for and includes the safety and security of the living environment, occupational health and safety and infection control. This Standard also covers catering, cleaning and laundry considerations.

An overview of Standard 3: Resident lifestyle

The Pocket Guide to the Accreditation Standards (2003) describes the expected outcomes of Standard 3. Resident lifestyle under the heading "results for residents". Standard 3.7 Leisure Interests and Activities speaks directly to the maintenance of the emotional health and wellbeing of those living in care. The Accreditation Agency's published outcomes require that a service ensure that "residents are encouraged and supported to participate in a wide range of interests and activities of interest to them". This part of the legislation asks that a service or facilitator "need not demonstrate improvement in each

expected outcome [of Standard 3] but should be able to show that performance in each expected outcome is understood and/or monitored”. The legislators’ expectation is that the activities are “here and now” and that they carry no further burden of proof of their effectiveness or any other healthcare outcome.

The art activity in this research project is undertaken with regard to the “here and now” performance criteria outlined above. The participants’ skills and wellbeing were quantitatively and qualitatively assessed during the activity. There is no expectation that the wellbeing outcomes, that may or may not be achieved during the art activity, will be maintained or measured beyond the activity.

The structure of this thesis

This thesis is divided into five parts.

PART ONE

Part One comprises the content of the first five chapters and a summary of the combined content of these chapters. The thesis begins with an introduction, and is followed by a consideration of the relevant articles and books and other published material that relate to the role and use of art in dementia-specific care. This bibliographical provision is designed to identify any gaps in the research knowledge.

An additional three chapters, firstly, a brief history of dementia and, secondly, a chapter on colour and vision and, finally, a chapter on the role of reminiscence in dementia care, are rounded off with a summary of all of the above chapters. This completes Part One.

PART TWO

Part Two comprises the content of two chapters and a summary. These chapters relate to what is documented and already known about the lived experience of individuals living with dementia. In particular, Part Two focuses on the way in which individuals living with dementia react to and engage in art activities. The unique role and place of the art facilitator in dementia-specific care is explained by leading practitioners in the healthcare field. Part Two is rounded off by a summary of both chapters.

PART THREE

Part Three comprises the content of three chapters and begins with a chapter detailing the project's phenomenological research methodology. It includes the design details of Matrix One - the art activity - an empirical structure which it was necessary to create for this study so that the facilitator could follow a process and deliver the art activity in the same way to each participant each time. Part Three also details the design and development of Matrix Two - the eight Kitwood tenets - a dementia-specific "holon". This holon was specially designed by the author of this thesis to observe aspects of wellbeing, particularly 'how' each participant experienced the art activity. Matrix Three - the Creative Expressive Ability Assessment tool (CEAA) - the tool that observes 'what' the participants experienced during the phenomenon is explained. The following two chapters detail the findings of the wellbeing research study, and the final chapter in Part Three is a short heuristic study that includes an appraisal of the author's personal and lived experience of the art activity during the facilitation process.

PART FOUR

Part Four is the thesis conclusion. This chapter draws together the content of all the preceding chapters to document possible forward directions and recommendations.

PART FIVE

Part Five is comprised of the reference list and the appendices (including the visual evidence of the art activity recorded on DVD) and the reference list.

Conclusion

The introduction chapter began with a definition of phenomenology and an explanation as to why this method has been chosen for this research project. A glossary of keywords preceded a quote by Alois Alzheimer on the importance of searching to find new ways to advance scientific research, and reference to Baroness Greenfield's recommendations for research into dementia in the 21st century. Dementia, the umbrella term that encompasses as many as eighty different diseases and syndromes, has been defined. The projected impact of dementia on the economy, set to become the biggest disability burden in Australia's history, has been identified.

The introduction chapter has defined the terminology used in this research project. It outlines what leading scholars have identified as the influence of an "old culture of care", the existence of a "pecking order" and of a "traditional dogma" that operates within the biomedical organizational structure and still dominates the aged care sector and dementia-specific research.

Although the Australian government has recognized, commendably, the importance of building a stock resource for the wellbeing of the baby boomer generation, it has stopped far short of addressing many of the vexed issues surrounding dementia and its research. As a result, dementia researchers,

unlike medical researchers in other fields, face funding and other obstacles including the perceived “gap” between scientific and art-based research.

This chapter has identified some progressive thinkers in North America and elsewhere who believe that a new approach to dementia-specific care, and particularly an appropriate research methodology, is central to an important cultural change movement. As a result of this impetus, the author of this thesis has designed and put forward a new dementia/disability model for consideration.

In addition, the aims and the parameters of the research have been identified, as have The Standards that researchers need to work within. The following chapter is a consideration of the articles and books and other published material that relate to the role and use of art in dementia-specific care.

CHAPTER TWO

A consideration of published information on art and dementia and wellbeing

In the previous chapter, The Introduction, the parameters of this research project and its methodology were outlined. This research project is a phenomenological study of the lived experience of participants living with dementia in residential aged care. The overall scope of this research project is not wide because it is primarily concerned with the investigation and gathering of information pertaining to the lived experience, wellbeing and skills of individuals living with dementia as they participate in a particular phenomenon, in this case an art activity. Therefore, this chapter, while wide ranging is not a comprehensive review of publications on the creative arts therapies in dementia-specific care in general; such sweep would be too wide a compass for the specific aims of this research project. Instead, this chapter is limited to a consideration of literature relating to dementia-specific art activities and wellbeing and the question of art activity facilitation to identify any gaps to progress the research project thesis.

It is envisaged that such a sweep and consideration of the literature might yield a two-fold value. Firstly, it will enable the principle researcher and the reader to understand more aspects of the lived experience and the often hidden creative ability of those in care. And, secondly, that the outcomes of the research project might assist recreation workers and art activity facilitators in the workplace in the future, to gain a deeper appreciation of dementia-specific art, and the unique role it has to play in wellbeing.

A consideration of information and opinions relating to the concept of dementia-specific wellbeing is separate and located in Chapter Nine - the

Discussion Chapter, and not included in this chapter. It seemed appropriate, practical and logical to position it in Chapter Nine - the Discussion Chapter, keeping an exploration of the concept of dementia-specific wellbeing and the lived experience closer to the discussion of the research project in general.

This consideration of the outcomes of current research trials and longitudinal studies on the subject of art and dementia begins with an introduction preceding a review of a study by Rusted, Waller and Sheppard (2006). An independent assessment by the author of this thesis of some, but not all, of the key articles on art activity and dementia identified by Gottlieb-Tanaka and Graf (2011) in their meta-analysis (soon to be published by the Canadian Alzheimer's Association), will be followed by an overview of a few selected general articles relating to dementia-specific art activity and facilitation that are not research trials or longitudinal studies. A critical appraisal of the content of selected books, in which the different ideas and facilitation approaches that experienced facilitators in the field hold and employ, will be put forward and discussed.

Barrett and Bolt (2007, p. 189) recommend creative arts research should be set in both an “historical and contemporary context”, all the better to highlight the “gaps” of the past and the challenges for the present and the future. This chapter will culminate by positioning this research project in the context of any identifiable gaps.

Introduction

The International Psychogeriatric Association's (IPA) education pack, *Behavioural and Psychological Symptoms of Dementia* (BPSD) Module 5, confirms an important observation. Module 5 states that, in dementia care, “in the past the need for social and recreational therapies has been overlooked” (IPA, 2002, p.11). This is perhaps the major reason why research studies that

focus on dementia-specific art activities for those living in care are few and far between. Brooker (2007) adds:

Given the heterogeneity of this population [those living in dementia-specific care], the varied skill level of staff, the enormous variety of settings where activities take place alongside the problems of finding suitable outcome measures, it is not surprising that the research evidence for most of these activities appears weak (Brooker, 2007, p. 25)

Aside from the paucity of general information on dementia-specific activities, with few notable exceptions (Levine-Madori, 2007 & 2011, Baines, 2007), there is almost no published material that describes in any detail the techniques and processes that art facilitator's implement during art activities sessions.

Less than five years ago the author of this thesis began her academic studies into dementia and the creative arts therapies. The author undertook an exhaustive literature search looking for published research on dementia and art activity and other creative arts that fall under the rubric of non-pharmacological interventions (NPI). At the time, PUBMED, one of the major healthcare search engines listed thousands of research articles on every medical approach to the treatment of dementia, but it listed not one single article on the relationship between art and dementia. When other health and psychology search engines, including biomedical databases such as Medline and CINAHL, were accessed, they too yielded scanty information and far too few references for a comprehensive analysis of the subject.

In desperation, the author sought assistance from the professional librarians of both Melbourne and Victoria Universities. Not surprisingly, the librarians could only source a very limited number of articles. After an exhaustive search a core group of eight articles, including one by Cohen-Mansfield (2002), and another by Grazel, Wiltfang and Kornhuber (2003), were located under the heading "treatment for behavioural complications of dementia". This core group of articles formed the beginning of the author's collection of articles on dementia-specific art and NPI.

Which is not to say that systematic literature reviews on psychosocial dementia-specific activities do not exist, but they are few (Ayalon *et al.*, 2006; Bartels, Haley & Dums, 2002; Basu & Brinson, 2010; Bird *et al.*, 2002; Finema *et al.*, 2000; Livingston *et al.*, 2005; Opie, Rosewarne & O'Connor, 1999; Robinson *et al.*, 2006; Verkaik *et al.*, 2005). The Livingston *et al.* (2005) review, for example, claims to have identified in excess of sixteen hundred studies on NPI generally, but, using the Oxford Centre for Evidence Based Medicine criteria, the authors claim, except for one hundred and sixty three studies, neither the methodology nor the data analysis was “rigorous enough” to provide conclusive evidence of the effectiveness of the interventions.

Depending on the reviewer’s performance criteria, the efficacy of art in dementia-specific care is usually regarded as inconclusive for a number of factors, not least that too few “controlled”, research-based, art studies are conducted. As already mentioned in the introduction, at the time Grael, Wiltfang and Kornhuber (2003) began their comprehensive literature review on the proof of effectiveness of NPI in 2002, they found no controlled studies of dementia-specific art activity. Even though the Livingston *et al.* (2005) study demonstrates there are plenty of qualitative research studies on art activity in existence, a lack of controlled studies gives the impression that there is no evidence at all of the value or effectiveness of art for those living in dementia-specific care. The authors surmised the reason why there are few controlled studies into art and other NPI is because there “are no commercial interests tied in with NPI [and] the politics of research are all but completely dominated by the belief that effective treatment may be expected by biochemical-pharmacological approaches” to dementia care (Grael, Wiltfang & Kornhuber, 2003, p. 123). Marshall and Hutchinson (2001) point to another set of factors that includes culture, race and ethnicity and the lack of a theoretical framework to guide most studies that end in research results that are both subjective and interpretive.

Over the past fifteen years there has emerged an increasing body of qualitative evidence examining the role and benefits of art and NPI for those living with dementia across a variety of healthcare settings (Allan 2003; Allan & Killick, 2000 and 2002; Balzac, 2003; Basting & Killick, 2003; Camp, 2001; Cohen, 1995 & 2001; Crutch et al. 2001; Emery, 2004; Fornazzari, 2005, 2005a & 2011; Gottlieb-Tanaka, 2004 & 2006; Greenfield, 2000; Henschel, 1996; Heron, 2000; Jensen, 1997; Johnston, 1992; Kahn-Dennis, 1997; Kamar, 1997; Kelly, 2007; Killick, 2000 & 2003; Killick & Allan, 1999a, 1999b & 2001; Kitwood, 1995 & 1997; Koenig-Costa, 2004; Kovack & Lloyd & Papas, 1999; Kuhn & Verity, 2007; Leslie, 2001; Levine-Madori, 2007 & 2011; Lokon, 2007 & 2011; McKernon, 1996; McFadden, 2005; Mell *et al.* 2000; Mottram, 2003; Sherratt, 2010; Stewart, 2004; Thomas, 1996 and Wood, 2002;). It was not until 2006, however, that Rusted, Sheppard and Waller (2006) published the results of the first and probably the only randomised controlled trial study on dementia-specific art therapy.

The data collection for this consideration of the literature began once again with searches on the biomedical research engines at PUBMED, CINAHL and Medline. The search engines were accessed and although in 2011 there were considerably more than eight core articles on NPI and the creative arts therapies, journal articles specifically relating to research studies on art activity and dementia are still very rare, as are studies on the relationship between art and dementia and wellbeing.

Art therapy set in a British context begins this consideration and is followed by the Rusted, Sheppard and Waller (2006) study.

Art therapy set in a British context

Putting art therapy and the Rusted, Shepherd and Waller's study into a British historical context, it must be remembered that from the mid 1940s, when professional artists began practicing art therapy in Britain, they did so as passive facilitators in a non-directive, and non-interventionist manner, whilst leaving whatever analysis of art there was to medical professionals (Case & Dalley, 1992). Waller (1988) informs us the art therapy discipline evolved naturally, and by the late 1970s, the British Minister of Health identified art therapy as "a wholly psychotherapeutic profession" within the National Health System (NHS) and art therapists began identifying themselves as "psychotherapists, albeit of a specialized kind". The discipline and training of art therapists today is influenced by psychodynamic, psychotherapeutic theory and principles "especially [influenced by the] Winnicott and the British Object Relation School". This school of thought sees art therapy not as "fun or recreation", but as a "serious treatment involving the person and the therapist" (Waller, 2002).

Burns *et al.* (2005, p. 143) describe psychodynamic therapy as therapy that was formerly known as the "conversational model". They write the "principal aim of psychodynamic therapy is the identification of interpersonal conflicts or difficulties, which are causing or helping to maintain emotional distress". And, although Waller (2002) believes that art therapists in Britain see their role as an "antidote" to models of treatment within the biomedical framework, and no longer "supplementary to medicine" and doctors, they are nonetheless aligned with other professions "perceived primarily as scientific health care professionals" and are part of the Health Professions Council (Waller, 2002, pp. 1 & 24).

Rusted, Sheppard and Waller (2006) were the first to publish a randomized controlled trial on dementia-specific art therapy. They conducted the study in

Britain over a ten-year period between 1995 and 2005. The research project trial, described as a “longitudinal, repeated measures, control group comparison”, was conducted in three phases, and in the context of residential day care (Rusted, Waller & Sheppard, 2006, p. 4). The project began with two, ten-week art therapy and control group pilot studies, followed by the main research project which was conducted over a nine-month trial period involving forty-five randomly chosen participants. For nine months, the control group participants were presented with a selection of unspecified “recreational activities”, but no “formal occupational therapeutic methods or any form of art and craft work” was included in the activities. Finally, the research data gathered from the twenty-one participants who completed the nine-month trial, and two follow-up interviews, was analysed and published.

The principle aim of the study was to “evaluate the immediate and long term effects of art therapy for older people with dementia, specifically to test the premise that participation in art therapy groups effects positive change in mood and cognition both immediately within sessions and later outside the session to impact behaviour”. The broader aim was to provide an evidence-based evaluation into the art psychotherapy process in dementia care through the “interactions between patient and artwork” using a variety of art materials (Rusted, Sheppard & Waller, 2006, pp. 517- 519).

As to the outcomes, the authors write that the use of art therapy “provided clear evidence of positive and durable benefits of aspects of mental alertness, sociability, physical and social engagement in clients with moderate and severe dementia. These changes were quantitatively and qualitatively different from patterns of effects achieved with a parallel program of recreational activity”, even though participant numbers were small and the authors admit that the standardized measures they used were “not sensitive enough to capture the changes reported by centre staff” (Rusted, Sheppard & Waller, 2006, pp. 531).

Waller (2001, p. 61) describes the trial as gathering the “biggest database of its kind and certainly the only one with both visual and verbal material collected over nine months”. There was one clear positive outcome - Waller and Sheppard (2006) used their research findings to form the backbone of new industry guidelines for art therapists working in dementia-specific care in Britain.

A consideration of some of the dementia-specific art activity research studies published over the past decade, identified in Gottlieb-Tanaka and Graf’s (2011) meta-analysis begins with three different projects undertaken by Seifert and her colleagues in Akron, OH, USA. Not all of the studies consulted by Gottlieb-Tanaka and Graf (2011) are included in this review given that they worked to a different performance criteria when they were gathering information for their study. A more pointed analysis of their work is addressed in the conclusion of this thesis. Others studies not identified by Gottlieb-Tanaka and Graf (2011) are included in this appreciation because they concentrate more on dementia-specific art activity and facilitation, the focus of this research project.

The first of Seifert’s (2000) studies involved a nine-month longitudinal study assessment of the memory of a seventy-three year old woman, living with Alzheimer’s like dementia, during the painting restoration of a family heirloom. The project involved the repainting and decorating of a base relief floral pattern on a small piece of furniture. The project granted the resident’s wish to attempt the restoration activity and made it possible to “satisfy the resident’s desire to improve the appearance of the heirloom”. The individual completed the restoration over a nine-week period and was interviewed on aspects of the project at five and then nine months later.

Seifert (2000, p. 66) was interested in whether a history of engagement in craft and art activity had “established an automaticity [sic] of sub-task procedures in a larger task” and/or if the resident would automatically remember the

investigator and the steps of the activity between engagements. Seifert reports that the participant's choice of colours and her colour acuity remained constant and, although she 'forgot' the floral pattern design she followed instructions, and the investigator worked in collaboration with her to apply colour, so that "the finished product was aesthetically pleasing". At the follow up interviews the participant remembered the investigator and aspects of the project that had a particularly emotional connection, but she was not sure if the project was completed (Seifert, 2000, p. 72).

Seifert's observations are that some artistic skills may be automatic and may also add to the ability to "complete (and enjoy) many of the components of a task". She is of the opinion that "customized activities may enrich and support one's level of cognitive functioning [and] afford valuable rapport-building opportunities for one-on-one interaction" (Seifert, 2000, p. 73).

In the second article, Seifert, Drennan and Baker (2001) discuss the outcomes of two art activities. In the first study, six untrained artists - three with dementia and three without dementia - and residents from an Ohio care facility participated in a pen-pal exchange with students from a Chicago middle school. All artists produced cards with coloured stickers on blank sheets of construction paper twice a week for ten weeks. Although the artists with dementia used "significantly more objects in their pictures than those without dementia" and created symmetrical pictures, the authors report the asymmetric complexity of the images decreased over the course of the study (Seifert, Drennan & Baker, 2001, p. 99). The authors did not comment on whether this was due to the decreasing novelty value of the activity or the progression of dementia.

In the second art activity, twenty-one individuals living with dementia, and five without, from four long-term facilities, "affixed floral stickers to a white page that already pictured a line drawing of a vase with stems" to create artworks to adorn the walls of their facility (Seifert, Drennan & Baker, 2001, p. 98). The

authors observed that the line drawings worked well as cues with artists with more advanced dementia and as their dementia progressed. The artists nonetheless discussed design options and sticker placement during the artwork phase of the project and expressed joy and accomplishment in their handiwork.

Seifert's third article in this review was written in conjunction with one of the same colleagues. Seifert and Baker's (2002) three-year longitudinal study of an art activity was undertaken to learn "about some of the benefits and limitations of art activities (for daily living and possible aids to assessment)" and to chart the stability and/or cognitive deterioration of the participants in the study over that time.

Twice a week, in what the authors describe as a fun filled two-hour session, participants were given a choice in the selection of a dozen colourful stickers to create a picture. Assessments were made of the asymmetrical placement of the stickers and the pictorial complexity of the image to determine working memory capacity and/or decline over the period. The authors observed that participants living with Alzheimer's like dementia took great care with the placement of the stickers and verbalized their thoughts during the picture's design and composition.

Seifert and Baker (2002) stress that to use art tasks as a diagnostic tool in this way the activity should be presented in a 'standardized' manner with similar instructions and materials. The authors conclude that although the pictorial complexity of the pictures declined over the period of the study, it was unclear how the asymmetric placement changed and, in the end, it was "too difficult to draw conclusions about long-term changes in art production" based on this study.

Musha *et al.* (2000) document the positive effects of art therapy on forty-one Japanese patients. For one year Musha and his colleagues, using a new

technique known as the Emotion Spectrum Analysis Method, analysed the electroencephalogram of patients fitted with electrodes as they used various materials to engage in a “wide range of creative arts”. The art therapy program was conducted by professional creative artists with the purpose of providing encouragement during an “enjoyable time in which strong interactions are provided between patients and artists followed by a comment session”. Musha *et al.* observed “high levels of joy [during the art activity] and after the comments session” and, they add, “we did not expect such emotional activation” during the study. The researchers claim they “observed remarkable improvement” in the research participant’s emotional health (Musha *et al.*, 2000, p. 441).

The “Memories in the Making” program has been in existence since 1986. It is one of the very few dementia-specific creative arts therapy programs to be the subject of detailed analysis.

In 2002, Clarissa Rentz (2002) used the Greater Cincinnati Chapter Wellbeing Observational Tool in her pilot project to assess forty-one participants in an “outcomes based evaluation” of the program. At that time, Rentz wrote (Rentz, 2002, p. 181) that “the emphasis must be on the creation of person-environment systems that are supportive and safe, which heighten a person’s sense of normalcy, competency, and wellbeing despite dementia, whether it be for a moment or an hour at a time”. In a later and much smaller evaluation, with only twelve participants, Kinney and Rentz (2005) came to the conclusion that research into the creative arts therapies can pose more questions than it answers. Together, the authors make the recommendation that “treatment options can and must include supportive structured, non-pharmacological interventions [such as *“Memories in the Making”*] that enhance and maintain an affected person’s sense of wellbeing, at least for a moment in time from beginning to end of a prolonged and often difficult disease outcome” (Kinney & Rentz, 2005, p. 227).

In 2002, Kim (2007) conducted an Applied Multi-Sensory Stimulation (AMSS) PhD study at the in-patient geriatric behavioral unit at Bethesda Hospital in St Paul, Minnesota. Kim explains the purpose of her study was to see if art therapy activities can be tailored and modified to complement “other appropriate treatment approaches” to enhance in-patient “wellbeing and quality of life”. Kim also wanted to better understand the nature of the relationship that develops between therapists and “patients” whilst they are in care (Kim, 2007, p. 2). Kim writes that patient’s usually spent between twenty-one and thirty days in the unit, and she was “allowed to use” four patients diagnosed, with dementia, who she “enrolled” in her study for ten, one-hour clinical art therapy sessions, after they were “withdrawn” or had “dropped out of” the unit’s Electroconvulsive Therapy (ECT) dementia treatment program! Kim confirms that all patients in the study were “prescribed a heavy regimen of medications” and some were routinely physically restrained (Kim, 2007, p. 62 & 126).

Kim wanted to determine, firstly, if there were any behavioural or emotional changes in her participants after engagement in multi-sensory therapy. And, secondly, if what she describes as a ‘sensory rapport’ needs to be established between the facilitator and the participant. To answer the first question Kim reports that although she tried various comparisons and combinations of her data, it is often too difficult “to establish the achievement of an emotional outcome through scientific measurement” but “promising behavioural change outcomes are reached first and the promising emotional outcomes appeared next” and could be seen to be beneficial (Kim, 2007, p. 129). On the second question, interestingly, Kim found “that a therapeutic relationship *per se* was not necessary to be established between therapist and patients”. Rather, Kim believes that her research demonstrates that the key to a successful relationship is to allow the participant to observe the art materials and form an attachment to them. The art materials in turn act as a “trigger” to art production, thus limiting the role of the therapist to one of assisting the

participant with the “selected [art] materials” so that they can attain their own therapeutic outcomes (Kim, 2007, pp 115-119). Kim did add, “the therapist’s verbal directions and encouragement have been shown to be valuable tools” to use to improve the relationship between the facilitator and the participant and to directly help the participant achieve the next level of engagement (Kim, 2007, p. 130).

Kim remarks that the National Institute of Health reviewed her AMSS study in 2006 and, not surprisingly, did not award her a grant because “there was no emphasis on randomized controlled trials demonstrating the efficacy of the AMSS sessions for the dementia populations” (Kim, 2007, p. 4). One can only hope that, over the past decade, “best practice” humane dementia care in the geriatric wing of the Bethesda Hospital has been implemented and that physical and chemical restraints and ECT treatments are no longer routinely used.

In 2006, Pepin *et al.* (2006) conducted a two-week research study with ten residents living with dementia in an aged care facility in Omaha, Nebraska. The study was undertaken to evaluate the effectiveness of five different art activities by measuring three behaviours namely - engagement, interest and pleasure - with reference to each participant. The observers tick scored the Apparent Affect Rating Scale to make their evaluations. Of the local artists facilitating the activities none had dementia-specific training, but each received a briefing to explain the “fundamental characteristics” of dementia.

At the end of the two-week trial and evaluation the authors were able to state, in order of preference, that music, dancing and painting were the top three most popular arts activities to stimulate interest, and participation invariably led to engagement and pleasure. Of special interest are the painting participant’s case study observations. Pepin *et al.* (2006) state that one resident whilst painting “became ‘stuck’ in mid-movement, unable to complete

an intended motion independently” and, although he required “numerous verbal cues”, he smiled and then independently “filled the brush with paint and made attempts to apply the paint to canvas” (Pepin *et al.*, 2006, p. 37). The authors report that interventions and reassurances by the facilitator “ameliorated angst and staved off frustration”, and staff “learned different ways of understanding and interacting with residents”. As a result, staff began to “look beyond the disease, to see a person instead of a disorder” (Pepin *et al.*, 2006, p. 38).

Anecdotal information gathered through the Pepin *et al.* research study indicates that “focused interventions are far more beneficial for elder individuals, emotionally and physically, than aimless activity”. But, the authors stress that “much remains unknown about the long-term effects of the arts therapies on this population” (Pepin *et al.*, 2006, p. 39).

Rankin *et al.* (2007, p. 60) write that the case controlled study is the first to use “semi-quantitative methods to compare the visual art of groups of dementia patients and healthy older adults”, and it is the only study of its kind to investigate the differences in art production between different types and sub-types of dementia. The author’s write that the “neuropsychology of visual artistic production, and its evolution in the setting of brain injury, remains fairly unsophisticated” (Rankin *et al.*, 2007, p. 48). This statement reinforces Zaidel’s (2006) earlier professional assessment, and makes this study very important in the quest to gain a broader understanding of the ways in which individuals living with dementia respond and engage in the creative process.

The Rankin *et al.* (2007) study explores the differences in drawing, mark making, colour preferences and composition during art production by individuals living with damage to different parts of the brain caused by Alzheimer’s disease or frontotemporal dementia (FTD) or semantic dementia, a

sub-type of FTD. A control group of individuals without dementia made up the rest of the research numbers.

After an exhaustive series of art-based tests, the authors are confident that those living with Alzheimer's disease do not display any particular colour discrimination or perceptions or preferences that are different from others who do not have dementia. There appears to be evidence that individuals living with Alzheimer's disease use a slightly less complex colour palette and tend to produce artworks with more muted colours. The authors confirm that the artworks become more abstract as Alzheimer's disease progresses. Further, in one drawing exercise, that of a room interior, those without dementia appeared to have as much trouble completing the task as those who do have dementia.

The study also identifies that individuals living with FTD, a different clinical dementia diagnosis than Alzheimer's, produce artworks that are distinctive and different from the artworks created by individuals living with other forms of dementia. Rankin *et al.* comment that overall the study shows that "linguistic and graphic ability largely exist independently", and hemispheric damage in particular regions of the brain allows "visual creativity to flourish" differently (Rankin *et al.*, 2007, p. 48).

Orennik, (2008) carried out a twenty-four week research study to investigate the influence of cognitive rehabilitation exercises with sixteen participants in Slovenia. The ninety-minute exercises included painting and drawing and beeswax modeling art, combined with memory tasks in the form of mathematical and reading activities. Eight individuals, representing half the research participants engaged in the cognitive rehabilitation exercises, and the other eight individuals, received "regular care only".

Orensnik observed that participation in the art activities increased “social interaction” and thus opened a “new field of communication”. And, he claims such activities increased some memory tests significantly. Orensnik enthusiastically recognizes that NPI have a place in dementia-specific care, but he makes very bold claims when he suggests that his research “*proves that NPI may present an important treatment with Alzheimer’s disease*”, and that “weekly therapies with learning and memory training improve cognitive functions, [and] reduce the progress of illness and postpone its onset” (Orensnik, 2008, p. 177). Interestingly, two Swiss researchers, Bogouslavsky (2006) and Hannemann (2006) also make similarly bold claims in journal articles detailing their research.

The following selected publications look at different approaches and attitudes to dementia and the use of art in care.

Dementia-specific art therapy from an Israeli perspective

Iyemere (2006) describes Abraham’s (2005) *When Words Have Lost Their Meaning* as a “valuable addition to the literature on art therapy for older people”. She writes it is a “positive and compassionate book... as it portrays an art therapy approach... [and] resurrects the desolate situation in which Alzheimer’s sufferers [sic] find themselves”.

Abraham specifically details her art therapy experiences with those living with Alzheimer’s disease in residential care in Israel. It is of special interest for two reasons: firstly, it is one of the first books of its kind to be totally devoted to art therapy in dementia specific-care; secondly, it is the first practical guide and contemporary yardstick by which a comparison of approaches to dementia-specific care, methodology and care models may be made.

Iyemere (2006) believes that Abraham's reading of dementia-specific care is positive, but the book paints a very bleak picture of life for those living with dementia in care, and portrays an extremely negative impression of the characteristics sometimes associated with people who live with dementia. For example, Abraham claims those living with Alzheimer's disease are "confused and troubled people", who are often "paranoid and obsessive" and prone to "harping anger and unjustified accusation" (Abraham, 2005, p. 49). In addition, Abraham claims that those with Alzheimer's disease commonly exhibit "bizarre and insulting... [and/or] "sexually inappropriate behaviour" (Abraham, 2005, p. 30). Whilst this may be Abraham's experience and may be true, it is nonetheless a harsh indictment.

Much is revealed in Abraham's description of work conditions and her perception of the art therapist's position in dementia-specific aged care. Abraham (2005, p. 106 & 157) claims the workplace is often smelly and details what she describes as the "daily grind of hopelessness" experienced by many working in an "atmosphere of gloom and loneliness". She also does not consider that dementia-specific care is "sufficiently intellectually stimulating" for some of her students. She qualifies this by suggesting that:

Art therapists have a tenuous place in the pecking order of the therapies; not quite psychotherapists, even though they often have extensive psychological education and training, and not quite occupational therapists, though as an observer, the activities that they initiate can look very similar, and not art teachers, even though they must be well trained in the understanding of the effects, sustainability, and manipulation of various art materials (Abraham, 2006, p. 140).

Even though Abraham's book was published in 2005, it merely pays lip service to a person-centred approach to dementia-specific care, and thus is disappointing.

Dementia-specific art therapy from a British perspective

Tyler (2002) expresses his opinion on the use of psychotherapy in dementia-specific art therapy in his chapter in *Art Therapies and Progressive Illness: Nameless Dread*, (Waller, 2002). Tyler has for many years worked in aged care and was an advisor to Waller and Sheppard when they formulated the British art therapist's dementia-specific guidelines in 2006 (Waller and Sheppard, 2006).

Tyler (2002) informs us that he uses art psychotherapy primarily to assist those living with Alzheimer's disease to resolve significant conflicts in the final stages of life. He explains that he uses art psychotherapy primarily because dementia is a "non-verbal process", and because he believes art psychotherapy to be both "healing and liberating". Tyler believes art psychotherapy has the capacity to help "increase control" for participants. Tyler's study is one of the very few dementia-specific art therapy studies and offers valuable insight into the use of art and psychotherapy techniques.

Tyler illustrates his technique when he explores the response of a 75-year old man, with Alzheimer's to an art activity. He says he approaches every client with the expectation that emotional conflicts and difficulties already exist. He begins by describing this particular client as agitated and "unable to express himself in a coherent verbal manner", adding that his speech has deteriorated to the point where he is no longer able to express himself in more than two word sentences (Tyler, 2002, p. 80). From this description it would seem that some form of dementia is well advanced, and it also indicates that the ability to process and understand the myriad of steps it takes to initiate and participate in an art activity unassisted may be problematic.

Tyler notes when escorting his client to the art sessions that his client often walks ahead and is distracted by doors and signs. When they reach the art room, the client is unable to sit down for the activity and busies himself opening and closing cupboards. When presented with the art materials - such as crayons, paint and paint pots - his client methodically arranges the art materials in groups neatly on the table.

Tyler says he interprets these actions within a “psychodynamic framework” by assuming that the grouping of the art materials is an important process indicating a need “to organize and sort out his experience”. Tyler puts forward several other theories, such as, the action may be “symbolic of attempts to deal with his confusion”, and/or maybe read as a “denial of his disintegration and fragmentation”. Or, alternatively, they may be seen as an attempt to “hold onto his perception of being useful”, as a “denial of retirement, or the redundancy associated with old age” (Tyler, 2002, p. 81).

There are many interpretation that might be proffered, but suffice to say throughout the case study and chapter Tyler does not acknowledge or mention the affect the Alzheimer’s disease progression is known to have on processing skills. If facilitators are to truly serve the wellbeing needs and special interests of those living with dementia in care, and if this case does anything it demonstrates the limitations and pitfalls of traditional art therapy.

By contrast to both Abraham and Tyler, Baines (2007) is one of the first art therapist’s to recognize that traditional art therapy practices and methods must change and adapt to meet the special needs of those living in dementia-specific care. Baines promotes a person-centred approach to art therapy that is very different to a psychotherapeutic approach. In her monograph, *Nurturing the Heart* (Baines, 2007), Baines relies on her vast experience working in aged care in Tasmania and advocates the adaptation of traditional art therapy

methods. Her practical methods and recommendations are documented in more detail in Part Three of this thesis.

Conclusion

The aim of this chapter was to limit its scope to a consideration of literature relating to dementia-specific art activities and wellbeing and the question of art activity facilitation. This consideration of the literature was designed in this way to identify any gaps in current dementia-specific research, so that this particular research project may be placed in the context of others. To progress the research project thesis and generate new knowledge, a deeper appreciation of dementia-specific art, and the unique role it has to play in wellbeing and how others facilitate art activity was sought.

As indicated, the overall scope of this chapter was not wide, it considered the outcomes and recommendations of current research trials and longitudinal studies and other relevant information pertinent to dementia-specific art activity participation and facilitation. The aim was to understand more aspects of the lived experience of dementia, including the often hidden creative and artistic ability of those in care, as they participated in a particular art phenomenon. In this chapter, a variety of dementia-specific art activities delivered under different conditions and facilitation styles was examined, and, their similarities and differences were documented.

What the information revealed

The outcome of this consideration of current information on dementia-specific art activity participation and facilitation is highly informative and relevant to this research project. It stands to reason, and it is accepted, that each author/researcher considers and expects different research outcomes from their art activity projects. But, this consideration revealed that authors' rarely

document from which philosophical perspective they approach the facilitation of the art activity. Nor, are they particularly clear about how they consider the problems associated with dementia-specific research. Not least, such problems as methodology and statistic, and/or the myriad types and levels of dementia under consideration. Brown (2008, p. 202) does go some way to explain this phenomenon by pointing out that one of the barriers, that creative arts researchers face is the “lack of knowledge of statistical methods...[and] the difficulty of capturing this methodology in writing”. One of her recommendation is that standards of practice be established by “credentialing bodies” (Brown, 2008, p. 207). The author of this thesis lays out other possible solutions to this immense problem, in the concluding chapter.

That said, the information canvassed revealed that not one of the researchers fully explained the dementia-specific art activity in any detail. Nor did any one itemize the art materials, or what it is exactly that they do to set up an art activity. Nor is any explanation given as to the reasons why they facilitate the art activity in a particular way. No one attempted to explain which part of an art activity promotes wellbeing, but although they could not convincingly quantify it they all made varying claims to the existence and enhancement of wellbeing for the participants derived from their research projects.

What the information canvassed revealed is what motivates an individual living with dementia to create, and what creative expression means to that individual’s lived experience and wellbeing is muddled and confused. It is therefore not surprising that research into this important subject is often dismissed as lacking scientific rigor. As a result, the correlation between art dementia-specific art activity and wellbeing is little understood and remains grossly under researched.

In addition, this consideration found no published research that details the physical processes involved in the implementation of a dementia-specific art

activity and no publication, with the exception of Zaidel (2005), that explores the neuropsychological stages and steps of an art activity beyond a few basic steps. Both of these subject areas then would appear not to have been explored in any great depth or detail to date.

If we are to meet the challenges of the next four decades in healthcare, the concept of dementia-specific wellbeing, and the identification of the functions and the role that an art facilitator performs, are critically important to understand. This research project means to explore the lived experience of a group of participants living in residential aged care during an art activity and, from that, drawn some conclusion about the relationship between art, dementia and wellbeing.

In particular, this research project intends to identify and thoroughly examine the stages and steps of an art activity. The special role that the facilitator plays in the process will be scrutinised and, possibly for the first time, notes will be taken to provide a better picture of the special abilities and skills that participants living with dementia bring to the activity. A gap has been clearly identified to fully justify this research thesis and its approach.

To gain a fuller understanding of the lived experience of those with dementia in past times, the following chapter takes a brief historical snapshot of dementia through the ages. As well as presenting an historical overview, the following chapter will identify some of the leading figures and their contribution to the growing contemporary acceptance of the creative arts in dementia-specific care.

CHAPTER THREE

A brief history of dementia set in an historical and contemporary context

In the last chapter this research project was set in context with other dementia-specific art activities. A gap in the literature was identified and established. Setting dementia in an historical and contemporary context allows us to understand the lived experience of individuals with dementia today more comprehensively. Such understanding is important when planning and preparing stock resources to meet the challenges of the future.

The aim of this chapter is to briefly set out the past history of dementia in its sociological and historical context. Then in a brief compass, some of the pivotal individuals who have influenced the evolution of the creative arts therapies and non-pharmacological (NPI), person-centred approach to aged care generally, and dementia in particular, will be identified.

The cause of Alzheimer's disease, the most common form of dementia, is still unknown and there is no known cure. While this chapter refers to aspects of scientific research, it does not set out to document the history of scientific discovery or biomedical drug research. Instead, this chapter aims to present a brief overview of the NPI approach to dementia-specific care, acknowledging significant figures and their contribution to the introduction of creative arts therapies in this field.

From the sixteenth century through to “modern times”

Bromley (1974) in *The Psychology of Human Ageing* presents an historical critique of ageing from ancient times and traces the intellectual origins of the British welfare state from the Elizabethan and Victorian Poor Laws through to the social reforms of the early 20th century. Bromley points out that the psychology of ageing is complex and has interested many writers since Plato and Aristotle. The debates on the ethics of ageing have influenced societal attitudes, but perhaps the greatest influence for change was the proliferation of books and ideas in the late 15th century. The invention of printing ensured the spread of literacy and the dissemination of ideas meant, for the first time in fifteen hundred years, that the influence and authority of the Catholic Church was seriously challenged (Steinberg, 1970).

A brief historical background to the Enlightenment

In the 17th century, the so-called Rationalist movement in philosophy began with Rene Descartes (1596-1650) and a group of mathematicians. Essentially the Rationalists believed that knowledge and an understanding of the world could best be obtained through reason alone. Leibniz (1646-1716), for example, promoted the notion of two truths - the truth of reason and truth of fact. On these assumptions the Rationalists came to the conclusion that knowledge gained through sensory experience was inferior (Magee 2010).

Post (1995) points out that an emphasis on the “light of pure reason” emblematic of the Enlightenment worldview displaced an acceptance and even an appreciation of the “fool” that was commonplace in the medieval and Renaissance periods. One result was that, in the “Age of Reason” such individuals were increasingly perceived as a threat to progress and society in general.

Foucault (1965) in his book *Madness and Civilization: A History of Insanity in the Age of Reason* explains this shift in societal attitudes in considerable detail. He argues that before the Enlightenment the “unreason” associated with dementia and insanity was accepted as an everyday part of life. It was a time when “fools” were often accepted as “holy recipients of special grace” - free from the everyday worries of the world.

The “Age of Reason” placed a new value, or expectation on human life, one that stressed productivity and purposeful rational activity. Post (1995) is convinced that this influence is still evident in our society. He argues that modern biomedical ethicists adhere to a rationalist approach that continues to require individuals living with dementia to “fulfil myriad rationalist indicators of personhood” (Post, 1995, p. 34).

Dementia in popular literature

Beginning with Shakespeare (1564-1616), the lives of those living with dementia increasingly made an appearance in popular literature (Porter, 1991; Post, 1995; Shenk, 2003).

William Shakespeare

Almost everyone is familiar with Jacque’s satirical cataloguing of old age, in Shakespeare’s play *As You Like It*. Jacque’s lament goes: “In second childness and mere oblivion, san hair, san teeth, sans everything”. The dark side of memory loss, portrayed by the tragedy of King Lear’s struggle with dementia, touches the heart of most readers. King Lear Act IV:

I am bound upon a wheel of fire,
that mine own tears do scald like molten lead.
. . . I am a foolish fond man.
Fourscore and upwards, not an hour more or less;

and to deal plainly,
I fear I am not of perfect mind.

(Cady & Cartwell, 1946, p. 975)

Jonathan Swift and “modern times”

Porter (1991, p. 5) describes Jonathan Swift (1667-1745) as offering “a typical ironical panegyric to the ‘madness’ in politics, religion and intellectual affairs”. In *Gulliver’s Travels*, first published in 1726, Swift satirizes the intellectual pretensions of early 18th century politicians, philosophers and scientists and also documents the ravages of dementia. In his description of Gulliver’s travels among the Luggnaggian people, Swift states that he sets out to “entertain” his readers with something “a little bit out of the common way”. Swift whose final five years of life “were marked by eccentricities, combative behaviour and dementia” (Post, 1995, p. 97), describes an uncommon account of an immortal people called the “*Struldbruggs*”.

The *Struldbruggs*, Swift writes “commonly act like mortals, till about thirty years old” and then by degrees grow melancholic and dejected. Melancholia increases with age until the age of eighty, when they are looked on “as dead in law” and they have most of their rights and property taken from them. At ninety “they lose their teeth and hair”, and they are “despised and hated by all sorts of people”. The *Struldbruggs* have no “distinction of taste” and eat and drink whatever they can “without relish or appetite”. He continues, adding that when the *Struldbruggs* talk they:

Forget the common appellation of things, and the names of persons even of those who are their nearest friends and relations. For some reason they can never amuse themselves with reading, because their memory will not serve to carry them from the beginning of a sentence to the end; and by still defect they are deprived of the only entertainment whereof they might otherwise be capable (Swift, 1987, p. 149).

Dennis (1964) believes that Swift may have had an inkling of his own slow progression into dementia because of the intuitive way he describes cognitive deterioration in his early writings. In *A Tale of a Tub*, first published in 1704, Swift perceptively describes memory loss when he writes of “a person whose Intellectuals were overturned and his Brain shaken out of its natural position which we commonly suppose to be a distemper”.

Sections of Swift’s other published works provide different examples. *Gulliver’s Travels* was written between 1721 and 1725, was followed in 1731 by a revealing poem on memory loss titled *Verses on the Death of Dr. Swift, DSPD*. Together with the clear instructions stipulated in his last will, Swift’s writing gives an indication that he had a deep understanding of the “infinite distress [of] the insane” and perhaps his own fate. Swift left his estate to “build a house for the fools and mad”; and as a result St Patrick’s Hospital was founded in Dublin in 1745 for the safety and wellbeing of the “deeply forgetful”. Not least of the hospital’s functions was to keep individuals living with dementia safe and away from prying eyes and the comical amusement of patrons of “freak show” entertainment.

Charles Dickens and 19th century urban living conditions

The social world described in Dickens’ novels shed powerful light on 19th century urban living conditions and the hardships endured by the poor and the aged. Trevelyan (1986, p. 551) credits Dickens and his social commentary - particularly, his attack on “workhouse management” in the novel *Oliver Twist* - with alerting the Victorian sensibilities of the plight of millions of ordinary citizens. In *Great Expectations*, one comical vignette describes an individual living with dementia. Here, Dickens provides a rare benign example of 19th century dementia care. Mr. Pip visits Wemmick, his legal clerk, at home. Pip is introduced to the clerk’s father whom Wemmick warmly refers to as the “aged parent”. Wemmick tells Pip that his father “isn’t capable of many pleasures,

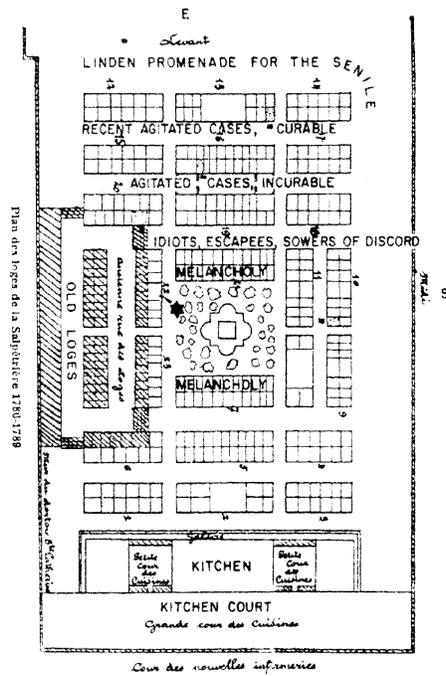
just tip him a nod every now and then and he will be as happy as a King. Isn't that right aged P?" They all smile and nod in unison (Lean, 1945).

With no accurate diagnostic methods, most individuals living with dementia were commonly regarded as non-productive social outcasts and labeled "senile" or mad. If not cared for by kind hearted relatives, and with little social infrastructure, the alternative was the "workhouse" for the "able-bodied poor", and the parish "poorhouse" for the blind, the sick and the mentally and physically disabled. In *Our Mutual Friend* (Dickens, 1998), Dickens describes a scene of pure dread. Mrs. Betty Higden's plea not to be relegated to the poorhouse has an echo that can still be heard more than a century later.

"The House", Mrs. Higden exclaimed with a shiver of repugnance... "kill me sooner than take me there...come to us and find us all a-dying, and set a light to us all where we lie, and let us all blaze away with the house into a heap of cinders, sooner than move a corpse of us there!" (Dickens, 1998, p. 199).

Their "back-wards" fate

Thane (2005) documents that the living corpses of those with more advanced dementia were often moved into the "back-wards" of lunatic asylums where they were forced to fraternize with the criminally insane. The detailed illustration below of the dormitory layout of the "Linden promenade for the senile" of Salpetriere, the infamous French mental asylum gives weight to this observation. Porter graphically documents the fate of many with dementia living under such conditions throughout the pages of *The Faber Book of Madness* (Porter, 1991).



5

“Plan des loges de la Salpêtrière 1786-1789”

Undeserving of support

Bromley explains the widespread belief that every individual had a responsibility to financially provide for his or her own old age, a belief that existed in British society since Elizabethan times. Society, he informs us, took it for granted that individuals who did not “live a good life, got the old age they deserved” and “poor people were personally and morally responsible for their poverty and were therefore undeserving of support” (Bromley, 1974, p. 56-57). Hamilton (1981, p. 211-212) tells us that the charity hospitals and poor law dispensaries in Britain in the mid to late 19th century were mostly staffed by women who were referred to as “poor law doctors”. These women were Britain’s first female medical graduates, and their sex often prevented them from practicing medicine anywhere but in the poor house. Bromley (1974, p.

56) confirms, during a time of “widespread poverty and social disruption” such doctors ensured the elderly infirmed were relatively well cared for.

Eugenics and its impact - The Nazi doctors

In 1883, Francis Galton (1822-1911), a half cousin of Charles Darwin, developed a theory he called eugenics. Although some historians would argue that eugenics in the early years had a respectable place in public debate, its perversion by the Nazis cast a dark shadow over the whole subject. Unfortunately, eugenics in its crudest form became the foundation stone, platform and justification for constituting the non-voluntary euthanasia of people living with disabilities (including dementia), in criminal mass murder in Europe between 1939 and 1941. From an office on the Tiergartenstrasse in Berlin, orders were given for the systematic murder of individuals who the Nazi regime classified as *lebenun wertes Leben* or “life unworthy of life”. In a project ‘ethically justified’ by the writings of the eugenics’ theorist, Professor Alfred Hoche, and directed by Wurzburg Professor of Psychiatry, Dr. Werner Heyde, 94,000 individuals, many of whom had dementia, were gassed or given lethal injections. The design of the T-4 project, as it was known, was two fold: it was seen firstly as an effective way for Nazi doctors and scientists to rid German hospitals of people they referred to as “useless eaters” and make way for wounded German soldiers and secondly, to trial and perfect methods of mass murder later put into effect as part of Hitler’s “Final Solution” - the Nazi blueprint for the extermination of European Jewry in the Holocaust (Lifton, 1986).

Even though this example of Nazi atrocities against individuals living with dementia is extreme and shocking, it demonstrates that the prism of the extreme case can shed light on the more commonplace case. Fortunately, we treat individuals with dementia differently in our day, and many have worked hard to bring about legislation to ensure aged pensions and healthcare

entitlements, in the advanced industrial societies at least, but it is still the case that individuals living with dementia are mostly cared for by relatives and are among the least valued and respected older members of our society. Less than two decades ago, the ethicist, Dan Brock (1993) made remarks on the psychological capacity of those living with very advanced dementia. He claimed because they lack “integrated and goal-directed behaviour”, they more closely resemble animals, and in some respects they are “worse off than dogs” (cited in Baldwin & Capstick, 2007, p. 176). Post’s (1995) rebuttal is poignant, noting that there is a place for dogs in dementia care - working as man’s best friend in pet therapy. More recently, in 2008, the Baroness Mary Warnock, a peer in the British House of Lords in Britain and a leading moral ethicist and euthanasia advocate, caused a storm of controversy. Warnock suggested that individuals living with dementia have a “duty to die”, because of the amount of care that they require, and she further adds that she hopes that some individuals will soon “be licensed to put others [with dementia] down”.

The Brock and Warnock perspectives demonstrate, that even with the dissemination of publications by peak bodies and special interest groups and the proliferation of autobiographical and biographical accounts of the Alzheimer’s disease experience, such as *Iris* (Bayley, 1999) and *About Alice* (Genova, 2009) to name two of hundreds, there is obviously still much to be done. Although progress is slow and it is an evolutionary process, nevertheless it can be reasonably claimed that much has been achieved since World War 2.

The evolution of a person-centred approach to dementia care and significant figures in that process

The second half of the 20th century saw the birth of a person-centred approach to dementia and this approach can be directly linked to the post World War 2 introduction of art as therapy into hospitals in England, which was followed in quick succession by the spread of ideas of the humanist theorists of the 1950s.

Eric Cunningham Dax

In 1946, Eric Cunningham Dax (1908-2008) fathered a momentous contribution to mental health reform when he appointed the art therapist Edward Adamson as artist-in-residence at Netherne, a psychiatric hospital in Surrey, England. This decision many believe foreshadowed the birth of art therapy as a profession in England, and as a concept it would soon spread worldwide.

Dr Dax and Edward Adamson's therapeutic studio

From the outset, the principles and practices of the therapist were clear to Dax. He saw Adamson's role as "passive", one in which the therapist facilitated with minimal intervention. Waller (1999, p. 6) notes that Dax was quite clear that Adamson "was not to attempt to interpret the picture or to show any special interest in the psychological problems of the patient", as this would assign a "very powerful role to the therapist". McNiff (1998, pp. 103-104) describes Adamson as the "ideal" artist-in-residence and "keeper of the therapeutic space". He says, Adamson perceived himself primarily as "an artist" who set up a "therapeutic studio" and began "working in the mental health field". McNiff sees Adamson's legacy exemplified by his ability to create an environment where individuals are "accorded the dignity of helping to cure themselves", by using the "healing effects of art".

1952 - 2008: Dr Dax and his Australian connection

On taking up the position as the head of the Victorian Mental Health Authority in Melbourne, Australia, in 1952, Dax brought with him a selection of artworks created by the first of his Netherne patients to participate in his reforms. With a singular determination to change conditions for those in his care, Dax's artists were afforded the unique opportunity through art therapy to "paint themselves well". Dax was instrumental in dismantling what he described as

some of the “most appalling” and “worst collection of psychiatric hospitals” he had ever seen. He achieved this by moving the care and support of the mentally ill into the community, whilst remaining a staunch critic of the poor services available to those he had helped to “de-institutionalize”.

Over the next seventeen years, as well as fostering and creating art therapy programs at all the major Victorian psychiatric hospitals and at some prisons, including the infamous “J Ward” of Ararat “lunatic asylum” in rural Victoria, he instituted a range of innovative mental health programs which included Australia’s first free telephone counselling service.

Boosted by the publication of his book, *Asylum to Community*, in 1961, Dr Dax’s international reputation soon spread. Fortunately, he was an inveterate collector, and over the next two decades the collection of patient’s artworks grew enormously to include thousands of pieces in various mediums. When moves were made to dispose of the accumulated works in 1981, he sifted through, selected and saved what he thought were the most significant pieces. Twelve thousand artworks formed the basis of the Dax Collection, which is one of the largest and most significant of its kind in the world.

Abraham Maslow and man’s hierarchy of needs

Advancements in medical technology in the twentieth century have, as many have observed, effectively seen the medicalization of the human body, so reducing it, in the eyes of many medical practitioners, to little more than a piece of machinery with working parts (Engel, 1977; Short, Sharman & Speedy, 1993; Lupton, 1985). In the 1950s, Abraham Maslow (1908-1970) one of the leaders in a new humanistic approach to psychology, published his seminal work on human beings and his and her hierarchy of needs (Maslow, 1956 & 1970). Maslow rejects the prevailing negative biomedical emphasis on what he refers to as a “sick psychology” and argues this attitude has led to a perception

of a generalized “sick population”. Instead, Maslow puts forward his notion that too much attention is placed on aggression and hostility as the key motive forces in society, and this has been done at the expense of the more positive and constructive side of human nature. He writes of the “psychopathology of the average”, and maintains once a hierarchy of emotional and physical needs, such as food and shelter has been met, and although the “average” man does not always take it, he then has an opportunity to extend himself above the “norm”. At this level, every individual has the opportunity to attain a sense of creativity and freedom through “self-actualization”. Maslow maintains one of the rewards of “self-actualization” is the ability of each individual to become whatever he or she is capable of becoming. Other rewards are the skills to sustain an acceptable quality of life - life that encompasses an open and fresh attitude, and is linked with a sense of personal confidence in the ability to meet life’s uncertainties.

Even today, Maslow’s focus on the ability of each individual to take charge of his or her own emotional health challenges many of the assumptions of the prevailing biomedical orthodoxy that dominates medicine and healthcare.

Carl Rogers and person-centred therapy

Carl Rogers (1902-1987) was another influential figure of this humanistic school. In the 1950s, Rogers (1957 & 1958) set out the ideas underlying his person-centred therapy. He based his counseling techniques on building trust and mutual respect between client and therapist, and believed this partnership allowed space for the client to move forward and achieve his or her goals. Rogers technique moved away from directive and psychoanalytical approaches to individual therapy and with it away from the notion that the “counsellor knows best”. He relies on the key assumption that, each individual has vast potential to understand themselves, and each has the capacity to resolve his or her own problems. Rogers stresses the quality of the therapeutic relationship

and a prime determinant in that relationship is that each person must be trusted in the self-directed growth process. The non-directive role of the therapist in the therapeutic relationship is to reflect and clarify the verbal and non-verbal communication of the client and these factors determine the overall success of the outcome.

The appearance of the person-centred approach in dementia care

Morton (2000, p. 29) traces the initial appearance of person-centred dementia care “back to the early 1970s when Naomi Feil began to insist on the need for empathy and a non-directive approach in her work, developing the origins of what was to become Validation Therapy”. He goes on to clarify what he describes as the “intellectual heritage”, responsible for driving the cultural revolution in dementia care that [has] filled the last decade of the 20th century”. Verity and Kuhn (2008) argue that by comparison with Kitwood’s optimistic person-centred approach to dementia care, the traditional biomedical outlook is marred by negative thinking and low expectations. They write:

Dementia has long been viewed mainly as a medical problem - an irreversible, progressive and hopeless disorder of the brain. In the medical approach, little can be done for the unfortunate ‘patients’ since there is no cure and few drugs for treating the symptoms. In the medical approach difficult behaviours expressed by people with dementia, such as agitation, are seen as inevitable symptoms due to brain damage. This approach is pessimistic in outlook and ignores the importance of good care on the wellbeing of people with dementia (Verity and Kuhn, 2008, p. 33).

Morton (2000) commends the “richness” of the intellectual heritage that has created a positive model of person-centred dementia care and believes its uniqueness can be found in “the diversity of its origins”. He credits many sources, but singles out for special regard social psychologists and disability rights campaigners and individuals in the creative therapies and reminiscence movement.

Indirectly, one of these individuals was George Engel (1913-1999), who developed a humanistic “biopsychosocial” healthcare model, and introduced it into hospitals in Rochester, New York, in the 1970s.

George Engel and the biopsychosocial approach

Engel was a professor in the schools of medicine and psychiatry at Rochester University. Although Engel’s focus was not dementia, as a psychiatrist he was concerned with the psychophysiological aspects of human development and the impact of psychological issues, such as memory and grief and loss, on the individual. In particular, Engel thought that understanding the psychosocial circumstances in which people exist and function, and how these factors affect the disease progression and the quality of life of those in his care, was a key determinant in how healthcare practitioners related to their clients and how successful that care would ultimately prove to be.

In 1977 Engel published what was later described as a “seminal paper on the biopsychosocial model that has become an organizational principle for psychiatric education in medical settings” (Wise, 1999, p.521). Shorter (2005) makes the point that although Engel’s concept of health and disease was apparent from the early 1950s, his paper, *The Need for a New Medicine: A Challenge for Biomedicine*, although written thirty years ago, is still highly relevant to any analysis of healthcare philosophies today.

Engel’s work details the failure of the biomedical model to meet the expanding demands of healthcare service provision to both the individual and society. Throughout his work Engel makes reference to the 17th century philosopher Rene Descartes (1596-1650) who argued that the mind and soul should be the separate preserve of philosophers and theologians respectively. Above all, Engel sees the failure of the biomedical model of care as due to the Cartesian

theories that underpin it. He argues Cartesian theory has effectively separated the mind from the body and, as a result, doctors and the medical profession, over the last one hundred and fifty years at least, have progressively assumed effective dominance and control of the treatment of the human body. Damasio (1994, p. 248) adds that today one could begin a catalogue of reproaches against Descartes beginning with his “having persuaded biologists to adopt, to this day, clockwork mechanics as a model for life processes”.

In 1977 Engel wrote that the “biomedical model is a model of disease no longer adequate for the scientific task and social responsibility of medicine . . . its limitations are easily overlooked and it has acquired the status of dogma - a dogma that requires discrepant data be forced to fit the model or be excluded” (Engel, 1997. p. 130).

In his retrospective essay (1997), he argues there is a crisis enveloping the biomedical model and it is this: the “cultural imperative of western society, namely... the canons of science, as described in the 17th century, continue to apply. The possibility that the premise itself is a fallacy is simply ignored” (Engel, 1997, p. 522). In terms of the advancement of a more humane approach to care, with special attention to the “humanness” of each individual, Engel regrets Cartesian mind-body dualism because he thinks “biomedical thinking, a twentieth century derivative of seventeenth century natural science, categorically excludes from science what patients have to tell us on the grounds of its being nonmaterial in form and not measurable, subjective, not objective” (Engel, 1997, p. 522). In his earlier work he argued the biomedical approach to disease has been successful beyond expectation, *but at a cost*, as it leaves almost no room in its framework for the social, psychological and behavioural dimensions of illness. In fact, he writes, the “medical crisis stems from a logical inference that since disease is defined in terms of somatic (biological) parameters, physicians need not be concerned with psychosocial issues which lie outside medicine’s responsibility and authority” (Engel, 1977,

p. 129). In addition, he argues, a professional dominance has strengthened and “perpetuated prevailing practices, deflected criticisms and insulated the profession from alternative views and social relations that would illuminate and improve health care” (Engel, 1977, p. 135).

Engel identified and recognized that each of these barriers stood in the way of his goal for a more inclusive, holistic and person-centred approach to care as set out in the blueprint of his biopsychosocial model. He envisaged that the best elements of scientific research and medicine would be incorporated into a modern framework that recognized that the social, psychological and behavioural dimensions all affect the individual and have an impact on illness and disease. Engel warned that “nothing would change unless or until those who control resources have the wisdom to venture off the beaten path of exclusive reliance on biomedicine as the only approach to healthcare” (Engel, 1977, p. 135).

Engel briefly achieved his vision, according to Dowling (2005), during the 1980s and early 1990s, as the biopsychosocial concept became the “watchword” for the medical and behavioral sciences in their common study of preventative measures in disease and health. While Dowling believes the focus of the first decade of the 21st century is neuroscience, he also argues that Engel’s legacy has ensured that at the very least patients, at some of America’s major teaching hospitals, are now seen as “united biopsychosocial persons” rather than “biomedical persons” divorced from their social and psychological dimensions (Dowling, 2005). And, Shorter (2005, p. 8) contends that Engel’s historical legacy is that “the biopsychosocial-style of thinking has become a lance in the struggle to help extract the pharmaceutical industry from psychiatry”.

Thomas Kitwood

Thomas Kitwood (1937-1998) was born in Lincolnshire, England, in 1937. After attending Rugby School on a scholarship, he studied natural sciences at Kings College Cambridge, graduating with a BA in 1960. He then studied for the Anglican priesthood and began a teaching career. Kitwood's deep religious conviction led him to take up a teaching position in Uganda, where he remained until Idi Amin seized control of the government in a brutal military coup in 1971. On his return to Britain, Kitwood completed an MA in the Psychology and Sociology of Education at Bradford University. From the mid-1980s, Kitwood's intellectual and academic interest and writings turned toward dementia and dementia care leading him to form the Bradford Dementia Research Group in 1992. Under Kitwood's guidance the group developed Dementia Care Mapping, and he was awarded a personal chair, the Alois Alzheimer's Chair of Psychogerontology in 1998, just before departing on a lecture tour of the USA. Within days of his return to Bradford from this tour, he died suddenly at the age of 61.

Kitwood vs. an "old culture of care"

Kitwood confesses that during the time Engel's biopsychosocial model was being introduced in the United States in the 1970s, he was still "completely seduced" by the prevailing "old culture of care" worldview. Morton (2000, p. 28) details the "negative features" and characteristics of this "old culture". He explains these characteristics include a "preoccupation with cognitive damage [and] a view of dementia as a 'kind of living death' [and] an indifference to the effect that others have on the subjective experience of the person with dementia". But, perhaps most worrying, is the "dismissal of confused attempts at communication as either unworthy of response or requiring only a mechanically delivered correction". Kitwood (1997, p. 3) admits he had no "substantive knowledge" of the field at the time and thought dementia was not

much more than “a death that leaves the body behind”. He says it was not until the mid 1980s that his interest in dementia care increased and that he began to question many common assumptions about dementia. His investigations, over the next decade, until his untimely death in 1998, led him to develop the first dementia-specific person-centred care model, based on Carl Rogers (1957 & 1958) person-centred therapy and counselling techniques. Kitwood’s person-centred care model and its application to an art activity are explained in detail in this research study’s methodology chapter.

Common assumptions about dementia in the 1970s

We now know that there are more than eighty types of dementia and Alzheimer’s disease is no longer referred to as a “rare psychiatric condition”, but is recognized as the most common form of a group of disorders, diseases and syndromes (Alzheimer’s Australia, 2006). Dementia is an umbrella term to describe cognitive impairment due to Alzheimer’s disease, vascular or multi-infarct dementia and Lewy Bodies dementia to name the more common forms, and in younger people it can be as a result of HIV/AIDS and Down Syndrome. Shenk (2003, p. 30) writes, in the mid-1970s “all of a sudden everyone knew someone touched by Alzheimer’s”. He says this is partly due to a “shift in public conception”, boosted by the very public disclosure of the diagnosis by Rita Hayworth and Ronald Reagan and the consequent media. Basting (2009, p. 41) agrees and remarks the Reagan family announcement in 1994 “did more to bring the term “Alzheimer’s” into the consciousness of America than any movie, magazine article, public service announcement, or book”. Pratchett (Alzheimer’s Society, 2010a, p. xiii) adds, “Alzheimer’s was the disease that did not get talked about, it sometimes seems to me that [today] people talk about nothing else”. He concedes that “people are frightened about the future [and] now is the time to give the lie to some of the clichés”. The Reagan family announcement marked the beginning of a gradual shift in public perception

away from the idea that dementia is a normal part of brain ageing, and toward the realization that dementia might just possibly be a treatable disability.

Auguste D. and Dr Alois Alzheimer

Auguste D. was only fifty-one when she was admitted to a Frankfurt psychiatric hospital in November 1901, and her symptoms did not tick any of the standard psychiatric boxes for her neuropathologist, Dr Alois Alzheimer (Page & Fletcher, 2006). Alzheimer studied Auguste D. for the next two years until he moved to Munich, and it was only when her brain was sent to him for autopsy in 1906, that the characteristic neurofibrillary plaques and tangles, identifying the disease that now bears his name, were revealed (Cheston & Bender, 1999). Shenk writes (2003, p. 77-78) Alzheimer “offered a causal link between neuropathological and psychopathological alteration [and] the critically important brain physiology vs. psychology debate was really just beginning and would last through the twentieth century and beyond”.

Up to and including the 1960s, the medical profession thought Alzheimer’s disease was a rare form of “presenile dementia” found only in middle aged individuals. Scientists thought “senile dementia” was only found in individuals over the age of 70. Whalley (2001, p. 103) writes that for the first six decades of the twentieth century “Alzheimer’s disease was believed to be a rare dementia in middle age, and was little taught to medical students”. He confirms that until 1968 “when dementia researchers met in London to talk about the causes of dementia”, both doctors and members of the public firmly believed “the most frequent cause of mental decline in old age” was cerebral arteriosclerosis or “hardening of the arteries” and this was a normal part of the ageing process. Thinking Alzheimer’s disease was very rare the medical profession misdiagnosed both Alzheimer’s and Lewy Body dementia and routinely dismissed the possibility of these diseases in older people.

Whalley (2001) writes, even in the 21st century “the association between cognitive impairment and advanced age is so well established that for many such impairment is inseparable from ageing. This view continues to have many adherents and probably underpins much of the therapeutic pessimism encountered in the management of Alzheimer’s disease. For some this disease lies at the extreme end of a normal cerebral ageing continuum” (Whalley, 2001, p. 125).

The 1970s view of the biomedical professions to those living with dementia - “the patient” seen as a set of symptoms

D.B. Bromley (1974), was a senior lecturer in Psychology at Liverpool University and a fellow of international gerontological societies, in the United States and Britain. He was also a founder member, and the first Chairman of the British Society of Social and Behavioural Gerontology. He outlines the position of “the patient” within the biomedical hierarchy and his descriptions of dementia, and its “symptoms”, offer historical insight. They help explain what Whalley (2001, p. 175) describes as today’s “therapeutic pessimism” surrounding dementia. In 1974, Bromley would confidently write that Pick’s disease and Alzheimer’s disease are forms of “senile psychosis” caused “as a consequence of degenerative disorders of the nervous system [that are] rare and difficult to distinguish” (Bromley, 1974, p. 315-316).

Bromley’s (1974, pp. 304-307) description of dementia in people over seventy as “senile psychosis” is classified as a “psychiatric disorder of later life”. He describes the progression of what is probably Alzheimer’s disease as follows: “memory impairment is one of the first and more obvious signs of an impending senile psychosis”. This impairment affects “the patient’s” energy, and “he becomes easily upset; he sleeps fitfully and potters about aimlessly. The senile psychotic may wander about at all hours, and shout and scream in imaginary arguments” and his delirious thoughts may progress to a point where he may “accuse people of theft, or interference” and not recognize familiar faces. He

describes the “pathological changes in senile dementia as diffuse” and the difference between dementia and normal ageing is the rapidity of deterioration and the higher mortality of those “suffering” from “senile psychosis”. Bromley further argues that this rapid deterioration may include “shallow depression sometimes involving transient paranoid ideas and morbid, misplaced fears of retribution for non-existent sins and crimes. The patient’s short-lived delusions are feeble attempts to find some meaning for his disordered thoughts, perceptions and feelings”. Bromley goes on to explain:

Within about six months of the onset of dementia, though the rate of progress is variable, the senile psychotic has usually become physically enfeebled, mentally slow, emotionally dull and apathetic and easily tired. His grasp on circumstances and events becomes rapidly worse, and [he] attempts to fill in the gaps in his memory with guesswork and fantasy. For a time he may try to disguise his real condition by covering up and excusing his mistakes and by putting on a cheerful, friendly attitude (Bromley, 1974, p. 304-305).

This will continue for a while until “the patient” will eventually “recall less of his past life” and “use empty phrases” and have “difficulty following a train of thought”. He will overcompensate by “trying too hard, or making excuses or doing the wrong thing” until eventually “the patient cannot think properly, speak coherently, or write effectively [and] his speech becomes incomprehensible, inappropriate, and finally a meaningless babble”.

Under Bromley’s scrutiny those with probable vascular dementia fare little better. Here, Bromley explains “the patient with cerebral arteriosclerosis reacts to his condition by becoming morose and pessimistic; his emotional control is weakened so that if he becomes tearful he is likely to weep bitterly, or if he becomes amused he is likely to laugh uproariously”. From a 1970s perspective, and under the impression dementia is a psychiatric illness, Bromley states, not surprisingly, that the general response to standard treatment including tranquillizers, anti-depressant drugs and electroshock therapy (ECT) is “poor”. Post (1995, p. 57) in a contrary reading, writes that

“our society has come to expect the prompt control of behaviour [such as those mentioned above] often through medical means”, but he says the use of “ECT is very concerning because even mild dementia may be considerably worsened”. Alarming, Kim (2003) reports that ECT was still being routinely used as a “treatment” for dementia in at least one hospital in the United States as recently as 2002.

The identification of basic psychosocial needs

Awareness generated by the media, and changing public attitudes toward dementia, has brought with it a new emphasis on research into ageing myths and stereotypes and the psychological and social (psychosocial) needs of humans (Bytheway 1997; Thornton, 2002; Kane, 2002). By the early 1980s Boettcher (1983) had identified the basic psychosocial needs of residents living in aged care. He argues basic needs such as safety and security and a room to call one’s own, helps build a sense of autonomy, personal identity, self-esteem; and only when these factors are combined with communication and cognitive understanding can individuals in care lead a more sustainable and acceptable quality of life. As Morton (2000) has indicated, many individuals contributed to the advancement of the rights of those living with dementia. These individuals variously - academics, medical specialists and advocates identified and added to the growing list of psychosocial needs of those in care, and pushed for changes to legislation instrumental in bringing about advances.

In 1987, in the United States, the regulatory requirements of the Nursing Home Reform Act came in as part of the Omnibus Budget Reconciliation Act 1987 (OBRA). On paper this legislation was designed to improve conditions for those living with dementia. Hendry and Douglas (2003, p. 96) write the OBRA legislation “assured the population of certain freedoms” including “the right to be free from any physical or chemical restraint imposed for the purpose of discipline or staff convenience and not required to meet the resident’s medical

symptoms”. Cody *et al.* (2002, p. 1403) write that, although the OBRA legislation “restricted the use of some anti-psychotic medications and other drugs, the regulation requires clinicians try nonpharmacological interventions first, except when there are immediate concerns about residents’ safety”. Whilst this sounds good in theory, Hendry and Douglas (2002) note the OBRA guidelines have been influential in decreasing the use of psychotropic medication, but the legislation’s influence to increase the use of NPI in dementia-specific care has not been demonstrated. This is possibly due to, and may be influenced by, the American litigation culture: staff concerns with protecting the rights of *all* residents, infused with a general concern and anxiety to protect themselves from litigation. Cody *et al.* (2002, pp. 1402) comment often that the “cultural and ethnic background” of staff and their training is an issue, and multiple factors and other influences may alter some group’s perception of problems and even lessen the perceived value of NPI and their usefulness.

In 1997, the American Psychiatric Association (A.P.A. 1997) published updated guidelines on dementia care and incorporated new psychosocial ideas into their publications. In the same year, Kitwood’s (1997) book outlining the first person-centred dementia-specific care model, including his future vision, was published in England. In Australia, the first of a set of sweeping aged care reforms were tabled in the Australian Parliament.

An Australian perspective - aged care reforms in the late 1990s

By comparison to the United States, Australia has a very small population of just over 21 million (Australian Bureau of Statistics, 2009), but the economic impact of dementia in Australia will be as great as in any other developed nation. An Access Economics report indicates dementia is currently the second largest disability burden after depression in Australia (Alzheimer’s Australia, 2003). It predicts the next decade will see dementia become the largest

disease burden in Australia's history, and over the next fifteen years the number of individuals living with dementia will increase by 60%. Dementia, it is estimated, costs the Australian economy approximately \$6 billion per annum (Alzheimer's Australia, 2005).

The elderly in Australia, due to legislation introduced during sweeping aged care reforms in the late 1990s (Commonwealth of Australia, 1997a, 1997b, 1998, 1999), are particularly fortunate. As a result, Australia is one of the few countries in the world where the provision of fulfilling activities, in aged and dementia-specific care, is linked to each facility's tri-annual accreditation. To remain accredited each provider has a mandate to provide lifestyle programming and services as part of their charter to maintain minimum standards of care.

Although the advancement of the rights and conditions for those living with dementia has been steady between the 1970s to 1990s, even in the late 20th century Kitwood could convincingly demonstrate individuals living with dementia are still too often misunderstood and they are still perceived as non-productive "social outcasts". He maintained until his death that society's attitude to the care of individuals living with dementia is a product of the continuing biomedical dominance of healthcare and a "malignant social culture" (Kitwood, 1995).

More than a decade after Kitwood's death, Low and Anstey (2009) have put his "social culture" theory to the test. In Australia, they have conducted what they describe as a "the only published community based study of dementia literacy" to identify community knowledge, social beliefs and awareness regarding dementia. They found more than 80% of the Australian public think "genetics, old age, brain disease and stroke or mini-stroke contributed to a person getting dementia"; many think other contributing dementia risk factors might include "personal characteristics such as weakness of character (32%) and laziness

(22%). These misconceptions reveal that dementia is still not fully understood and individuals living with dementia are vulnerable to being stigmatized by some sections of the community. Overall, the study found most people (85%), “would not recognize the early symptoms” of dementia and, even though they have a “high rate of recognition” of dementia, they are generally “overly optimistic about [the] prognosis”. In fact, over five percent (5.2%) expect a “full recovery” from dementia after diagnosis. Not surprisingly, carers are not as optimistic and many still think “loss of memory is a normal part of ageing”. Most caregivers do not seek an early assessment because of “the stigma associated with dementia and the belief that little can be done for a person with dementia”. In the United States, many also fear losing their health insurance after a positive diagnosis.

Post-Kitwood and the decade of the brain

The 1990s have often been described as the “decade of the brain” (Levine-Madori, 2007) and Greenfield has been one of the central figures in brain research during those years. Writing in *The Lancet*, Greenfield (2001) describes Whalley’s, *The Ageing Brain* (2001) as “one of the best accounts of Alzheimer’s disease I have ever read”. Whalley’s description is very clear and understandable and compared to Bromley’s 1970s worldview, it offers an accurate “picture at present”, delivered in “compassionate and authoritative” language, and does “not judge old people by the standards of a different generation” (Greenfield, 2001, p. 1466).

A visit from a thief in the night

One of Whalley’s own patients shows remarkable insight when describing the “silent, unobserved loss of mental abilities and memories” due to Alzheimer’s, and refers to “a visit from a thief in the night” (Whalley, 2001, p. 112). The following describes Whalley’s more technical description of the disease:

Alzheimer's disease is associated with the loss of cortical neurons. The loss is well established at death, when typically about 30% of cortical cells are missing. Surviving cells show reduced dendrite sprouting and synaptic formations. The medial temporal lobe often shows more extensive cell loss than other cortical areas, and this loss is much greater than that of normal ageing. Genetic factors may modify cognitive decline in ageing, and may combine with unknown environmental agents to accelerate this reduction of the cortical reserves (Whalley, 2001, p. 112)

No one knows what causes Alzheimer's disease, but scientists do know how it affects the brain. In less technical terms, the first part of the brain affected by Alzheimer's disease is a part of the limbic system called the hippocampus. This is the part of the brain that processes short term memories and stores them into long term memory. To explain Alzheimer's disease simply is to describe the damage done to memory by two abnormal proteins called tau and beta amyloid (Abeta). Tau causes changes within the microtubules inside the neurons and Abeta peptide forms outside the neurons and wraps around and fills the spaces between live neurons and chokes and interrupts the flow of messages. This substance is sticky like starch, and attaches to dead cell debris and plaits together into strands called "fibrils" and these form into tangled balls - the characteristic "plaques and tangles" that are often associated with Alzheimer's disease. This restriction creates more loss of neuron, the brain begins to shrink, and progressively memory and understanding diminish until eventually the ability to remember and reason are gone. Greenfield (2010) reminds us that because scientists still do not know the cause of Alzheimer's they have not been successful in developing any new drugs treatments in the past fifteen years. Greenfield says that all available medications do not halt the disease, but instead they, "work on the principle of increasing the availability of a chemical messenger", that is known to diminish as Alzheimer's disease progresses.

Whalley explains that tau and Abeta accumulate in the "ageing organs" of all older people, but the fibrils only "accumulate in the brains of some people, all people with Alzheimer's disease and all Down Syndrome patients over the age

of forty” (Whalley, 2001, p. 129-130). Snowdon’s “Nun Study” (2001) reinforces the fact that Alzheimer’s disease is “not an inevitable consequence of ageing” and he found that every human being experiences Alzheimer’s disease differently. Garnered from the autopsies of nearly seven hundred brains, Snowdon discovered it was possible for some nuns in the study to experience “widespread damage and no symptoms”, whilst others displayed “obvious symptoms” often experiencing only “modest damage” to their brains (Snowdon, 2001, p. 100). Greenfield (2010) admits she has often questioned why “certain cells in the brain embark on a pernicious cycle and others, if they are damaged for example in a stroke, enable [the brain] to make a recovery of function afterwards”. Why abnormal proteins have such a devastating affect on some individuals, whilst sparing others, is the unanswered mystery of Alzheimer’s disease.

New focus on the emotional health and wellbeing of those living with dementia

In the early 1990s, Allen-Burge *et al.* (1993) promoted the importance of research into the emotional wellbeing of those living with dementia. They maintained then that this issue was “a global health care concern” (Allen-Burge *et al.*, p. 213). They called for the design of new programs and increased research. As a result, the 1990s saw the introduction and beginnings of treatments and therapies associated with various individuals committed to the worldwide advancement of NPI.

Commenting on modern dementia care, The International Psychogeriatric Association (2002, p. 11) confirmed that, “in the past the need for social and recreation therapies has been overlooked”. The research and development of psychosocial programs designed specifically to address the mental health and wellbeing of individuals living with dementia is significantly underfinanced and, as a result, research into this critically important area has been and is still largely unexplored. The reasons for this neglect are many but the most

important is probably the overwhelming dominance of a pharmacological approach to the treatment of those living with dementia in aged care. Cohen-Mansfield (2001) believes the relatively meagre research into psychosocial programming is a reflection of the limited understanding of the usefulness of psychosocial interventions, combined with the inherent difficulties faced by researchers. Grasel, Wiltfang and Kornhuber (2003), for instance, could find so few published research papers or trials on the efficacy of NPI that they assumed that non-pharmacological interventions (NPI), for example, are seldom used in dementia care. And, they further assumed that few studies are attempted because it is generally thought research is both “labour intensive” and therefore not “cost effective”. However, they do not discount the fact that most dementia research is funded by pharmaceutical companies who have no vested interest in funding research into non-drug alternatives.

The prominence of ageism and “therapeutic nihilism”, in dementia specific care

While Whalley (2001) has spoken of the effect of “therapeutic pessimism” in relation to and the aged, it is common for researchers in dementia-specific care to be struck by the prominence of ageism and even “therapeutic nihilism”.

Ageism and “therapeutic nihilism”

Malone and Camp (2007, p. 151) believe “the single greatest barrier to the provision of high quality care for persons with dementia is not a lack of resources, but a belief”. They found that a form of ageism, described as ‘therapeutic nihilism’ in the 1980s, has the potential to profoundly influence both attitudes and therapeutic outcomes.

Malone and Camp (2007, p. 151) elaborate on the place of “therapeutic nihilism” in dementia care, and maintain the general climate is influenced by individuals who perpetrate the myth that:

Because persons have dementia, they are incapable of learning new things, incapable of showing anything but decline, and that the best caregivers can do is be patient and deliver palliative care as the inevitable deterioration of dementia unfolds. This is, in essence, learned helplessness on a system-wide scale. It results, in large part, because of an overemphasis on the deficits associated with dementia (driven by a primary emphasis on diagnosis and treatment of deficits), to the exclusion of acknowledging and utilizing the strengths and abilities still available to persons with dementia. Therapeutic nihilism is insidious because it destroys hope and condones acceptance of the status quo (Malone & Camp, 2007, p. 151).

Semel (2006) alerts us to a discernable trend in current literature, that presents warnings about the futility of treatment and the general hopelessness of those living with dementia, that tend to reinforce all the inherited negative readings of dementia-specific aged care. She believes there is an underlying bias influenced by ageist perceptions. Kelly (2007, p. 313) in her review of *Art therapy with Older Adults: A Sourcebook* (Magniant, 2004), notes it is “a pity” that, “the determinism and more negative stance towards those with dementia, [and the] therapists’ underlying assumptions of loss and decline, seemed to colour their judgments about the meaning of their clients’ work”.

Malone and Camp (2007) remind us of Kitwood’s (1997) robust challenge to therapeutic nihilism, exemplified by his push for the implementation of a psychosocial model to replace the dominant medical model in dementia care. Kitwood believed that self-fulfilling prophecies are created and flourish in a climate of negative attitudes and expectations particularly, he noted when mainstream publications go unchallenged. More than a decade since Kitwood’s death, an “old culture of care” still surrounds those living with dementia. This culture continues to produce attitudes that reinforce both negative stereotypes

about dementia-specific care and helps sustain a climate that is the antithesis of a focus on person-centred quality of life.

Common myths, negative stereotypes and misconceptions

Some of the more common myths, negative stereotypes and misconceptions that surround dementia, centre on so called “behavioural and psychological symptoms”. Zeisel (2009) describes these “symptoms” as the “four big A’s”: agitation, anxiety, apathy and aggression. Vafiadis (2001) reminds us that, “medically speaking the many causes of the psychotic state [such as agitation, anxiety, apathy and aggression] are *well known*”. He lists an impressive array of known causes and comments that “the potential combination of contributing factors [is] vast and variable” and each has the potential to “fluctuate over time” and some may be “simultaneously active”. Vafiadis concludes that the psychotic state is almost “impossible to determine medically” as there are “no available laboratory tests” and the interpretation of tests can be very difficult because any individual may be influenced by such things as “electrolyte imbalance, glucose disturbance, hypoxia, infection, cerebral metastases, metabolic disturbances, drug-related effects, emotional disturbances” and many other factors. It would seem reasonable to assume that the unmet needs of an individual are only rarely recognized or documented during biomedical assessments of such states (Vafiadis, 2001, p. 114).

Following Kitwood’s identification of the link between unmet needs and behaviour, in the United States, much of Jiska Cohen-Mansfield’s academic career has been spent studying and researching the causes of psychosis in those living with dementia. As the creator of the Cohen-Mansfield Agitation Inventory (1991), an assessment tool used widely in aged care to rate human behaviour, developed on the basis of a vast body of research focusing on residents in aged care, she has fully documented the so-called “symptoms” and their negative

associations. As a consequence of her research Cohen-Mansfield has authored many hundreds of journal articles.

Cohen-Mansfield and the ‘unmet needs’ model

Cohen-Mansfield (1991) has charted the variations of “symptoms” in residents living with dementia and has found that as many as 93% of them in some nursing homes may be significantly affected by psychological and environmental factors.

Cohen-Mansfield maintains that her research indicates there are three main influences which have a profound effect on almost all those living in residential aged care. She describes these influences under theoretical model headings. They are:

1. The ‘unmet needs’ model

This model recognizes that the needs of individuals living with dementia are not always apparent to the observer or caregiver and often go unmet. Unmet needs are particularly difficult to anticipate when the caregiver is unfamiliar with the resident and when the ability to clearly articulate thoughts and feelings is diminished as dementia progresses. The rudiments of this model are central to a holistic person-centred approach to care.

2. The behavioural/learning model

The behavioural/learning model concentrates on an assumed connection between antecedents and learned behaviour. Staff not infrequently make inaccurate assumptions or react inappropriately to what are perceived as psychological “symptoms”. Such “symptoms” may be expressions of pain or

discomfort, but might well be misinterpreted by staff as “attention seeking” behaviour.

3. The environmental vulnerability/reduced stress threshold model.

This model hinges on documented observations of individuals living with dementia and on an assessment of the level of stress each can tolerate. Cohen-Mansfield, (2001, p. 362) writes, that individuals can “progressively lose their coping abilities... resulting in anxiety and inappropriate behaviour when the environmental stimuli exceeds the threshold for stress”. The affect that “excess disability” and “environmental pressure” can have on the individual is discussed in detail in the chapter on colour and vision of this thesis.

Cohen-Mansfield writes that these models are not mutually exclusive, and may be complementary. Above all, they underline the importance of addressing the underlying needs of individuals first, using NPI in order to identify the person’s unmet needs, and then, if necessary, using NPI in conjunction with medication.

Further, Cohen-Mansfield (2001) outlines three main arguments for the introduction of NPI in dementia specific settings. They are as follows:

Firstly, to identify and address the psychosocial/environmental reasons that may underpin behavioural and psychological “symptoms” associated with dementia. Secondly, to avoid drug aetiology and the known side effects that should limit the use of some pharmacological interventions. And, thirdly, to enhance the caregiver’s ability to identify the needs of the individual before they are masked, as often happens, by pharmacological interventions (Cohen Mansfield, 2001, p. 361-381).

The Habilitation Therapy concept

In the 1990s new and interesting trends in dementia care management emerged in North America. Three individuals in particular explored the physiological and psychological benefits of NPI in a holistic, mind-body approach to dementia care. Raia and Koenig-Costa and Zeisel, individually and in collaboration introduced a new paradigm of care that gives primary focus to “minimizing the symptoms of Alzheimer’s disease and related diseases, rather than focusing only on the search for a cure”. They maintain healthcare professionals are well placed to introduce affordable NPI interventions that may well bring “new life to the mind and body of people living with Alzheimer’s” whilst scientists continue to focus on their search for a cure (Raia & Koenig-Coste, 1996 & Zeisel & Raia, 2000, p. 2). The foundation work on “Habilitation Therapy” was published by Raia and Koenig-Coste in the mid 1990s (Raia & Koenig-Coste, 1996) and the concept, that relies extensively on NPI, has since been put into practice by Zeisel, in his role as director of the Hearthstone Foundation, and implemented at Hearthstone residential aged care facilities in New York, Connecticut and Massachusetts.

Habilitation therapy is based on two important assumptions: first, that the brain of a person with Alzheimer’s cannot be restored to its prior condition - hence therapy is not ‘re’ habilitative; second, that an innate drive exists in almost all people to maximize their potential, even when the person is affected by progressive cognitive deterioration.

Koenig-Coste (2004, p.7), in her book *Learning to Speak Alzheimer’s: A Groundbreaking Approach for Everyone Dealing with the Disease*, describes an “habilitated person” as using “the upper limits of his or her function, intellect, emotion and spirit”. She explains that the term “habilitation” implies that the therapy “aims to help people live and work through every day life”. This is achieved by staff and caregivers tapping into an individual’s “mood” in order to

“bring about a person’s ability to live and work to their full potential”. Based on five main tenets, the “habilitation therapy” seeks to meet the unmet needs of individuals. These tenets are:

1. Make the environment work by adjusting and simplifying the surroundings to allow for that sense of “perpetual loss” so widely experienced by individuals living with dementia and their carers.
2. Assume that individuals “can still register feelings that matter” and that communication is still possible.
3. Acknowledge that individuals have residual skills and focus on the remaining ability of each person.
4. Try to live in the individual’s world, and in that person’s reality.
5. Enrich each individual’s life by creating moments for success and praise (Koenig-Coste, 2004 pp. 7-8).

Raia and Koenig-Coste (1996), in their original “habilitation therapy” framework, expand on their view of the role of the amygdala. They speak to the role “emotion plays in therapy [which they maintain] is crucial and of significant importance in programs and quality of life treatment outcomes in dementia care and management”. Ratey (2002) simply explains the emotional function, purpose and critical importance of the amygdala. How the amygdala relates to dementia and art is discussed more fully in the colour and vision chapter of this thesis.

A new direction

Zeisel and Raia (2000) argue that programs that use care-giving environments and activities, those designed to maximize “cognitive capacities that remain intact while compensating for those cognitive capacities that decline”, have a significant role to play in the future direction of dementia care. Such environments have the capacity to help individuals “develop a sense of self and

belonging to a larger community” and this will “significantly enhance quality of life” (Zeisel and Raia, 2000, pp. 5-7).

Luree Miller (1993, p. 16) writes that “senility is a word loaded with history and horror...[and] the whisper of it in one’s own family creates such a profound anxiety it is next to impossible to think clearly”. Miller (1993, p. 25) observes that, “dementia and deteriorating mental ability does not occur swiftly and dramatically like a heart attack. It does not galvanize the family into action. It creeps like crab grass until one day the balance between healthy lawn and straggly weed is so apparent you can no longer ignore it”. It is this kind of plain statement, based on extended observation, that stirs authors such as Zeisel and Raia (2000) to call for research into new approaches to care that enhance the wellbeing and quality of life for individuals living with dementia; and not least their families. They also believe that along with a shift away from an “old culture” of dementia care, with its inherent “history and horror”, the development of new terminology is essential.

The new millennium

In the new millennium a steadily growing group of health care professionals around the world, with American dementia care specialists in the lead, have advocated with ever increasing persuasiveness, the benefits of NPI (Allan, 2003; Allan and Killick, 2002; Basting & Killick, 2003; Camp, 2001; Cody *et al*, 2002; Cohen, 1995 & 2001; Cohen-Mansfield, 2001; Gottlieb-Tanaka, 2004 & 2006; Kitwood, 1995 & 1997; Killick and Allen, 1999a, 1999b, 2001; Killick, 2000, 2003; Koenig-Costa, 2004; Kolanovski *et al*, 2006; Kovack *et al*, 2005; Levine Madori, 2007; McFadden, 2005; Raia & Koenig-Costa, 1996; Teri *et al*, 2000 & 2002; Thomas, 1996; Verity & Kuhn, 2007; Whitehouse and George, 2008 & Zeisel *et al*, 1994, 2003; Zeisel & Raia, 2002).

In 2006, select members of this group gathered at the UWM Centre on Age and Community (University of Wisconsin, Milwaukee campus) to formulate strategies to broaden the research scope and implementation of NPI. The final delegates' report (Bernfeld & Fritsch, 2006) concluded that person-centred care is the core element necessary for cultural change in this sphere. The unanimous finding of the delegates states that “creative-expressive programs have very few side effects, and have real potential to benefit the resident in terms of mood-related problems” (Bernfeld & Fritsch, 2006, p. 12).

The way ahead for research - the natural synergy between dementia and creativity

The delegates acknowledged that the way ahead will not be easy, particularly given that the general consensus in the aged care sector is that the “randomised controlled trial (RCT) affords the highest level of respectability in circles concerned with evidence-based practice” (Bernfeld & Fritsch, 2006, p. 12). They further acknowledge that “traditional instruments used to study persons with early-stage dementia are often inappropriate in long-term care, because resident’s dementias are so advanced” (Bernfeld & Fritsch, 2006, p. 12). The delegates maintain the best way for the aged care sector to understand the concepts and values of person-centred care, and its relation to the individual’s emotional wellbeing, is to conduct and publish research that investigates the natural synergy between dementia, creativity, and self-expression.

Montessori (1966, p. 207) wrote that “social change”, of the type proposed by the UMW delegates “cannot come from the ideas or energies of individual reformers” working alone, rather change will only come from “a slow and steady emergence of a new world in the midst of the old”.

The significant figures in the movement for dementia-specific cultural change.

In alphabetical order the following individuals, in conjunction with the development of original dementia-specific program designs, are working in unison to institute the emergence of “a new world in the midst of the old” through innovative program design and progressive education.

Aadlandsvik (2008, p. 326) contends that writing is often connected to the eye, and she is convinced that we can learn to “see” the inner world of those living with dementia by writing poetry. She shares her vision with John Killick (1997, p. 7) who has no doubt that the “language of those with dementia is poetry”.

Kate Allan and John Killick and “Dementia Positive”

Kate Allan and John Killick are the co-founders of Dementia Positive, an organization and partnership established in 1997 that focuses on the communication needs of those living with dementia (Allan & Killick, 2000; 2001; Killick & Allan, 2011a; Killick & Craig, 2012). The consultancy has been instrumental in promoting communication through creativity by expounding the virtue of individual and teamwork approaches to art and creativity; specifically, it has been instrumental in the introduction of the therapeutic use of the creative arts and poetry in Great Britain. Allan and Killick believe dementia is more than a medical condition and the care partner relationship can have a profound affect on the needs of the individual with dementia. They see their mission as developing new ways of communicating their work philosophy in support of individuals living with dementia and their care partners. Most recently, this includes an exploration of the creative use of modern technology (Killick & Allan, 2011b; Killick & Craig, 2012).

Kate Allan pursues these goals in her work as a clinical psychologist. Her specialist interest is in the communication needs of those with hearing

impairment and advanced dementia (Allan, 2001; 2003 & 2010). John Killick's approach is different but complimentary; for thirty years he was a teacher and took up fulltime writing in 1989. He has held writer-in-residence appointments in HM prisons and at the Dementia Development Centre at Stirling University in Scotland. He is widely known for his work in helping individuals living with dementia to create and publish their poetry (Killick, 1997; Killick 2003; Killick, 2009; Killick & Cordonnier, 2000;). In addition, in 2003, he collaborated with Anne Basting of the University of Wisconsin, Milwaukee on an arts and dementia care resource guide (Basting & Killick, 2003). Performances titled "The Funshops", where humour, laughter, playfulness, and a "carefree state of mind" prevail, are Killick's latest venture where he combines creative improvised drama and humour in partnership with the Scottish Dementia Working Group (Killick, 2010, p. 14).

The Dementia Positive website, www.dementiapositive.co.uk, publishes a comprehensive list of publications by the Allan and Killick partnership.

Anne Davis Basting

Dr Anne Davis Basting was born in 1965, and is founder and director of the University of Wisconsin Milwaukee Centre for Aging and Community, she represents the first of a new era of young and articulate "dementia as disability" advocates. Basting (2009, p. 159) is certain that the early diagnosis of dementia in a growing number of "baby boomers" will see "a joining of the disability rights and dementia advocacy movement". She points out that it is important for the public to become aware that dementia care advocacy is unlike the disability awareness movement of the past. She says "the disability rights movement's focus on independence is clearly not at the core of dementia advocacy"; indeed she challenges advocates for the rights and independence of individuals with disabilities, to properly consider the complex and interdependent relationship that those living with dementia have with

their formal and informal care partners. Basting believes care partners and dementia advocates from the baby boomer generation, a generation increasingly being diagnosed with dementia, have an important role to play by demanding greater access to person-centred care. She is confident that such a coalition will drive cultural change.

A disease of the environment

Basting (2009) makes the point that much current research into dementia dangles “the hope of scientific research” before the world, holding out the expectation of a cure. At the same time, she believes, the media hoopla that “clusters around” the merest hint of a scientific breakthrough has the effect of stalling the introduction of “concrete steps” that need to be taken in order to change attitudes and care practices. She (2009, p. 68) is certain that “Alzheimer’s is not only a disease of the mind but also of the environment” and that too often individuals living with dementia “are sewn into figurative straightjackets by institutions that tell them they are diseased, inappropriate, challenging, passive objects in need of care - ‘the living dead’”. In such environments, activity facilitators function in circumstances that Engel (1977) described as the “peck order”, where management and staff with vested interests uphold many stereotypical negative views of residents with dementia. This “peck order” ensures that only certified “therapists” with qualifications that pass biomedical standards, however inappropriate, gain access to positions of higher responsibility in healthcare settings, the kind of attitude that underpin an outdated old cultural view and one that needs redefining.

Basting (2009, p. 164) based on her wide experience, makes an astute observation when she notes that, “you don’t need to be a certified therapist to create moments of meaningful engagement” with individuals in aged care facilities. This is not to say that anything other than the highest standards of care and professional practice should be adhered to, it is simply to note that

the recipients of care are not always placed at the centre of the care equation. The reasons for this are due to a variety of reasons that are well documented by Engel and Kitwood and others; it is important to be historically aware of this background, but it is not the focus of this research study.

TimeSlips

Anne Davis Basting is also the creator and director of *TimeSlips*, a creative storytelling and writing program for individuals living with dementia. When speaking of the value of the creative arts in dementia care she writes (2006, p. 16-17) “the arts offer great value to people with dementia and warrant tremendous hope for the future”. She believes arts programs “designed to go beyond keeping people with dementia busy” are especially good for those individuals “who have edited themselves into silence for fear of saying the wrong thing” because “the root of silence” is part of Alzheimer’s disease. Basting designed *TimeSlips* to depart from the “once upon a time” disposition, i.e. the beginning, middle and end approach to storytelling. She (Basting, 2003, p. 25) writes, “as we age we learn to see that pattern as an ideal rather than a mirror to our everyday lives”. With this in mind, she chose a method for the program that “opens the storytelling process to incorporate any answers the group contributes” in which “facilitators present the storytellers with an image upon which they base their stories”. Basting is careful to choose photos that are obviously staged in some way, such as a woman flyer seated in an old by-plane, and she deliberately does not use photos of family members, or the family pet, or images that may elicit a strong personal connection.

The choice of staged images gives each storyteller a free go in creating a story where all creative ideas and contributions are acknowledged by the facilitator. Each participant’s contributions are written down without editing and read back to the group, “echoing the emotional responses as well as the literal language” as the story unfolds, until the group decides the story is finished.

The story is then typed and copied and presented to the storytellers and staff. Although there is increasing interest in the use of creative expression programs in dementia-specific care, *TimeSlips* remains one of the few programs to be researched in any detail to date (Bahike *et al*, 2010; Fritsch *et al*, 2009 & Phillips *et al*, 2010).

The Bradford Dementia Group and Centre at Bradford University UK

The Bradford Dementia Group is part of Bradford University's School of Health Studies and was established by Tom Kitwood in 1992. The group is a multi-disciplinary, multi-professional group committed to excellence in research and education, and the delivery of training to create an informed and effective workforce in line with the British National Dementia Strategy (Department of Health, 2009). Although, strictly speaking the group's work does not focus on the creative arts, in the Kitwoodian tradition, the group's mission is to make "a difference to policy and practice in dementia care" by working with practitioners and healthcare professionals to improve the wellbeing and quality of life for individuals living with dementia and their families.

Recently, individuals from the group, and healthcare experts from across Britain, worked intensively with the British Standards Institute to develop the first national guidelines for dementia care in the United Kingdom. The guidelines, launched in February 2010, are based on Kitwood's person-centred care framework and the Dementia Care Mapping program that was designed and developed by Kitwood and his colleagues at the centre in the early 1990s. Professor Murna Downs heads a nexus of academics past and present at Bradford Dementia Group who work to develop and further the Kitwood legacy in many areas, including the creative arts.

Cameron Camp and Montessori Based Dementia Programming (MBDP)

Maria Montessori (1870-1952) believed that "the systematic mastery of the environment [throughout history] met an innate need of the developing human

being from the earliest age and was the key to both individual development and the progress of civilization” (Kramer, 1989, p. 63). Malone and Camp (2007, p. 152) write that Montessori began her work with “underprivileged children thought to be ‘un-teachable’” and offered them “alternative ways to experience their environment”. Lillard (1972, p. 31 & 59) notes that Montessori rejected the prevailing Cartesian philosophical position and its influence on both medicine and education - an influence that divided the intellectual and the physical - throughout “her life as an educator with children from insane asylums and slums”. Montessori was careful to ensure that learning was undertaken in simple surroundings, preferably “relaxing and warm” and decorated in “bright and cheerful and harmoniously” arranged colours.

The idea of applying Montessori’s person-centred methods to dementia-specific care was a logical step for Cameron Camp in the early 1980s, and his interest in experimental psychology led him to develop Montessori Based Dementia Programming (MBDP). The activities Camp developed were tested at the Myer Research Institute in Ohio. They are based on building each person’s self-esteem and by addressing the “normal and healthy” psychological need of every human to belong in society and feel secure. The activities follow Montessori’s principles and are achieved through the implementation of a “normalized environment”. In this environment, staff members identify the skills of a “normal” individual, albeit one who happens to have memory deficits, and then the staff introduce an activity based on the individual’s past and present work or life experiences. The activities can be as simple as gardening or flower arranging or using a spanner in a men’s workshop project. Each activity is designed to meet the unique needs of that person, based on the imperative of improving the participant’s “physical, social and emotional engagement” with his or her environment. The creation of activities that have meaning, plus the provision of “clues” to help the individual successfully complete the activity, almost invariably means, a positive outcome will be achieved.

Gene Cohen - linking ageing and creativity

The late Gene Cohen (1944-2009) was professor of health care science and psychiatry, and the director of the Centre on Ageing, Health and Humanities at George Washington University. Reflecting on the early days of his career in aged care, *The Creative Age: Awakening human potential in the second half of life* (Cohen, 2001) he writes:

Not so long ago, old people were considered a dead-end career choice for a young doctor... The teachers and colleagues who questioned my sanity and career choice had good reason to do so. Where I saw a field of pioneering discovery, they saw no field at all. They saw a wasteland. Influenced by the myriad negative myth and stereotype that painted hopeless and depressing pictures about work with elderly patients, they wondered if I had a morbid fascination with dying and decrepit old folks. My view could not have been more different; quite apart from what can be done to help those who are dying, these individuals were in fact *living*, and I was certain that many could be living better - much better (Cohen, 2001, pp. 1).

Cohen was quick to realize the residents of aged care facilities he entered were not a “morbid, immutable lot”, as his colleagues had suggested, but rather he observed older individuals who “were quite realistic in their expectations and savored greatly any improvements through medical treatments or therapy” (Cohen, 2001, p. 2). This sparked his interest and he began to observe his patients more closely. Soon Cohen’s (2000) research indicated that the desire to participate and to create is common in the aged. He also discovered that a loss of physical energy, or even a disability, would often result in individuals experiencing a new and heightened level of creative energy.

Cohen (2006b, p. 9) has embraced Robert Ader’s stream of scientific research called ‘psychoneuroimmunology’ which focuses on the ‘interplay’ between creative energy and physical and emotional health and wellbeing. Cohen (2000) consistently advocated the implementation of expressive art therapies for the

elderly, and believes not only do such therapies have positive effects on serious disorders, but the processes generated through engagement in creative self-expression facilitates the individual's efforts to cope with emotional and physical pain. One study by Cohen (2005) found participation in art activity increased physical energy levels while decreasing medication levels and visits to the doctor. From his experiences, Cohen concluded that the 'interplay' between creativity and wellbeing is inherent in all of us and that age and disability do not need to be a barrier; indeed, it can often be a stimulus to the creative process.

Similarly, Reed's (2005, pp. 10-11) study on creativity and lifespan development found that most older artists, "attributed their improved creativity to experience" and that "consistent work habits" evolved out of the "reliable skills of maturity". Reed comments that as we age, "the process" can become "more important than the product" (Reed, 2005, p. 15). The following examples of well-known artists appear to reinforce this observation.

Age and disability no barrier

Despite macular degeneration and progressive visual loss in old age, Schmidt (2006, p. 29) explains the painter Georgia O'Keefe's (1887-1986) "curiosity, coupled with a deep desire to remain vital led her to different media". O'Keefe continued to paint in oils and watercolours and experiment with pen and ink until she was legally blind. She then busied herself by directing artists to paint images for her. O'Keefe spent her final years developing her "tactile senses" in another media by creating ceramic artworks (Drohojowska-Philp, 2004). The centenarian artist, known as "Grandma" Moses (1860-1961), another of America's favourites perfectly illustrates that age and pain is no barrier to either creativity or productivity.

Grandma Moses, in a hand written note entitled "*How do I paint*" (Kallir, 1973, pp. 145-146) writes she began her painting career at 78, because she was "unoccupied" after her husband died and had to have "something to do". Moses says she couldn't work on her farm when her "neuritis and artheritis" (sic) got "so bad". She writes that her new career began slowly at first and found painting a "very pleasant hobby if one does not have to hurry". Even in the early days, she is soon enjoying painting commissions if only "to live up to my promises". With homespun simplicity, reflecting no doubt a strong puritan work ethic, Moses' advice to would-be artists is "not to take it up for a business proposition, unless they really have talent, and are crippled so as to deprive them of physical labor". In her hundredth year, with her left hand supporting her right "painting" hand, Moses worked on completing some twenty-five pictures, each recording the seasonal life and times of small town America in a by gone era. The final images were described as "dissolved into colour". In her final months, when ordered to rest in bed by her doctor, Moses strongly protested that she was wasting good painting time.

Creative self-expression through painting and other media would seem to present an ideal past time for many ageing individuals, such as Grandma Moses, who for the first time in their lives actually have time on their hands for art and creative self-expression. Lane (2010) believes that age provides the perfect opportunity to start exploring the possibilities of self-fulfilment. He describes later life as a "time for experiment and creativity, time for exploring our different potentials, time to live in accordance with our dreams, [and] time to be ourselves" (Lane, 2010, p. 16).

The creative arts and their application in dementia-specific care

Turning to the creative arts and their application in dementia-specific care, Cohen believes creativity is both an emotional and an intellectual process, and is "universally recognized as a basic human attribute". He is convinced

understanding the capacity of creativity in relation to dementia “is profound” (Cohen, 2000, p. 12). He maintains using creativity as a “mechanism” in dementia care creates an opening for individuals to “displace negative feelings, such as anxiety or hopelessness, with positive feelings of engagement and expectation”. Cohen advises, (2001, pp. 5 & 7) aged care service providers to “peel away negative stereotypes that muddy the waters” and try to understand that “the potential for creative expression in the second half of life is not the exception but the rule”.

Judith-Kate Friedman and *Songwriting Works*

Judith-Kate Friedman is a multi-award winning composer, musician and song writer who created the *Songwriting Works* program in the early 1990s when she was a California Arts Council, ‘artist-in-residence’ at the Goldman Institute on Aging. Friedman facilitated the program in cooperation with many youth and intergenerational groups, and more recently her work has increasingly been with individuals living with dementia in long- term care facilities.

Friedman (2010) believes that all people have innate musical ability and creative gifts. As she puts it, “when we get together we talk, we laugh, we improvise and find collective joy”. She describes her work as akin to “musical mural painting”. *Songwriting Works* is structured to encourage group participation and musical improvisation based on the exchange of ideas and stories.

The *Songwriting Works* process

Under Friedman’s musical direction, participants initially “warm up” to the process by singing a familiar song that is appropriate to the group’s background and age. The theme of the new song is created by “work-shopping” ideas that are written on a whiteboard. Phrases and words and rhymes and alliterations relevant to the theme soon emerge. These phrases become the lyrics of the

new song. Friedman, as music facilitator, then sets the lyrics to music. The group rehearses and then, after some minor adjustments, they perform their new and original song together. Friedman's *Songwriting Works* program literally "gives a voice" to the thoughts and aspirations of the many varied groups who participate.

Dalia Gottlieb-Tanaka and the Society for the Arts in Dementia Care

Dalia Gottlieb-Tanaka is an architect and founder and president of the Society for the Arts in Dementia Care (CECD) Canada. According to its website, the Society is built on the premise:

That people living with dementia have the right to dignity, to be heard and to be valued. The Society provides an interdisciplinary forum for creative expression in dementia care, bringing together academic research and practical knowledge through collaboration between the medical profession and the creative arts. The Society aims to disseminate knowledge and establish ties with dementia care organizations worldwide, thereby improving the quality of life for people with dementia (www.cecdsociety.org).

Gottlieb-Tanaka's personal and professional contribution to the development and promotion of dementia-specific creative arts in North America is significant. Not least she has been the convener of an annual international CECD conference on creative expression and dementia since the Society's inauguration in Vancouver in 2001. Her professional contributions include the design and development of the award-winning *Creative Expression Activities Program* that was successfully implemented in British Columbia in the early 1990s (Gottlieb-Tanaka, Small & Yassi, 2003; Gottlieb-Tanaka, 2006a). The program has gained Gottlieb-Tanaka both The American Society on Aging and the MetLife Foundation awards.

Moriarty (2003), in a review of Gottlieb-Tanaka's work, observes:

Wanting to take forward a traditional program for the arts and crafts

instruction into something that would engage more fully with the interests of people with dementia, Dalia found that there was no practical tools or materials available that would help her to do so. At first she used her own personal intuition, and now she is undertaking research based on interdisciplinary theoretical models and including input from older people, their families and carers and staff and volunteers (Moriarty, 2003, p. 125).

Gottlieb-Tanaka conducted this research over a four year period and the findings are laid out in her 2006 PhD thesis for the University of British Columbia. In that thesis, Gottlieb-Tanaka (2006) writes extensively about “everyday creativity, personhood and empowerment” and improvement to the quality of the lived experience of those living with dementia. In an earlier article titled “Creativity, Dementia and the Therapeutic Environment” (Gottlieb-Tanaka, 2004) she writes: “An understanding of the interplay between the cognitive and physical abilities of a person with dementia, and the need for creative expression activities and a therapeutic environment, can make a difference in quality of life” (Gottlieb-Tanaka, 2004, p.10).

The “transforming power of art”

Gottlieb-Tanaka believes in what she describes as the “transforming power of art” and that it can be directed through a creative arts therapy approach to dementia care. During her research she could not find practical tools or published guidelines on which to base creative expressive activities; nor could she find any appropriate research tools by which to measure the “power of art”. Gottlieb-Tanaka maintains that whilst individuals engage in creative activity they are “transformed” in different ways. She realized early in her research that to gauge such transformations close observation of wellbeing domains - such as and including memory, attention, problem solving, and emotion - needed to be observed and recorded *during* the creative activity. With the assistance of her colleagues, Peter Graf, Professor of Psychology and

director of the Memory and Cognition Laboratory at the University of British Columbia, and Hilary Lee, an occupational therapist in Perth Western Australia, she designed The Creative Expressive Abilities Assessment (CEAA) tool. CEAA was thoroughly tested across a wide range of abilities, in Canada and Australia during 2007/2008 and was published in mid-2008.

The Creative Expressive Abilities Assessment tool in more detail

The CEAA assessment is designed to provide a new and much needed dementia-specific wellbeing measurement tool. The CEAA is predicated on Dr Gene Cohen's notion that an individual's creative abilities act as critical keys in determining wellbeing and quality of life (Cohen, 2001). The CEAA is based on "solid quantitative research" and designed specifically to "obtain in-depth information about the expressive abilities" of individuals living with dementia as they participate in creative expressive activities.

Gottlieb-Tanaka's post-doctoral research work is a comprehensive analysis and investigation of the role and use of creative arts therapies in current literature. The publication of this research is destined to make a significant contribution to future public awareness of the value of the creative arts in aged and dementia-specific care worldwide.

Like Lokon and the Opening Minds with Art (OMA) program

OMA, the Opening Minds with Art program, is a person-centred intergenerational art program for individuals living with dementia founded by a textile artist named Like Lokon. Lokon is also a gerontologist and a research associate at Scripps Gerontology Centre at Miami University in Ohio. The OMA program is based on Kitwood's principle and theory that every person living with dementia is capable of creative expression and Lokon says her main mission is to "build bridges across age and cognitive barriers" (Lokon, 2011).

The OMA program runs once a week at the Scripps Centre for ten weeks. During this time Lokon conducts skill-based training with staff and volunteers in the aged care sector. The training includes information on the basics of dementia and communication linked to the facilitation of techniques suitable for use in one-on-one art activities that promote creative expression in the workplace.

In a presentation to the Society for the Arts in Healthcare Conference in San Francisco, in April 2011, Lokon (2011) explained that the activities are designed to be “complex but easy to do” and trainees are taught to present activities in such a way that the individuals living with dementia can “make manageable and failure-free choices”. The activities allow participants to “go with the flow” and become “active agents in the creative process”. Lokon believes that “educating the public in the positive aspects of dementia care” is paramount. As she puts it, “I try to educate the public about everyone’s creative potential into later life” and that is why each OMA program culminates in a gallery exhibition of the participant’s work at the conclusion. She thinks that this is the best way to “show the public what individuals living with dementia can do”.

Linda Levine Madori and Therapeutic Thematic Arts Programming (TTAP)

Linda Levine-Madori (2007) says she designed and developed Therapeutic Thematic Arts Programming (TTAP) because, like Gottlieb-Tanaka before her, she found that in the 1980s and 1990s there was “a complete void as to what type of therapeutic programs could be implemented” for individuals living with dementia (Levine-Madori, 2007, p. 114). TTAP is based on a humanistic approach that has emerged from the developmental and lifespan theories of Erikson (1959) and Baltes and Baltes (1990) and the fundamentals of recreation therapy. These theories form the program’s theoretical underpinning. TTAP is designed primarily to stimulate areas of the brain using the creative arts, such as art and music, incorporating current personal interests and also past pursuits

developed across the lifespan. Levine-Madori (2007, p. 59) writes that the goals of the program are “accomplished using connected, creative activities around a theme to provide a stimulating and rich group experience”. The activities are designed to increase wellbeing, particularly for older participants. She says the essence of TTAP for individuals with Alzheimer’s “lies in the assessment of both the weaknesses and strengths that emerge within the course of the disease”. Once each person’s strengths have been determined they can then be incorporated into a nine-step plan by the recreation therapist to suit the individual at his or her level of communication and physical ability. Levine-Madori says once a theme has been decided, the therapist follows the nine steps until each participant completes the activity. She explains the steps can be varied and are dependant on the type of activity chosen and the nature of the group.

“Memories in the Making” program

The “*Memories in the Making*” program was designed in California in 1983 by Selly Jenny and Marilyn Oropeza. The program was initially developed in conjunction with the Alzheimer’s Association of Orange County with the intention of raising funds for the non-profit organization’s educational program. It was thought the artworks created by those living with dementia would create public awareness of Alzheimer’s disease while sales from the exhibitions, and reproductions of artworks on greeting cards and calendars, would produce much needed revenue. It soon became apparent that the value of the program, with its emphasis on creative expression and reminiscence, created something of immense value for the contributing artists.

“*Memories in the Making*” is not a traditional art therapy activity in which the artwork is interpreted by a therapist, but instead each participant is encouraged to paint and name a picture that tells a story. The art facilitator provides the art materials and supports the artist by listening and validating the various expressions of emotion and feeling. The images from memory are

both created and recreated in what “Sam” Heinly, the current national training manager for the program, describes as a “failure free” environment.

A more detailed discussion of the “*Memories in the Making*” program, including a summary and an analysis of the research finding into the efficacy of the program, appears in Chapter Two - A consideration of published information on art and dementia and wellbeing, in this thesis.

Kenneth Rockwood and the Capital Health Memory Clinic artist-in-residence program in Nova Scotia, Canada

Kenneth Rockwood’s (2004) experience is similar to Cohen (2000) and he writes that there is a general public perception that working in dementia care “must be depressing”. He thinks this perception “seems to impair recruitment of trainees and perhaps even institutional and public support for people with dementia”. With these factors in mind he developed an artist-in-residence program in Halifax, Nova Scotia in 1998. He stated, “goal at the outset was to show that our work was not depressing”. The program was established to help establish the “therapeutic ambience” of the clinic, thus enabling “clinicians to see themselves through the patient’s eyes”. Rockwood believes this is important because he has found that “brain-modeled environments” shape the clinician’s world while “the patients experience typically receives short shrift, as we focus on the seemingly more ‘objective’ (commonly taken to mean ‘important’) parts of our work”. He says although funding was a problem at first, it is now organized through the hospital’s charitable foundation and the artists-in-residence are chosen through “annual competition” applications. The artists are observers and do not paint directly with those living with dementia because, Rockwood explains, the “experience of the artist as observer” is the point of the program. He says the fact that artists are not necessarily “blinkered” by past “medical experiences” of dementia allows them to create images that are “narratives of the patient experience”. The artworks perform two useful functions: firstly, they document the emotional impact of dementia;

and, secondly, the medical student's "interaction with the art" has been shown to aid in the development of insights through observation in the trainees. He says the expectation is the "artists will, at some point in their residency, contribute to our understanding of dementia, and even to the addition to new knowledge".

Rosalia Staricoff and the Chelsea and Westminster Hospital arts in healthcare research study

The unique and scientifically evaluated research study and trials conducted by Rosalia Staricoff (2004), into the effects of the visual and performing arts in health care, at the Chelsea and Westminster Hospital, London, between 1999 and 2002, are not dementia-specific *per say*. But given that the increased number of older individuals likely to fill hospital beds in the near future will be admitted *because* of some form of dementia Staricoff's research findings are important and worthy of inclusion.

The research study review of the medical literature from 1990 to 2004 was published as a ninety page report for the Arts Council of England. In her summary (Staricoff, 2004, p. 8) of the effects of the arts on mental health, which includes many references to dementia specific care, Staricoff writes:

The use of the arts in mental healthcare helps to improve communication skills of mental health users, helping in the relationship with family and mental health providers. It also provides patients with new ways of expressing themselves, stimulates their creative skills and enhances self-esteem. The use of the arts in mental health services also brings about behavioural changes in mental health users: patients become more calm, attentive and collaborative. These changes help in the everyday managing of a mental health service, diminishing the need for medication and physical restraints (Staricoff, 2004, p. 8).

Notwithstanding, the Staricoff (2004) report has come under criticism. Peter Scher (2004), writing in *Hospital Development*, comments on the Staricoff literature review:

Do we really expect to find direct proof that design and the arts cure illness? If proof were found we would presumably expect massive funding from health care budgets for the work of designers and artists comparable with that spent on the work of clinicians. Not surprisingly no such proof has been found (Scher, 2004).

One rebuttal to Scher's criticisms is that, unlike pharmacologic interventions, NPI does not claim that curing illness is its therapeutic objective. NPI's purpose is to add quality and meaning to life, and add value in aged care and in the wider community, and consequently should be assessed by appropriate performance criteria using well documented and proven qualitative and mixed method research tools (Baltes and Baltes, 1990; Burgess, 1954; Havighurst 1961; Havighurst & Albrecht, 1953; Lemon *et al.*, 1972; Menec, 2003 & Brod *et al.*, 1999; Neugarten *et al.*, 1961; Rowe & Kahn, 1997).

Bill Thomas and *The Eden Alternative*

In the early 1990s, Dr Bill Thomas, a young Harvard medical school graduate was so concerned by the plight and living conditions of the elderly in institutional nursing homes in the United States that he developed a new model and philosophy of care. Thomas' model of care philosophy is internationally known as *The Eden Alternative*. The name evolved because Thomas and his partner, Judith, were inspired by the concept of beauty in the "Garden of Eden" as described in Genesis. Armed with the idea that "it is better to live in a garden" than in the "cold, sterile" hospital wards characteristic of nursing homes of the period, they formulated the concept of small home environments called "Green House" habitats for individuals living in residential aged care. Thomas (1994 & 1996) explains that pets and gardens and children have a vital role to play in this "green" environmental habitat and that each is positioned to alleviate what Thomas describes as the "three plagues" of aged care - "boredom, helplessness and loneliness".

Thomas describes *The Eden Alternative* as a “complete principle-centred philosophy” offering a “creative way” to de-institutionalize aged care facilities and enhance the emotional wellbeing of residents whilst, in the process, introducing sustainable cultural change.

Even though Thomas has overseen the successful introduction of *The Eden Alternative* in all of the fifty states of the United States, and worldwide in Europe and Australia, his model and its operation is not without its critics. Peterson and Warburton (2010, p. 128) claim that the concept of the introduction of plants and animals is “rejected as naïve by some gerontologists”, and these authors also claim that the “efficacy” of *The Eden Alternative* has not yet been proven because all previously published analysis to date of Thomas’ methods “lack rigor and critique”.

Jane Verity and the *Spark of Life* program

Jane Verity, the founder and director of Dementia Care Australia, developed the *Spark of Life* program two decades ago, after training with Tom Kitwood at Bradford University in the early 1990s. Verity is credited with bringing the concept of person-centred care to Australia. As a mark of the international success of this program, the *Spark of Life* was awarded the 2009, international, Global Ageing Network award for excellence in ageing services. Verity’s philosophy (Verity and Kuhn, 2008) is overwhelmingly an optimistic one. She believes the practice of person-centred care is an art form that requires subtle “ability, [and] creativity and insight”. Verity’s years of experience have shown her it is possible to “rekindle the spark of life in people living with dementia and those who care for them”, using a person centred approach to care, with particular attention to communication and relationship development, set in an atmosphere “where the human spirit can thrive”. The *Spark of Life* program is designed to offer “simple practical solutions” to everyday challenges at home and in residential aged care. Solutions are achieved by care partners and skilled care staff who are trained to work at a “detailed, personal level to

reach [each individual's] deep emotional core", and to identify the unmet needs of those in their care. The *Spark of Life* program has been adopted by aged care facilities in the United States, in Europe and Australia, and the program is often run in conjunction with the *Eden Alternative*. In Australia, Verity is assisted in her endeavour by Hilary Lee.

John Zeisel and the Hearthstone Foundation

John Zeisel has made a major contribution to the development of the non-pharmacological intervention approach to dementia care over the past two decades. Zeisel's early background was steeped in art and learning. His mother, Eva Zeisel (1906-2012), was a ceramic artist and his father, Hans Zeisel (1905-1992) was a respected statistician and legal scholar.

John Zeisel founded The Hearthstone Alzheimer's Family Foundation in 1995; firstly, to provide support and education to the five million people living with Alzheimer's disease and their care partners in the United States and, secondly, to initiate scientific research that included evaluation components and, thirdly, to promote the wider use of non-pharmacological interventions in dementia care generally.

The Hearthstone approach to care is based on years of clinical experience, linked with a thorough knowledge and understanding of the neuroscience of the brain. To achieve their educational and training goals, Hearthstone has instituted various other creative approaches that include communication training involving care partner participation. Hearthstone has also had significant success delivering education and training program on alternative health care provision with an emphasis on diet and exercise.

Other programs Zeisel has already instituted at Hearthstone are explained in more detail throughout the first chapters of this thesis. Some of his programs and interventions include the introduction of innovative environmental design

and therapeutic gardens in facilities. To raise awareness of Alzheimer's disease, the Foundation is responsible for the implementation of the highly successful *Artists for Alzheimer's* program in art galleries in North America, Europe and Australia followed by *Swansongs* - a travelling musical and story performance - and the *I'm Still Here* travelling art exhibition.

The Hearthstone Foundation's overarching goal is to increase the scope and influence of non-pharmacological options in dementia-specific care and, by doing so, increase the wellbeing and quality of life of those living with Alzheimer's disease and that includes the families concerned. This is not to say that drug treatments are avoided or dismissed altogether, but rather the Hearthstone way is best described as the moderate coordination of proven non-pharmacological interventions in conjunction with medication in a holistic approach to care planning and service delivery.

Conclusion

This chapter documented, in a brief compass, a history of dementia by setting the concept in both an historical and a contemporary context. The purpose was to better understand the lived experience of individuals with dementia in care today, so that advances in research in this field may be made.

The chapter began with the debate on ageing in ancient times and continued through to the demise of the "fool" in society, after the invention of printing and the rise of Rationalism in the 17th century. Evidence was cited that indicates that the Cartesian rationalist concept of the separation of the mind and the body had a profound affect on societal attitudes at the time and still influences medicine today.

It was found that many notable writers of the 17th, 18th and 19th centuries generally satirized the effects of ageing, but many also documented the "back-

wards” fate of individuals living with dementia and others that society felt were undeserving of support. The fate of the disabled under the Nazi doctors, in the darkest era of modern history, remains a powerful salutary lesson to society. If anything good emerged from this period it was society’s reaction to the excesses of such inhumanity. The end of World War 2 heralded a new era as it saw the birth and introduction of creative arts therapies into hospitals and institutions.

This chapter followed the evolution of a new person-centred approach to therapy and, by extension, the care of those living with dementia influenced by the ideas and theories of the humanist philosophers of the 1950s. This chapter identified the key figures who continue to challenge the common assumptions, negative stereotypes and nihilistic attitudes that still surround dementia, and it outlined their collective direction and goals to create more humane living conditions for those in care.

Finally, this chapter ended with the further identification of significant individuals who believe there is a “natural synergy” between art and dementia. These individuals are leading a cultural change movement by championing the right of individuals to person-centred care by advocating for the expanded use of non-medical treatments and non-pharmacological interventions in dementia-specific programming. This chapter has set some of the lived experiences of those with dementia in the past in an historical and contemporary context and identified that there are few original dementia-specific creative art programs in existence. As a result, research into the role and use of art in dementia-specific care is rare.

This research project is primarily concerned with researching the lived experience of individuals today during a dementia-specific art activity. The next chapter explores colour and vision and dementia. It documents the research findings of leading scientist who are exploring the impact that both

these factors have on the lived experience of those living with dementia, including the ability to participate in art and enjoy creative pursuits.

CHAPTER FOUR

Colour and vision and dementia

Even without words, we speak the same language in colours

Holly Queen-Daugherty (2001)

This last chapter set some of the lived experiences of those with dementia in the past in an historical and contemporary context and identified that there are few original dementia-specific creative art programs in existence. As a result, research into how individuals living with dementia react to colour and enjoy their experience of art during dementia-specific art activities is rare. And, any research that has been undertaken is mostly scientific and technical.

The aim of this chapter is two fold. Firstly, the aim is to set colour and vision in an historical and modern landscape by bringing together the thoughts and observations of leading colour and vision experts with those of academics studying dementia in relation to the neuropsychology of art. And, secondly, the aim is to present these findings in non-technical language and in as straightforward a manner as possible. This combination presents an opportunity to gain new understanding and a unique perspective on colour, dementia-specific art and the creative process. A stock resource in plain language that documents how colour and art contributes to the lived experience of those with dementia is therefore timely.

Colour is not a trivial subject

Oliver Sacks is an internationally respected physician, neurologist and writer, who was born in London in 1933, but has lived in New York since 1965. He is currently Professor of Neurology and Psychiatry at Columbia University. For decades, Sacks has been interested in, and curious about, the origins of colour. His case studies on the impact of colour, plus the artistic creations of his many

clients over his long career, have prompted him to remark that, “colour is not a trivial subject”. He says that even though the problem of colour has tantalized the imagination of natural scientists, poets and philosophers, for centuries he has observed that, “most of us, most of the time, overlook its great mystery” (Sacks, 1995, p. xv).

Sacks (1985, 1995 & 2007) believes emotional connection and resonance is created through art and music and the phenomenon of colour, but regrets empirical science does not consider what determines “personal being”, or has any time for what we still refer to as ‘the soul’.

The neurologist’s vision

In Sacks’ (1985) experience, the combination of colour and art can play a particularly relevant role in forming important links and connections to the outside world for those living with neurological disorders. He wonders whether there are philosophical as well as clinical lessons to be learned from dementia, and other cases of organic damage to the brain, as he firmly believes in the “undiminished possibility of reintegration by art”. He maintains much can be learned by “touching the human spirit” of those living with dementia through the creative arts and much “can be preserved in what seems to be at first a hopeless state of neurological devastation” (Sacks, 1985, pp. 37-38).

Science sees the light - piecing the mosaic together

Both Oliver Sack and Rudolph Steiner (1861-1925), the Austrian philosopher and educator, have been inspired in their work by the German poet and philosopher Johann Wolfgang Von Goethe (1749-1832), particularly his treatise on the theory of colour, first published in 1810 (Sacks, 1995 & 1996; Steiner, 1994). Goethe was one of the first creative thinkers to challenge Isaac Newton’s (1642-1727) scientific interpretation of colour. In 1660, Newton separated

white light through a glass prism. The conclusion he drew from his experiment led him to believe that trapped decomposed colour from the sun formed a rainbow colour spectrum in white light. Nearly two hundred years later, whilst writing his 1,400 page manuscript on the theory of colour, Goethe contends that “optical illusion is optical truth” and, from this position, argues that colour is not trapped in white light at all, but is instead a perception and interpretation, linked by connections between the soul and the brain (Sacks, 1995, p. 22).

The argument was finally settled with the help of modern science, in the form of the optical telescope, and the discovery of the “fundamental architecture” of the retina. This discovery was informed by photographic images of different receptor types in the eye. When all the information was gathered, at last, armed with an understanding of the unique pattern of human retinal photoreceptors, modern scientists were able to piece together the individual bits of the puzzle to complete the colour and vision mosaic.

Finlay (2002) describes the phenomenon of colour, throughout the pages of *Colour: A Natural History of the Palette*. She writes (2002, p. 9) colour is just “the vibration of emissions of light”, and that, like scent or sound, it is “an invention of the human mind responding to waves and particles that are moving in particular patterns through the universe”.

How the visual system works

In a more scientific explanation, Piper (2008) informs us that colour vision is the ability to detect light. He says at the back of the eye, the retina contains 100 million light sensitive rods and 5 million cones that convert light into neural signal. To perceive colour we need an iris to control how much light enters the eye and a lens to focus and direct photomagnetic light onto the retina. Livingstone (2002, p. 87) writes, “we can perceive millions of colours -

amazingly - we do so using only three different kinds of light receptors". In more detail, Williams (Piper, 2008) explains that, there are three different channels in colour vision and three different types of photoreceptors - red, green or blue - arranged in a unique mosaic pattern. Cones are sensitive to all wavelengths in the visible spectrum of light. Electrical signals are sent down the optic nerve to the visual cortex, the brain's control centre, where they are sent to other parts of the brain for analysis. After the signals are processed for colour, distance and movement they are returned to the visual cortex, where all of the elements combine and complete a full colour picture.

Zeki, (Piper, 2008) explains what reaches the eye is electromagnetic radiation and there is nothing in light to indicate what colour will be generated. In *Inner Vision: An Exploration of Art and the Brain* (1999), Zeki details the process by which colour is generated in the visual cortex and other specific parts of the brain. His book presents the monochromatic world experiences of individuals living with the aftermath of stroke. First hand accounts have reinforced the idea that colour is a result of light waves reacting with pigments. The pigments trigger electromagnetic signals which produce colour perceptions that belong to, and are solely a product of, the brain. Sacks (1995, p. 27) credits Zeki with the honor of being the individual who "was finally able to prove" that a specific colour centre exists in the brain.

Zaidel (2005) citing Kalat (2002) and Shafritz, Gore, & Marois (2002), draws our attention to a more detailed psychological explanation of the process. She writes (Zaidel, 2005, p. 79) that these authors agree "separate neuronal pathways process colour and forms, and their integration into a single composition is a reflection of *binding*, a psychological concept that explains the integration of several distinct functions".

The process of *binding* is totally dependent on the overall health and function of the eyes. Vision quality, the role of the rods and cone receptors in colour

processing, when combined with neurotransmitters, such as dopamine, all play significant roles. Each has the potential, in all artists, to alter visual acuity and colour perception. Another factor is the amount of light entering the eye. Light affects overall clarity of colour, how images are seen, and how they are reproduced. Zaidel (2005, p. 59) explains that “we see shapes, forms, colour and patterns in the external world because they reflect light that enters the eye and stimulates special receptors in the retina which, in turn, give rise to sensations of colour. The retina itself is brain tissue and the photoreceptors are actually specialized neurons”.

The historical background to colour and visual art

Although scientists have identified that some insects and birds can see colour, Livingstone (2002, p. 38) writes, that “the parts of the brain that process colour information [to a complex level] are present only in primates”. This indicates that the use of colour in visual art has been central to human existence since pre-historic times. There is general consensus that simple diagrams, such as line drawings in the sand, were the foundations of representational art. These drawings had practical application too, as when used to direct others to a ready food supply or to pinpoint enemy positions and formations and explain battle plans. As human populations increased, body decoration and ornamentation are thought to have emerged as a way of identifying social group membership and the social status of individuals within those groups. When early human societies gained more control over their environment and their food supply, it enabled such groups to engage in activities beyond everyday survival. Communal activities such as singing, dancing and drumming emerged, allowing the more talented artists within these groupings to begin painting and carving three-dimensional figures (Dissanayake, 1988).

Zaidel (2005, p. 179) adds that “one form of cognition on which art relies, as does language is abstraction, and symbolic representation [that] may be expressed in music making, dancing, praying, and social clustering”. Zaidel reminds us that all societies practice art because “art is a human-made creation with a social anchor that communicates ideas, meanings and emotions. [Art] represents talent, skill, [and] creativity, [and] it gives rise to pleasure through the elicitation of an aesthetic response, even while for the most part, [it] does not seem to have a direct utilitarian purpose” (Zaidel, 2005, pp. 3-4). Finlay (2002, p. 78) puts it simply, “wherever and whenever men and women have lived, they have painted”. And, Mendez (2006, p. 5), adds, “art does not represent objects as they appear to the eye but, rather, reflects basic neurocognitive mechanisms and interpretations” that are central to the uniqueness of humans. Humans have exploited pictorial symbolism utilizing colour since early times and it remains one of the most effective and universal forms of communication.

A living cultural link to the past

For one ancient still surviving culture, colour and art continues to perform an important utilitarian function. A study of this culture demonstrates a direct link to the powerful relationship humans have always maintained with colour and symbolism. Traditional Australian Aboriginals practice “the longest continuous painting tradition in the world”, as well an ancient oral tradition using art and dance and music in storytelling (Finlay, 2002, p. 26). Tacon (Piper, 2008) explains how the use of particular colours “links everything together” in Aboriginal culture. He says colour embodies spirituality and perpetuates traditions and creativity. In the Rainbow Serpent “dreamtime” stories, for example, the ancient symbols and the ceremonial images painted on rock faces and in caves have linked Aboriginal people to the land and the animals and other individuals for tens of thousands of years. Spivey (2005) maintains the Aboriginal oral tradition has survived this long because the stories have been

combined with music. He says, modern Aboriginal painters learn the meaning attached to images and, in turn, the same images seen over and over, act as triggers to keep alive links to stories they already know. Attenborough (Spivey, 2005) believes the key to Aboriginal storytelling longevity is because the stories do not exist by themselves. In highly charged emotional moments that captivate and transport the artists to an imaginary world - through body painting and dancing, and singing and the musical rhythm of click-stick and the didgeridoo - Aboriginals come together and create a lasting memory of the narrative.

Vision and Alzheimer's disease

Mirzeoff (2007) makes the point that vision is an intellectual process, and although painting is a predominantly a visual process Miller and Hou (2004) observe there is little research on the regions of the brain that involve the visual and artistic process in those living with dementia.

Whittaker, Burdon and Shah (2002) note that disturbances in pattern processing and recognition are common and well documented in Alzheimer's disease. This may result in reading difficulties, blurred vision or an inability to recognize faces or pick out individual objects in groups. The reason for visual field loss may be a result of a significant loss of neurons and optic nerve axons within the visual cortex. Pache *et al.* (2003) links the loss of photoreceptor cells in the visual cortex to the presence of the characteristic plaques and neurofibrillary tangles associated with Alzheimer's disease and a lack of melatonin receptors.

Trevor-Roper (1970, p. 169) informs us that the "occipital area of the brain on which the visual images are reproduced and then perceived by the mind lies adjacent to the parietal area in which such precepts are coordinated and rationalized". Miller and Hou's (2004) research has shown that focal degeneration of both the parietal and temporal regions occurs as a result of the

progressive nature of Alzheimer's disease and this often causes impairment in visuospatial processing and functional skills. Goldman-Rakic (1996) observes that visuospatial skills are basic skills required to paint and draw, and to grasp objects within a field of view, and not get lost in familiar surroundings. The degeneration of these skills lead to predictable changes in both an artist's precision and ability to judge spatial relationships such as perspective and depth. Maurer and Prvulovic (2004, p. 236) write that, "artistic techniques such as drawing, painting and sculpturing [sic], require the integration of a wide range of visuospatial and visual motor skills". They say colour and form are informed by the occipital and temporal cortical areas and perception of space and movement are informed by the parietal area. Damage in any of these areas will "reflect the structural and functional organization of an artist's brain" and can be seen to affect drawing, depth perception, angle discrimination, visual attention and motion detection in the artworks of those with Alzheimer's disease. Wijk *et al.* (1999) report, surprisingly, that although individuals may experience predictable and impaired artistic precision (as mentioned above), there is often well-preserved visual acuity and colour vision.

A new scientific view of colour and art

Zaidel, in her book *Neuropsychology of Art* (2005) draws together colour and art and examines the impact of neurological disorders on the brain applying a relatively new science called neuropsychology. Zaidel confesses that although the neuropsychology of art is in its infancy, it has the potential to increase our knowledge of cognitive impairment and creativity and the use of specific colours and symbols have a crucial role to play in the lives and environmental design for this generation.

The environment, colour, design and dementia

In the past, purpose built architectural considerations to meet the special needs of those living with dementia in aged care facilities was not seriously considered. (Calkins, 2004; Fleming, Forbes & Bennett, 2003; Gottlieb-Tanaka, 2004 & 2006; Zeisel *et al.* 2003). Miller (1993, p. 54 & 16) makes the obvious but necessary observation that beautiful surroundings are important to reassure residents particularly given that the fear of “ending in a poor house” sown before the Depression years can still haunt the memory. Thoughts of “barren, institution-like homes with cold, linoleum floors, hospital green walls and white iron beds” are for many just as terrifying as the profound anxiety attached to the “fear of mental incompetence”.

Indeed, even today, those living and working in care are rarely consulted or included in either design or the colour decision making process, even though the negative affects of environmental pressure and correlates is well documented (Calkins, 2004). For example, Cohen-Mansfield, (2001, p. 362) has observed individuals living with dementia who “progressively lose their coping abilities and perceive their environment as more and more stressful, resulting in anxiety and inappropriate behaviour when the environmental stimuli exceeds the threshold for stress”. Cohen (2006a) positions this phenomenon within an ‘excess disability’ (Brody *et al.*, 1971) framework and believes, as it relates to dementia-specific care, stress in residents is partly due to an absence of structure. Failing an external structure, he thinks people with Alzheimer’s disease have a tendency to gravitate toward stressful spaces and unstructured activities. Post (1995, p. 115) comments that “excess disability or functional impairment that is greater than is warranted by an individual’s disease or condition can be removed by environmental modifications, stimulation and medical care. The residual strengths of individuals can be the foundation of enhancement of life”.

For the past fifteen years, Zeisel (2009), in conjunction with colleagues (Zeisel *et al.*, 1994 & 2003) has written extensively on the positive role that non-pharmacological interventions can play in improving the environmental surrounding of those in care. Like Zeisel, Sloane *et al.* (1998) and Gottlieb-Tanaka (2004 & 2006) and Calkins (2004), have independently identified and documented the impact of multiple environmental causal links, including noise and atmospheric conditions and the effect these conditions may have on residents. They all agree that certain architectural design features can be shown to confuse and disorient residents. And, Allen-Burge *et al.* (1998) suggest both over and under environmental stimulation can cause distress in some aged care residents. And, Cohen (2006a) maintains pleasant surroundings, that are reminiscent of past memories, create an important counterbalance.

Wijk (2001) has made an extensive study of colour perceptions in old age and with those living with Alzheimer's disease. Wijk's research confirms, predictably with age, sensory deterioration when combined with gradual loss of cognitive skills renders some individuals less able to recognize familiar surroundings and features. There are other notable losses. Stewart (2004) notes Alzheimer's disease affects serial and sequential processing, and this process has a profound affect on an individual's navigation skills. Gazzaniga (2009, p. 220) adds that, "in order to navigate the world successfully, one needs accurate information. Survival depends on it".

But colour remains. Wijk (2001) reminds us of the great significance colour has to most people in most environments. She says this is especially so for people living with dementia as the capacity to differentiate objects in different surroundings using colour as a marker, is paramount and even though colour plays a pivotal role in helping us to encode and decode our surroundings it is mostly taken for granted. In dementia-specific care Wijk advises that when environments are lit and decorated with consideration of this sensitivity the possibility to successfully navigate is increased. Wijk maintains this is because

colour strengthens our ability to see and isolate shapes, and has the ability to define movement and support perceptions of depth. Wijk also advocates the combination and selective use of colour with textures because, she argues, together this combination has the unique ability to visually stimulate and comfort at the same time.

Colour and brightness

Zaidel (2005) contends brightness is a critical determinant in how colour is perceived by those with dementia. She believes careful consideration should be given to colour in all aspects of aged care design, not least the art that decorates the walls of living and communal areas. She recommends the artworks should include the popular red and purple hues enjoyed by this group and the images should not be too detailed as this can cause confusion.

Colour preferences with Alzheimer's disease

Wijk *et al.* (1999) conducted extensive research in the late 1990s on colour preferences. They found colour preferences, irrespective of cognitive decline, remain reasonably stable throughout life and the elderly generally retain a high appreciation of colour and functional design. Interestingly, colour preferences remain relatively unaffected by Alzheimer's disease. Whilst the ability to name mixed colours with elaborate titles may be lost, due to memory loss, in fact is, irrespective of the level of cognitive impairment, the ability to name primary colours remains mostly intact. Whalley (2001, p. 120) makes the point that the ability to "identify colours" is the function of the occipital lobes and these lobes are "rarely affected by Alzheimer's disease".

Across a decade of research, Wijk and her colleagues have reported that the group with Alzheimer's disease share similar colour preferences to those of control groups. Blue, red and green being the most commonly preferred. Their

research has also demonstrated that those with Alzheimer's disease are able to perceive contrasts in colours, and find lightness and shade differences easiest to detect. It was also found that while the groups preferred red, blue and green as colours, visual discrimination between colours in the red and yellow colour range was found to be greater than in darker blue and green hues. Whilst examining Carolus Horn's artworks, Maurer and Prvulovic (2004, p. 241) noticed a general loss of shading in the artists' work and they also found a marked increase in yellow-red hues and a decrease in the blue-green range of colours. Zaidel (2005) and Trevor-Roper (1970) both offer scientific explanations for these changes in colour perception.

Colour and "blunted sight" - Age changes the eye

Patrick Trevor-Roper (1914-2004) was an ophthalmologist whose academic interest was the exploration of art and the therapeutic use of colour. In *The World Through Blunted Sight* (1970), he documents the affect defective vision has on art, personality and character. Trevor-Roper (1970, p. 92) makes the observation that "some people carry more yellow pigment at their macula and might therefore be expected to be relatively insensitive to blues and violets". Zaidel (2005) reinforces this assessment when she says that with age the fluid at the centre of the eye turns slightly yellow and the lens thickens, preventing shorter wavelengths of light from reaching the colour receptors. Whilst, it is not unusual for artists to change their use of certain colours over time, research now confirms many older artists rely on fewer blues because of gradual changes to the lens of the eyes. Both authors agree it is not unusual for ageing artists to experience blurriness when closely viewing objects due to the loss of flexibility in the eye's crystalline lens. Eyes that are impaired, damaged or compromised by poor vision have the potential to shape and restrict creative and artistic endeavour irrespective of skill or talent and cognitive impairment.

Trevor-Roper's study also provides some valuable insights on ageing. He writes that, "sometimes artists simply find detailed work too difficult in old age" and observes "ageing artists are often forced to work in broader ways, because their hands, nerves and senses become less responsive; and indeed, this may be aggravated by structural damage in the retinas". To illustrate his point he refers to a noticeable lack of detail in Leonardo Da Vinci's last pencil drawings. Here, he comments, Leonardo "relinquished his fine silver pencil in favour of a red and blue crayon which he could see more readily" (Trevor-Roper, 1970, p. 37).

Colour constancy

Espinell (2003, p. 1782) remarks on the phenomenon of colour constancy. He explains that, "the visual system adjusts so that we perceive the same colour in the object irrespective of light change". Hulbert (Piper, 2008) comments that the brain has evolved to detect differences in light conditions in order to make sense of the world around us. She says memory uses colour and shape to recognize objects based on their surface properties.

Martin (Piper 2008) explains, that in the past we used behavioural patterns and our ability to respond to light simply to survive. Given that our survival no longer depends on our ability to identify such things as poisonous fruit and other dangers in our environment, human colour vision is less focused. He estimates one in two hundred women and as many as one in ten men, may have colour vision problems. These changes to vision and colour perception occur naturally with age.

Colour and meaning and emotional response

Wijk *et al.* (1999) point to research (Bornstein, Kesser & Weisskopf, 1985) that suggests early in life, the ability to recognize colours, and distinguish the

subtle differences between colour shades and tones, is learned and laid down in long term memory.

Trevor-Roper (1970) makes the same observation as Sacks (1995) when he comments that we rarely take note of specific colours in daily life as our primary concern is with what things *mean* to us. Trevor-Roper (1970, p. 75) is of the opinion that most humans can “discriminate between the full range of spectral colours” and our colour discrimination may begin within the first weeks of life. More importantly, the connections and associations that link mood with colours are quickly established and exist at a very early age. He contends that even though colour vision is a latecomer in our evolution the emotive content of colour is complex, and our “colour awareness primarily reflects the establishment of an emotional response to individual colours, rather than any physiological re-orientation” (Trevor-Roper, 1970, pp. 64-65). This response may be instinctive or, more intriguingly, indicative of symbolic values established and acquired through the ancient and traditional use of colour in, folklore, literature, naturalist’s observations and education.

Malchiodi (2007) comments on the way colour can “reflect our emotional self”. She believes common colour associations stimulate our thinking and provide an opportunity to develop our own unique meanings for colour and colour combinations. Colour, she says can have significant cultural meaning and can also help us to express thoughts, perceptions and physical sensations. Commenting on art as an activity, Malchiodi points to the continuing appreciation of the value of art in the advancement of neuroscience. She notes that “many parts of the brain are active during creative expression”, as an example being the spontaneous movement of the brush across the canvas, which she says, “may predominantly involve areas of the brain related to motor skills” (Malchiodi, 2007, p. 108). She also comments on the complex combination of neurological skills, such as the “sequential operations” used in

“making a drawing about a memory or event” as an example of the continuing evolution of our understanding of the complexity of the brain.

The role of the other senses and the perception of colour

Trevor-Roper (1970, p. 92) maintains that whilst “almost any debility can distort one’s colour values” he does not discount the powerful influence of “a wide miscellany of drugs” on colour and emotions. Atkins (2009) describes a medication regimen, including dopamine for the treatment of Parkinson’s disease, as having a “profound effect” on the brightness of the colour palette. Loss of hearing too has the ability to escalate emotional changes in the way individuals “see” colour. Trevor-Roper (1970, p. 66) notes, that withdrawal from life and social contact prompted one of his adult patients to describe “deafness as taking all the colour out of life”, and his research with children revealed, “profoundly deaf children have significantly lower colour discrimination”. Rubin (2005) too has observed that those experiencing depression report a less defined colour spectrum.

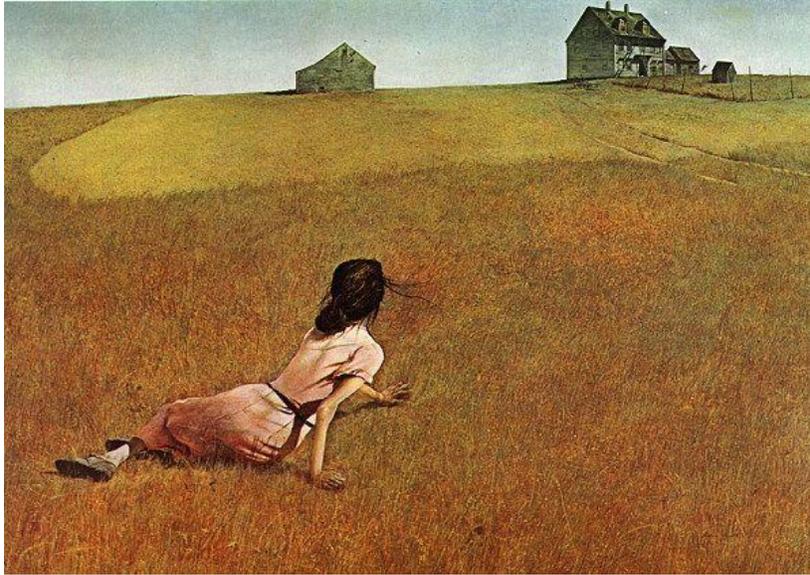
Emotional responses on creating artwork and responding to images

Cameron (1994, 1996 & 2001) recognizes the wide expanse of the therapeutic canvas. She has written perceptively on the senses and the emotions and the important role they play in understanding the creative process and the contemplation of art. She writes (2001, p. 9) that “sight leads to insight, hearing leads to being there, touching puts us in touch, and scent brings us to our senses”. Ramm (2003) points out that during the process of creation artists’ emotional responses to their work are rarely recorded and the gauged response to artworks by observers is also not common. Finlay (2002, p. 132) writes that, “when we see a finished painting we tend to access it for such things as composition, emotion, colour and perspective” and she too cannot say what the artist thinks about moment by moment. She poses several questions and

wonders whether the “laying down of paint happens without any mental images at all”. Finlay, ruminating on the subject, makes the suggestion that whether an artist thinks of “butter or tiramisu or diesel”, or nothing at all, the tactile act of stirring and splattering and smearing paint is sometimes an act “where time is forgotten”. She believes artists look at paint and measure its ability to drip, and then carefully assess each colour to see what it goes with when deciding “whether it is welcome on the palette”. Zeki (1988) thinks when artists work they are “generally not concerned with philosophical views but rather with achieving desired result... [and] distilling the essence of their visual experience” to achieve their best combinations on canvas (cited in Harvey Wood & Byatt, 2008, p. 252). For those living with dementia, the opportunity to create art is relatively rare, and to view works of art and express an opinion is even rarer. When the opportunity is provided the responses are often happily surprising.

The Artists for Alzheimer’s program

One notable example of a program that encourages open expression is the *Artists for Alzheimer’s* program designed by Sean Caulfield and John Zeisel of the Hearthstone Foundation. Hearthstone residents living in aged care facilities in New York, Connecticut and Massachusetts have taken part in the program at the Museum of Modern Art (MoMA) in New York and leading galleries on the Eastern seaboard of the United States. This is not part of the *Meet Me at MoMA* program, but it is instead, a separate and special program that exposes individuals living with Alzheimer’s to selected works of art with the purpose of using the power of art to elicit emotional reactions and responses.



Christina's World - Andrew Wyeth.

The emotional reaction and response to Andrew Wyeth's *Christina's World*

The emotional reaction of those living with dementia, to Andrew Wyeth's *Christina's World* is noteworthy (see above). Wyeth has written that, "when you lose simplicity, you lose drama", and this artwork is stunningly dramatic because of its quite simple pictorial composition.

On viewing this painting, most able-bodied observers comment that the sight of Christina's foreshortened, disabled body creeping toward the drab, grey farmhouse in the distance, creates a feeling of helplessness. Alone in the landscape, they are anxious for Christina and feel very uncertain that she will make it home safely.

One would imagine that those living with dementia would register the same emotional response. But, overwhelmingly, their response is much more positive. Wyeth's painting is a straightforward pictorial composition, but it is rich with emotional resonance. The simplicity of the painting composition enables viewers with dementia, many of whom experience slightly diminished

spatial processing, to slowly look at each element in the picture, and then slowly process it for emotional significance. They are then able to progress to an overall emotional understanding of the theme of the work without being confused by any extraneous detail or distractions. The work's simplicity enables viewers with dementia to enter the picture, understand its meaning or meanings, and then react to it on both a personal as well as an emotional level. Not only that, some also seem to be able to process the image to such a degree that they register and understand that Christina's legs are disabled. Zeisel (2009) reports one observer noticed Cristina's "spindly" arms and legs and then questioned why other parts of Christina's body appeared to be healthy. Zeisel reports that Wyeth painted the portrait of Christina, who was his disabled neighbour, but he admits to modelling part of Christina's body on that of his wife Betsy. Rare film images of a special viewing of *Christina's World* at MoMA record that at least one observer did not seem to be concerned about the distance Christina must cross to reach the security of home (Blackmore, 2006).

Irene Copeland Brenton, looks fully engaged and happy in the gallery setting and, although Kennedy (2005) observes her ability "to read and to find the right words to say" is severely diminished by advance dementia, he describes her response to Wyeth's artwork as "almost loquacious". Copeland Brenton's emotional involvement in *Christina's World* is complex. Her response demonstrates surprising depth, she has a visible emotional reaction to the work and relates not only to the isolated young woman but also the feeling of comfort and security that the farmhouse evokes.

Zeisel (2009, p. 94) reports the painting elicits comments from participants such as "there is something special about that house" [and] "she's yearning for something in the house" [and] she wants to get to the house [and] so do I". Shaw (2006, p. 2) has observed similar reactions in other individuals with dementia. She reports a very positive response to the painting; so positive that most think Christina will make it home and they think her inner thoughts might

centre, as one participant put it, on “the world she lives in and the world that she wants to live in”. With consideration of all of these aspects, *Christina’s World* is well chosen to be part of the *Artists for Alzheimer’s* program.

Kennedy (2005) reports, after viewing representational artworks at MoMA, individuals living with Alzheimer’s “retain a kind of emotional memory long after the visit ended”. Other observers have commented that the artworks seem to have the ability to “spark interpretive and expressive powers that had previously lay hidden”.

Sacks (Kennedy, 2005), in an interview in *The New York Times* on the *Artists for Alzheimer’s* program at MoMA, and the Museum of Fine Art in Boston, puts forward one explanation why those living with Alzheimer’s positively respond to visual art. Sacks says engagement in art is “not just a visual experience - it’s an emotional one”. Referring to the numerous case studies on memory loss, he has documented over the past three decades, Sacks says “in an informal way I have quite often seen quite demented [sic] patients recognize and respond vividly to paintings and delight in painting at a time when they are scarcely responsive to words and disoriented and out of it. I think that recognition of visual art can be very deep”.

The art critic, Sir Herbert Read (1961), in *The Meaning of Art*, attempts to describe the process associated with the contemplation of art. He proffers the suggestion that as we contemplate a work of art there is an immediate release of emotion. He does not think this release is commonplace or an ordinary release of emotion such as one might experience from an outpouring of grief. He describes the emotional release as two different things at once. He likens the feeling to that of a “heightening” and a “tautening of awareness” and, at the same time, a “relaxing sublimation” (Read, 1961, p. 32). Read believes our feelings are normally inhibited and repressed while the emotions aroused by a work of art, or the contemplation of artistic creation, constitutes something of

a liberation of our personality. He believes these two elements together create an escape for the viewer from the arbitrariness of life.

Scanning for concept and meaning

Zaidel (2005, pp. 152-153) describes the process of viewing works of art as employing primarily a left hemisphere skill. She proceeds to detail how the process works with those living with dementia. She says objects in pictures are “like words in a sentence”; details need to be “perceived rather rapidly” to gain an understanding of both the single theme and the concept of the picture as a whole. She says most pictorial scenes consist of “several objects and figures positioned in a way that denotes an interaction”. In her experience, those living with dementia fixate their “gaze on each pictured object at a time, instead of rapidly taking in the whole display”. By taking in and naming only one single object at a time, individuals are usually unable to “derive meaning” from the picture, because “the integration of pictorial information” is too slow if it takes place at all. This in turn delays the “rise of meaning” with the consequence that individuals are unable to form a single theme that has meaning.

In *Painting the Mind* (Feltus, 2006), Snyder (2006) makes the point that slowness in forming a single theme with meaning is not uncommon in able-bodied observers. He says untrained artists are generally overwhelmed by concepts when they look at a painting, and he put forward the suggestion that the reason trained artists can successfully create and rapidly interpret images is because they scan a painting for the theme and then focus on the details behind the concepts. Edwards (2008) reports untrained artists tend to scan pictorial images from left to right as though reading a book and often become immersed in the finer detail.

This is one reason why *Christina's World* (discussed above) is an ideal choice to adorn the walls of an aged care facility. Zeisel (2009, p. 92) writes that individuals with Alzheimer's disease indicate their understanding of the works by "describing clearly and openly what they see, interpreting the story of the painting, seeing links to their own lives, expressing emotions about the work, identifying objects and critically appraising the subject matter". All of these observations support Zaidel's (2005) call for the selection of paintings that make it easy for those living with dementia to scan the visual images. The observations also complement Wijk's (2001) recommendation for specially selected colours and textures for furnishings and fittings.

The role of the amygdala and visual imagery

Sacks (2005) has found music also engages "parts of the brain that remain intact long after the onset of dementia and have a lot to do with procedural memory" - the skills used to use tool and operate devices. Music and events remain intact in the emotional memory, in the amygdala, long after the onset of Alzheimer's disease. Leading academics have identified its significance (Bucks & Radford, 2004; Mori *et al.*, 1999; Roudier *et al.*, 1998; Wright *et al.*, 2006; Zaitchik *et al.*, 2006).

Goleman (1996, p. 15-16 & 22) describes the amygdala as "pivotal" because it acts as a storehouse "repository for emotional memory". It contains the "wordless blueprints" that form each individual's emotional experience and gives personal meaning to life's events. Zeisel and Raia (1996) were among the first to recognize the link between the amygdala and Alzheimer's disease. In the 1990s they presented evidence to suggest the amygdala is one of the last areas of the brain to be affected by this disease. And, as such, it remains "readily accessible until very late in the disease" (Raia & Koenig-Coste, 1996, p. 2 & Zeisel & Raia, 2000, p. 7).

Raia & Koenig-Costa (1996); Koenig-Costa (2004) and Zeisel (2009) believe the amygdala and verbal and non-verbal communication are the master keys in deciphering emotional blueprints. With this in mind, Raia and Keonig-Costa developed the framework of a new paradigm of care called “Habilitation Therapy”. In their original “habilitation therapy” framework, they put forward the view that the role emotion plays in therapy is crucial and of significant importance in programs and quality of life treatment outcomes in dementia care and management. Raia (1999, p. 22) writes the concept reflects Abraham Maslow’s (1968) premise that “there is an innate drive in all people to maximize their potential”. Habilitation therapy is discussed at greater length in the chapter that addresses the history of dementia.

In his recent book, *I’m Still Here*, Zeisel, (2009) again reinforces the significance of the amygdala. He argues it “is the key to communicating and having a fulfilling relationship with a person living with Alzheimer’s”. He believes new but different relationships can be built because a healthy amygdala can allow those with Alzheimer’s to become “exquisitely sensitive to emotional events and other people’s emotional states” (Zeisel, 2009, p. 77-78).

Caulfield (2003) is another researcher to draw the link between the amygdala and art and emotion. When he created the *Artists for Alzheimer’s* program he searched for ways in which art could “transcend the limitations of conventional communication and language”. A long-time advocate for the creative and expressive arts in dementia-specific care, his experience has reinforced his belief that art provides “particularly appropriate forms of expression” for people with Alzheimer’s disease. He writes that even in severe cases of neurological damage the brain retains about 70 to 80 billion intact neurons, particularly in the amygdala. The creative drive Caulfield maintains is supported by skills and abilities often hidden in those living with Alzheimer’s. He believes that by expressing emotions, feelings and moods through humour aesthetic pleasure a continuing interest and enjoyment in life can be sustained.

Visual creativity and perception - the what and where pathways

Miller and Hou (2004) maintain many regions in the frontal lobe carry out functions related to visual creativity and perception and are essential for art-making. Flaherty (Feltus, 2006), a Harvard neurologist, has been exploring a new theory of creativity that suggests the creative drive is a “front to back” process. She says the relationship between the frontal and temporal lobes determines creative drive and enables us to be discerning in our judgment of art.

Miller and Hou (2004) maintain creativity and artistry requires visual perception and they argue that two processes must occur in progression before an artist can begin to create an artwork. Zaidel (2005) points to Ungerleider and Mishkin's (1982) description of these two processes. Zaidel explains that two separate neural pathways, commonly called the dorsal (superior) stream and ventral (inferior) visual stream are involved in the visual perception recognition process and they determine ‘where’ it is seen, and ‘what’ is seen respectively.

The dorsal stream, the ‘where’ system is a spatial orientation information system that informs us where objects are located in space. The ventral stream tells us what object information is coded. Miller and Hou (2004, p. 842) explain, “artistry requires visual precision and uses the dorsal stream to frame the scene perceived in the ventral stream and [so] place them on the canvas”.

McNaughton (2007) indicates the ventral or ‘what’ system is in fact a fast colour-blind system that is sensitive to high contrasts. She contends, the three dimensional form of an object is actually determined by the luminosity and the hue of each colour. She adds that, “the merest hint of graded shades gives the eye subtle clues as to the form, depth and substance of an object and, with the addition of reflection, can also indicate the positions of other light sources and nearby objects” (McNaughton, 2007, p. 26). Livingstone (2002, p. 38) writes,

“colour and luminescence are analysed by different parts of the brain” and that is the biological basis why colour and luminescence play distinct and separate “roles in the perception of art or real life”.

McNaughton (2007) notes that visual artists often use ‘wrong’ colours and shading in paintings to trick the ‘where’ system - a slow system more attuned to motion, depth, space and figure/ground perceptions - into creating three dimensional tonal illusions. McNaughton also draws our attention to the fact that red and green are just two *equiluminous* colours that appear as the same grey tone in black and white photographs.

Perspective and pictorial logic

Zaidel (2005, p. 21) contends that for centuries artists and philosophers have pursued an intellectual debate on the question of linear perspective, systematic pictorial logic and realism. McNaughton (2007, p. 2 & 27) writes, “perspective creates the illusion of depth on a flat surface”, where objects in the landscape converge on a “vanishing point” on the horizon. She maintains the “illusion created by perspective is so pervasive that it throws up all sorts of strange effects”. She says the brain “knows” how to understand these distorted illusions based on its ability to interpret clues in the space around objects. Interestingly, she maintains perspective illusions are probably “broadly brain-based hypotheses” because traditional people, unused to cityscapes, are not as affected by, or as alert to, the illusion of perspective as urban dwellers.

Perceptual constancy - why untrained artists find it hard to transfer a three dimensional image onto a two dimensional piece of paper

Zaidel (2005, pp. 142-144) is convinced that “figuring out the desired perspective from a vanishing point principle requires planning, and analytical thinking”. She maintains one answer to the philosophical question of pictorial

realism lies in a concept referred to as “perceptual constancy”. Untrained artists, she believes, experience many difficulties drawing objects from life. These difficulties are perspective and the translation of two-dimensional images as they form on the retina. Because the drawing surface is also two-dimensional, it is the transferral of an image onto paper that untrained artists find so difficult. The artist must first visualize the image and then adjust the perspective before drawing can commence. Zaidel says that prior to the development of perspective, “depth was depicted through axial perspective a technique in which parallel lines converge on multiple points along the vertical axis” (Zaidel, 2005, pp. 143-144). The slightly disconcerting visual appearance of axial perspective can be found in one of William Hogarth’s illustrations from the 1754 edition of Dr Brook-Taylor’s self-help book explaining perspective (McNaughton, 2007, p. vi - see Appendix E).

Carolus Horn was once a highly successful, professional graphic artist, and was living with probable Alzheimer’s disease when Maurer and Prvulovic (2003) began a detailed study of his work. They observed and documented quite pronounced examples of axial perspective, particularly in the artist’s later works. Axial perspective is also a dominant feature of the composite perspective landscapes created by an untrained, Italian artist called Franco Mangnani (see Appendix H). Mangnani is described by Sacks (1999 & 2007) as someone affected by left temporal lobe neurological damage as a result of “a strange illness”, possibly epilepsy.

The memory and recognition of objects in perspective

Just as the principles of colour constancy determine objects by their shape and surface properties, humans see and recognize objects from various perspectives on the basis of concepts stored in long-term memory. McNaughton (2007, p. 36) writes that from “childhood, patterns of material, shapes and functions sink in,

so that years later when we see a ceramic bowl, we know it will hold soup, smash if it is dropped, and can even imagine the side we cannot see”.

Three-dimensional perception of depth is created when the brain combines visual signals from both eyes; and McNaughton (2007) illustrates this with an example using a recognizable object. For instance, when one hand is placed a meter in front of the other we do not perceive the closest hand to us as much larger than the other hand that is further away, and this is because our brains know that our hands are the same size. Zaidel (2005, p. 144) describes these kinds of “gross disparities” as being “evened out by the constancy principle”. She says artists who undergo formal training are primed to ‘see’ these disparities, they exaggerate the perspective and then transfer the adjusted configuration onto a two dimensional surface. Trevor-Roper (1970) adds that by overlapping fields of vision give us an accurate judgment of distances and “most artists, to a greater or lesser extent, subconsciously use a ‘cylindrical gnomonic projection’ (such as Mercator’s map of the world) to transpose their view on to a two dimensional canvas from the surface of the imaginary sphere encircling their heads” (Trevor-Roper, 1970, p. 36).

Alzheimer’s disease, and drawing and the cases of William Utermohlen and Willem de Kooning

The influence Alzheimer’s disease, and even much rarer forms of dementia, has had on the artistic skills of a select group of professional artists has been studied and documented. In particular the study of the progression of the disease in both William Utermohlen and Willem de Kooning yields valuable information enabling us to further unravel and understand the mystery of Alzheimer’s disease. For instance, the use of pencils and line drawings in the final stages of Alzheimer’s disease, as exemplified in the case of both artists, indicates the desire to be artistically and creatively involved to the end.

William Utermohlen's last artworks

Cummings (Carroll, 2006) writes that William Utermohlen's self portraits, painted between 1996 and 2000 graphically demonstrate a loss of visuospatial skill. Over this four-year period, Utermohlen abandoned oil paints to express himself in grey lead pencil line drawings. As the devastating effect of Alzheimer's disease consumed Utermohlen remaining skills, he progressed from realistic, colourful painted portraits to grey lead pencil abstractions. There is an almost ethereal quality in Utermohlen's final pencil portrait on paper; they are almost characterized by, randomly placed pencil smudges and dots which make it difficult to distinguish the work as self-portraiture or indeed to even recognize the artist's former talent (see Appendix F).

Ramm (2005) describes drawing as the oldest and perhaps the most fundamental form of visual art. She suggests drawing is both a conscious and an unconscious act and, although it requires a high degree of right brain activity, she maintains it is often the power of thought that drives both the process and the pencil across the page. Edwards (2008) explains the unconscious process involved in drawing and describes this phenomenon as a "whole" global skill; something once learned, it becomes as automatic as walking and reading.

Citing Ginsborg (2003), Ramm observes that drawing itself is "flat and monochromatic" and its role is not meant to "address colour relationships". Determining colour relationships during painting on the other hand, draws on considerable intellectual skill and imbedded strategies. These skills, which include problem solving and decision making, are slowly lost in the progression of Alzheimer's disease.

Malchiodi (2007) puts the progression from paint to pencil into perspective when she details her experience, using both lead and coloured pencils, with a variety of clients in her professional practice. She observes pencils are easier

to control, hold and maneuver than brushes. She describes pencils as being on the “most controlled end of the continuum”, which allows each user to add more detail and be more precise (Malchiodi, 2007, pp. 84-85). Johnson and Sullivan-Marx (2006) concur and add “structured media”, such as graphite pencils, which are easier to control and allow for correction. They note that an artist who once successfully managed different mediums may, when a reduction in scope is forced on them, make mistakes, which in turn can generate frustration. Paper surfaces also vary greatly, from very smooth to porous and rough, and pencils are more resilient than brushes and paint in such conditions. Nadeau (1996) writes of, “the importance of the soft lead” not least the advantage that it “takes less physical pressure to produce a mark [and] a simple, well chosen pencil and a piece of large drawing paper can provide hours of exploration and accomplishment” (Nadeau, 1996, p. 37-38).

Utermohlen chose a lead pencil as his final instrument, perhaps to simplify the process, as described above, to meet his creative need. It would not be unreasonable to suggest that Utermohlen has used his remaining skills, and the power of visual thought, to progress toward what Rubin (2005) describes, as a “primal pleasure” and a “deep engagement” in the creative process. Adrian Hill (1951) too ascribes a certain pleasure and “magic” in being totally immersed in the sensation of seemingly aimlessly moving hand and pencil across the page. But, Utermohlen was personally motivated by another factor. He believed painting and drawing was always “about how you feel”. And, to this end, he set out to create a record of self-portraits depicting his feelings and emotions as the disease progressed. During their research, Crutch and colleagues (2001) documented Utermohlen’s emotions, as he lost the power of speech. They interpret the artist’s final works as depicting a variety of states of mind including terror, fear and isolation, but the drawings are fluid and free and quite beautiful in their simplicity.

Crutch *et al.* (2001) also document Utermohlen's deterioration, a trajectory probably due to perpetual and visuospatial information processing problems that indicates possible damage to the visual cortex. The authors suggest that whilst memory for words may fade before our memory for faces, in Utermohlen's case his relatively well-preserved visual memory function may have been a factor in his ability to accomplish his final drawings even when profoundly affected by Alzheimer's. For Willem de Kooning, the internationally acclaimed abstract expressionist, his progressive cognitive impairment heralded, remarkably, a new spontaneity in his work.

Willem de Kooning

According to Espinel (1996), Willem de Kooning's artistic decline was probably due to a number of conditions including malnutrition, Korsakov's syndrome and possibly Alzheimer's disease. Stephens and Swan (2004) explain that when de Kooning's wife re-entered the painter life, after more than two decades of separation, he returned to painting. It had been a hiatus of almost ten years, and the effects of dementia were evident. He was extensively aided by studio assistances who kept him "on task", "cued" him to his studio surroundings and redirected his attention when he lost track. White (Clark, Tanner & White, 1995, p. 30) comments, de Kooning "painted for most of his life with drawings actually on the canvas. He always had a line to serve as a guide". Espinel (1996, p. 1096) adds, as de Kooning's dementia progressed he "scattered his early masterpieces about his studio, consulted their photographs and projected their images onto blank canvases" where he "copied and retraced images". Ramachandran (2007; Ramachandran & Blakesee, 1998) has studied the effect of line drawings on the right brain's recognition of pictures. He thinks outlines are very useful because our brain is limited in how much neural activity it can process at any given time. When outlines are presented, without the distraction of irrelevant visual images, there is evidence of right brain stimulation especially conducive to creativity. de Kooning borrowed from his

earlier works and the combination of the traced outlines of brush strokes and colours and forms, meant he was probably trying to understand his own unique painting process, but for whatever purpose, he began to paint in what some believe was a new, freer and perhaps improved form. Espinel (1996) notes that these new paintings are less detailed and less technically proficient than before, but they are more “exuberant, spontaneous and so full of life” that the brush strokes “moved rhythmically and [the] shapes danced freely” and overall the paintings “dazzled us all” (Espinel, 1996, pp. 1096-1097). Clark (Clark, Tanner & White, 1995, p. 29) comments, as de Kooning’s dementia changed so did his colour palette, “the colours seem to come out of nowhere” and, similar to Carolus Horn, he reduced his palette to primary colours - yellow, red, and blue mixed with shades of orange and green.

In the final years, Steven and Swan (2004) describe de Kooning’s output as “prodigious”. Before dementia each of de Kooning’s artworks was meticulously reworked and took the artist as long as eighteen months to complete, but he began to “churn out paintings many of which appear more formless and clotted”, one every two weeks, and in a new style that “never really settles down” and cannot “be pinned down” (Steven & Swan, 2004, p. 635). Espinel (1996) reports the artist’s paintings continued to become more and more abstract until eventually he too is reduced to using lead pencils on paper.

A retrospective of de Kooning’s work opening at New York’s Museum of Modern Art (MoMA) in September 2011. The collection is incomplete because MoMA’s chief curator, John Elderfield, made an executive decision not to display the last works painted by de Kooning. Elderfield (Devine-Thomas, 2011, p. 81-82) claims that the paintings done as de Kooning’s dementia progressed are “unrealised” and “transitional to something else that never happened”. His opinion is that “there is a sense of being slightly unmoored despite the sense of calm and serenity’...where the absolute sense and subjectivity which one has in all of his previous pictures, is taken away”. Elderfield thinks this can be

attributed to de Kooning's dementia, but justifies his decision to not allow the public to make up their own minds on the quality of the paintings by adding, "I did not want to end on a lesser note".

The effect of neurological damage on artists

Espinel (2003, p. 1781) writes that it is likely that art is "the result of a unique interplay of neurocognitive mechanisms". He reinforces the theory that creativity is an all brain phenomenon and that each artist uses skills unique to him or her. Even when neurological damage affects either or both hemispheres of the brain, Rubin (2005, p. 32) is sure art may help "facilitate neurological integration". Zaidel (2006) too is convinced creativity is a whole brain process, and maintains that although the actual process is still unknown, it can be demonstrated that preserved skills imbedded in healthy tissue have the capacity to work in unison with diseased brain tissue to support the creative process.

Studying the effect of strokes, Levi (Butcher, 2005) reports art as therapy can greatly assist neurologists in their assessments. He sees scope for art when used as a diagnostic instrument, because the process can identify which parts of the brain are not functioning correctly. Levi argues that art fits neatly into an expanded rehabilitation care model and activities such as painting and drawing have the potential to aid individuals with vascular dementia recover fine and gross motor skills and lost coordination.

Cummings and Zarit (1987, p. 2731) write that, "the effects of brain damage on artistic creativity has rarely been investigated". They make the observation even though a "limited number of artists" have been studied the overall research demonstrates "the reliance of artistic expression on neurological integrity". Sacks (2007), alerts us to the observations of Theophile Alajouanine

(1890-1960), one of a select group of neurologists who began to document the affect of neurological damage on artists in the early decades of last century.

Left hemisphere damage

Alajouanine, was a neurologist and a physician to many creative artists, including Maurice Ravel (1875-1937) who probably died from a form of frontotemporal dementia (FTD). Alajouanine documented the preservation of Ravel's creative musical ability, and compared this against the composer's progressive speech loss. Although there is much debate surrounding Ravel's neurological condition and his musical legacy, *Bolero*, with its repetitive musical form, written in 1927, ten years before his death, is an indication of the composer's perfectionism (Amaducci, Grassi & Boller, 2002; Gardner, 1982). Miller *et al.* (2005, p. 3) comment that a characteristic of many artists with FTD is they often spend many hours, repetitively re-working tiny details in the quest to "slowly perfect their product". Alajouanine's (1948) contribution included the detailed studies of many other visual artists. Even without the assistance of modern technology, Alajouanine was to document left hemisphere injury and draw the conclusion that damage to the left side of the brain does not routinely impair painting or artistic skills.

Chatterjee (2006) studied left hemisphere damage and he writes that such damage often leads artists to introduce a more vivid colour palette and stylistic changes to content. Crutch *et al* (2001) have observed many artists with left hemisphere damage and report that whilst there is a tendency to over simplify drawings, the ability to place objects in a spatial layout within the picture does not seem to be affected. Mendez (2006, p. 2) agrees that damage to the left hemisphere "does not usually impair artistic skills". Left hemisphere changes to artistic output and creative technique are quite significantly different from the impact that damage to the right hemisphere of the brain can have on an artist's work.

Right hemisphere damage

Neurologists have identified that right hemisphere damage can have a profound impact on artistic skill and picture composition. Schnider *et al.*'s (1993) research has established injury to the right hemisphere, even in experienced artists, can devastate an artist's ability to copy and paint. Schmidt (2006) explains the phenomenon in more detail when she writes:

During a period of creativity, a network in the lateral frontal cortex of one or both hemispheres of the brain is stimulated... When visual ideas are being imagined there is an increased blood flow to the brain's right hemisphere. During this activity, the primary visual cortex, the most highly developed part of the brain, pulls the disparate information together. The primary visual cortex is able to navigate complex concepts into the dorsal (where) and the ventral (what) area. Recent MRI analysis on experienced artists shows that the right prefrontal cortex (where high-order thinking happens) is most active during painting (Schmidt, 2006, p. 31).

Crutch *et al.* (2001) concur and add that right hemisphere damage predictably tends to affect both the "what" and "where" capacity of the artist. The affect can be observed when artists have difficulty placing objects and figures within the overall layout of a landscape. Artists may also be able to work on sections of a painting but be seemingly unaware of unpainted gaps and missing details in other parts of the painting across the whole work. Gazzaniga (2008, p. 292) describes this as "*hemineglect*" and writes "the right hemisphere attends to the entire visual field, whereas the left hemisphere attends only to the right field". Gazzaniga (2008, pp. 202 & 299) points out there is "no brain area paying attention to what is going on in the left visual field" or that knows about "the left half of the body and whether it is working or not". Miller (1993) explains that "because brain damage is highly selective response patterns are not always consistent", but an injury to her Mother's "right occipital lobe" as a result of vascular dementia "blackened or obscured the left half of her visual range" causing hemineglect. As a result, Miller reports her mother "could see

only the right half of objects and scenes she focused on” and she no longer had the desire to paint (Miller, 1993, p. 104).

The preservation of skills in trained and practicing artists

Crutch *et al.* (2001), and other researchers (Fornazzari, 2005; Stewart, 2004), confirm individuals with probable Alzheimer’s disease display a combination of drawing and painting deficits. In fact, Fornazzari (2005) has observed multiple combinations and artistic deficits in those living with Alzheimer’s disease. His research and documented case studies confirm that trained artists can continue painting even when their working and episodic memory is severely impaired. Fornazzari believes this is possibly due to the preservation of well developed visuo-constructive skills. He says many trained artists experience a slow deterioration in their capability to paint. He also recognizes that painting for many artists acts as a means of communication and is one way for an artist to preserve brain activity. He points out there is ample evidence to suggest, “creativity in any of its forms, [whether it be] visual, musical, literary, or performing arts, may be conceived as a cognitive capability” (Fornazzari, 2005, p. 419). Fornazzari advocates active exploration and research into creativity, with a focus on artists with Alzheimer’s disease and other dementias, and maintains that creativity, especially through painting, provides a positive means of communication.

Embedded strategies

Cummings and Zarit (1987), as well as Crutch and colleagues (2001), all suggest that experienced artists retain well developed artistic skills, embedded strategies and creative motivation for longer than untrained artists. And, even though organizational skills progressively decline in all dementias, motivation and artistic skills do not seem to decline at the same rate in experienced artists. In addition, language and even memory loss bears no strong relationship

to a decline in drawing ability in experienced artists. Drago *et al.* (2006a, p. 1287) report their research indicates “differences in functional hemisphere specializations between artists and non-artists” and this may have some influence on the retention of artistic skill. They also suggest that it is possible that the limbic system plays “a critical role in allowing artists to use their technical skills to develop images that represent or can elicit emotions”.

Drago *et al.* (2006b) believe they are the only group of researchers to study the artistic ability of individuals living with Lewy Bodies dementia. The results of their research indicates that, “there is a gradual decrease of the ability to visually express artistic subject matter [but] the only quality not to decrease with time was novelty” The authors say “the ability to produce novel artworks or any novel enterprise is heavily dependent on divergent thinking”. Drago and her colleagues think it is possible that divergent thinking originates in the frontal lobes of the brain (Drago *et al.* 2006b. pp. 3014-3015).

Visual vocabulary

Cummings & Zarit, (1987) and Rankin *et al.* (2007) confirm the colour palette of most artists becomes simplified and more subdued during the progression of Alzheimer’s disease, until eventually even the most experienced artist produces monotone images and abstracts. In whatever art medium, there is a progressive reduction in the complexity and amount of shading, and eventually the abstractions lack perspective, angles and spatial relations. Even with this reduction, Chatterjee (2006) has observed that a well-established visual vocabulary continues to play an important role in the ability to create new works with trained and experienced artists. He says trained artists develop and acquire visual vocabularies from a variety of sources, including the study of other artists and the rigors of formal art training much of which they maintain long after one might expected them to have lost such vocabularies as their dementia progresses.

Stewart's observations

Stewart (2004) describes some distinct characteristics that contribute to the expanded visual vocabulary often found in trained and professional artists. She refers to visual and spatial skills that develop over the course of professional practice. Stewart had observed that over time these skills become “over learned” in professional artists in particular, skills which appear to be more resistant to the disease process. Stewart's study provides other important clinical information and observations. She has documented different levels of artistic skill and ability in untrained artists, living variously with the effects of mild, moderate and profound Alzheimer's disease.

Mild dementia

Stewart has observed almost all those who live with mild dementia are able to produce artworks that contain representational images. The artworks contain depth of field and perspective and a high degree of detail and proportion. Overall, Stewart has found, the artworks are consistently and appropriately coloured.

Moderate dementia

Moderate dementia brings distinct and predictable changes to the artworks. In Stewart's experience, approximately three quarters of the artists now use a reduced colour palette, and continue to attempt to create representational forms and figures. She has also observed some artists who retain the visual capability to employ baselines and skylines to define perspective and the illusion of depth in their pictures.

Profound dementia

In the final and more profound stages of Alzheimer's disease Stewart concedes the therapist must provide significant assistance and encouragement to individual artists. At this stage of the disease the artworks become increasingly more abstract and less colourful and there is a propensity for artists to randomly apply colour. Stewart's findings reinforce and support the observations made by Miller and colleagues at the University of California Department of Neurology.

Frontotemporal dementia (FTD) and Miller's research at the University of California

Miller *et al.* (2005) have identified and described different artistic styles associated with various forms of dementia during their research work on dementia and creativity. They describe the work produced by artists with Alzheimer's disease as generally "formless and surreal", in contrast to works and talents that may be "triggered" by a particular variant of frontotemporal dementia (FTD). Weder *et al.* (2007) confirm that FTD is the most misdiagnosed of all of the dementia, and that it usually affects individuals between the ages of thirty-five and seventy-five. They indicate that a familial link to dementia is not uncommon. Miller (BBC, 2005) estimates that less than ten per cent of all of those living with dementia may be affected by FTD, and, Rankin *et al.* (2007, p. 49) conclude that, even though documented case studies are increasing, these artists may be "isolated patients" who are "the exception rather than the rule".

Miller *et al.* (2005, p. 1) write that, "until recently there has been a tendency to ignore the emergence of new skills in the dementia setting". They report that increasing numbers of individuals living with semantic dementia associated

with left hemisphere damage are displaying astonishing characteristics. They comment that FTD normally affects the frontal and anterior cortex - areas normally associated with progressive loss of language and changes in behaviour. But, interestingly, Miller and his colleagues have found that when some individuals who are only affected by neurological damage to the left hemisphere, and the visuospatial functions necessary for visual and artistic creativity in right hemisphere are relatively spared, a small percentage may exhibit previously unknown, and spontaneous artistic talent. However, de Souza *et al.* (2010) question whether spontaneous artistic talent is, in fact the emergence of new skills or creative thinking. They write that the emergence of artistic talent “still remains to be explained” and, that it should not be mistaken for the artist having “mastered a [new] mental production”, but instead it should be viewed as the result of a “release of involuntary behaviour” (de Souza *et al.* 2010, pp. 3739-3740).

Mendez (2006, p. 2) thinks that, “among the dementias, FTD [caused by a tau protein abnormality] may be a disorder that can affect the brain in just the right way to illustrate [the] mechanisms of artistic expression”. He reports that the “release of right hemisphere artistic abilities [are] associated with the loss of left hemisphere semantic abilities”, and can sometimes result in the increased creative musical, mechanical and mathematical ability of some individuals, but, he adds, this loss does not increase creative skill in “verbal areas such as writing and poetry” (Mendez, 2006, p. 5).

Miller *et al.* (2005, p. 3) observe that artists with FTD often display “a compulsive need to paint”, and pay meticulous and precise attention to detail. They add the artworks rarely demonstrate symbolic or abstract components, rather they are typically realistic and impressionistic representations and almost always drawn from the artist’s imagination and memory. Mendez (2006, p. 5) has also observed what he describes as the “compulsive features” of FTD, and says this can sometimes “manifest as repetitive artistic behaviour”.

In Britain, Greenfield (2000, pp.12-14 & Heron, 2000) documents certain characteristics, described by Miller as atypical of FTD, in her BBC documentary film *Brain Story*. Although Dick Lingham's social skills, tact and diplomacy have been lost with the progression of his dementia, he spends hours absorbed in painting and illustrating. Above all, this exercise demonstrates Lingham's need to create his finely detailed 'line and wash' illustrations, which help pacify his anxieties, and considerably decrease the day-to-day burden experienced by his primary care partner. And, even though Greenfield and Miller and Crutch and Rankin and Mendez and their colleagues, agree that the time the window of artistic fluency is open with FTD is brief, Crutch *et al.* (2001) argue that "the examination of artistic and creative talent in the context of dementia is so revealing that the study of such artists is an important way of discovering new forms of cognitive functions" (Crutch *et al.*, 2001, p. 2133).

Miller and Hou (2004, pp. 842-844) comment "the emergence and evolution of visual creativity in dementia offers a window of opportunity into the creative process, whilst hinting at the extraordinary cognitive flexibility of individuals who experience progressive loss of cortical neurons". Miller believes we can best harness this potential by focusing less on the weaknesses and paying more attention to the strengths of those living with dementia.

Conclusion

Emery (2004) writes that art and technology in the form of neuroimaging presents neurologists with a unique opportunity to study and correlate how changes in perception in those living with dementia can be monitored and linked to "visual pathways" and cognitive decline. But, Scannell (2004) makes the point that the "urge to speculate on that relationship often arises" among academics, and even with every "diagnostic tool in hand, [they] cannot locate human creativity". She acknowledges that technology no matter how sophisticated will probably never reveal the "vast inscrutable internal worlds

from which this creativity originates”. Speculating on the source of the creative wellspring in those living with dementia Scannell, is content to simply add, that “creativity flows from their being that artfully defies our medical investigation and scientific discourse” (Scannell, 2004, p. 2).

Perhaps one of the most important characteristics of dementia-specific art and creativity that this chapter has revealed is that divergent thinking, so necessary to the creative process, probably originates in the frontal lobes of the brain. In addition, the ability to recognize and identify colours, and to distinguish the subtle differences between colour shades and tones, is learned and laid down in long-term memory in early life and is one of the functions of the occipital lobes. Evidence has been gathered that suggests that Alzheimer’s disease rarely affects these lobes and this, in itself, presents a doorway to creative opportunity and an opportunity for increased wellbeing.

Since pre-historic times, men and women have painted and designed and created objects wherever they have lived. Art has played an important role as a social anchor in the past, but above all, divergent thinking and good colour sense are arguably the two primary characteristics that are the key to any successful creative art endeavour. Art is also a proven medium by which those living with dementia can communicate their thoughts and ideas with meaning and emotion. Contrary to the continuing belief that recreation programs such as art can be costly (Passmore *et al.*, 2007), art today is easily accessible, and the art materials are safer. With planning and foresight, programs can be designed to be affordable to most organizations. With the knowledge that colour acuity and appreciation and many art related skills are retained until very late in the Alzheimer’s disease progression, it augers well for future program design, and the development and implementation of dementia-specific art activities.

Drawing together all of the above information and looking toward the future, in the progression toward a more universally accepted person-centred approach to care, the knowledge presented in this chapter offers insight and its simple discoveries point in new directions, not least new ways to increase individual lived experience and engagement with the world. And, increased engagement in the arts is more than likely to positively influence wellbeing and the quality of the lived experience of those who partake.

The aim of this chapter was to set colour and vision both in an historical and a modern landscape by bringing together the thoughts of leading experts on colour and vision with the observations of those scholars studying the neuropsychology of art and dementia. The aim was, in plain language, to increase an understanding of the relationship between these two different but interlinked fields of research. Not surprisingly, what has been revealed is that colour and vision and the neuropsychology of art has a profound role to play in the lived experience of individuals with dementia, particularly the way they see colour and participate in art activities. In the next chapter, the important role that reminiscence plays when documenting the lived experience of those in dementia-specific care will be explored.

CHAPTER FIVE

The important role of reminiscence in dementia-specific care

Autobiography becomes a significant source of social creativity in the second half of life. It builds upon natural tendencies with ageing to reminisce and elaborate on stories, either oral or written or visual form. This summing up process in general comprises a key dynamic underlying the role of older persons as keepers of the culture

Gene Cohen (2000, p. 97).

The last chapter revealed that colour and vision and the neuropsychology of art has a profound role to play in the lived experience of individuals with dementia, particularly in the way they see colour and participate in art activities. But, the lived experience of the art activity is equally important, and reminiscence is the one element that is integral to the story and theme of the collaborative, communal artwork in this project. Schweitzer (2011, p. 175) writes that arts-based “reminiscence work in dementia care has consistently emphasized the importance of listening to the person, drawing them out, supporting their self-expression, connecting them and enabling them to connect to others”.

In this research project, the themes and symbolic imagery that adorn the “*Getting to Know You*” communal artwork were drawn from case study interviews and the personal life-story and lived experiences that each participant shared with the facilitator. Trust was established through reminiscence and where possible a relationship built on mutual respect between the facilitator and the participant was begun. This trusting link enabled the facilitator to introduce the art activity and his or her personal images on the artwork surface to each participant.

Kotai-Ewers (2011, p. 160) writes that “stories matter in dementia care”. The aim of this chapter then is to present a brief background to the rise and use of

arts-based reminiscence to understand why stories matter so much in dementia-specific care.

The importance of a life-story and an “inner script”

Jill Ker Conway (1998) comments that if postmodernism means anything, and that is hotly debated, it is the abandonment of the idea of linear development, or the concept of universal historical progress, that everyone over fifty was raised on. She contends various converging trends represent society's abandonment of this concept. She writes that of particular significance are the horrors of such places as Bergen-Belsen, Dachau and Hiroshima, in combination with the other miseries inflicted by totalitarian regimes in the 20th century, making it difficult, if not impossible, for us to believe in progress as we once did. As a result, the abandonment of a central cultural point of view, once focused on power and worldly success, has led to a growing trend toward autobiography that particularly reflects individual identity and parental relationships. She points out that the main themes of autobiography before the Second World War were worldly success, moral and spiritual growth and the uses of power. She puts forward the view that the post-war years have seen a new emphasis on individual life experience stories that reflect a changed and very different sense of time.

The importance of reminiscence in old age

Erikson's (1959) developmental theory emphasizes the importance of reminiscence as each person enters old age, which he describes as the last of eight life developmental stages. The developmental task of this “ego integrity versus despair” stage is the reworking and resolution of one's past. Erikson maintains that the psychological health of each individual in old age is usually defined in terms of the life review process. The achievement of a deeper sense of identity and self-respect is dependant on the ability to review life, including its dislocation and losses, across the entire lifespan (MacKinlay, 2011; Sherman,

1991; Thorsheim & Roberts, 2000;). Yalom (2001) writes that as we work toward achieving this task our focus grows, ideally, away from ourselves toward a concern for the care of successive generations.

Reminiscence in aged and dementia-specific care

Increasingly, over the last two decades, it has become more acceptable to consider the role of reminiscence in the development of individual identity across a life-span, with particular reference to aged care and dementia-specific care.

Before the pioneering work in the 1960s of Pulitzer prize-winning author Robert Butler (1927-2010) on the life review process, reminiscence was often considered a “normal” sign of what was then referred to as “senility”. In the 1970s and 80s, Butler, who is credited with coining the term ‘ageism’, dispelled many commonly held myths about ageing and earned himself the title of the “father of modern gerontology” (Butler, 1975). Prior to that time, it was generally thought that progressive cognitive impairment, culminating in dementia, was a normal and expected stage in the human lifecycle, if one lived long enough, and an integral part of the ageing process. Wholihan (1992) describes part of Butler’s considerable contribution when she writes:

[He was] the main force responsible for popularizing the concept of reminiscence within the field of geriatrics. He [Butler] describes life review as the universal, spontaneous process of recalling and judging past experiences, in particular unresolved conflicts that are surveyed and then reintegrated. He postulated that this review occurs most frequently in early old age and in anyone facing death (Wholihan, 1992, p. 1).

Beisgen (1989, p. 100-101) maintains that the principles of reminiscence therapy provide an obvious pathway to enable older people to “cultivate the life review process”. She regards reminiscence as of primary value in dementia-specific care because it creates an opportunity to “look back, reflect and find

meaning in life experiences... [and, in particular, it] provides clues to feelings and behaviours”. Hepple (2004, p. 374) reinforces this view and sees the recent resurgence of reminiscence therapy in the UK as undoubtedly helpful in the treatment of those living with dementia, and regards an understanding of the individual’s pre-dementia personality to be “a promising way of processing the challenging dynamics of dementia care”.

It might reasonably follow that autobiographical reminiscence, when used to better understand an individual’s identity and parental relationships, or when utilized in the process of assisting individuals to come to terms with atypical events in the continuing search for life’s meaning, is a useful tool in both an aged care setting and in generally assisting in the therapeutic progression.

However, the Woods *et al.* (2008) analysis of reminiscence therapy for dementia - a non-pharmacological intervention - found only four randomized and quasi-randomized trials, “suitable” to meet with Clarke and Oxman’s (2002) standard Cochrane Collaboration reviewer’s instrument. The examined data focused on changes in cognition, behaviour, communication, mood/wellbeing and impact on care-givers. These factors were assessed using psychometric tests and rating scales. In addition, descriptive characteristics (such as the quality of randomisation, blinding etc.) and study results were also examined. Given that the Clarke and Oxman instrument is widely regarded as the “gold standard” for systematic reviews of the efficacy of pharmacological treatments, it is not surprising that the Woods *et al.* (2008, p. 2) findings indicate that although no harmful effects were identified from the outcomes measured, there was a need for more research given the “inconclusive evidence of the efficacy of reminiscence therapy for dementia”.

Brooker, formerly Professor of Dementia Care Practice and Research at Bradford University in Britain, and now Head of the Dementia Centre at Worcester University, has consistently questioned the methodology of such

research, when applied to dementia, for the past two decades. In 2000, for example, Brooker and Duce (2000, p. 354) reported that the “positive outcomes for reminiscence therapy for people with dementia have been noted by a number of authors”. Brooker and Duce question the sensitivity and appropriateness of some research methodology, because they say much of the published research indicates finding to the contrary. In fact, most researchers report that “the benefits of reminiscence therapy [are] weak”. Brooker and Duce (p. 355), argue that qualitative outcomes such as “increasing contributions, enjoyment and engagement” are valid in relation to dementia, but they write that these criteria are rarely seriously considered in most research trials. Brooker and Duce are of the opinion that encouraging men and women to take stock of their lives and their experiences, in a supportive environment, leads to greater personal understanding and self-worth and, this in turn, has the potential to increase wellbeing.

From their own perspective

In relation to Australian women, Steinberg (1997, p. 80) comments that, “women over 80 are now special”. She maintains case studies and interviews that focus on the experiences and recollections of such women yield significant data on health and wellbeing, as well as useful insights into events and common connections. She writes, most older women in Australia have strong rural ties, have experienced two World Wars, the great Depression and many have survived major personal trauma. Kamler (1999) is of the opinion that the creation of a “cultural space”, where older women talk about life from their own perspective, produces a richer sense both of what they have accomplished and what lies ahead. Kamler, like Brooker and Duce (2000), is convinced that life stories have a material effect on older women’s wellbeing, and that this can positively influence how women perceive and prepare for their future.

Cameron (1994) explains that although the creative process we engage in cannot be accurately quantified in intellectual terms, it is often driven by the need to review our experiences in an effort to make sense of ourselves. Cameron is convinced the therapeutic value of recovering a sense of identity through reminiscence and story telling is far reaching. Isey (2007, p. 1) the founder of the StoryCorp Project in the United States writes we, “find wisdom, wonder and poetry in the lives of the people all around us”. He says the stories that everyday people record, in mobile recording booths that travel across the country, “embody the true spirit of the nation”, and celebrate the identity of the uncelebrated (Isey, 2007, p. 7).

The relevance of an “inner script”

Ker Conway (1998) maintains that, irrespective of our education or social standing, each of us carries an “inner script” that lies, “just below the surface of consciousness”. When discussing the place, value, and importance in our society of inner reflection and self-expression, she writes:

Whether we are aware of it or not, our culture gives us an inner script by which we live our lives. The main acts for the play come from the way our world understands human development, the scenes and key characters come from our families and socialization, which provide the pattern for investing other emotional significance; and the dynamics of the script come from what our world defines as success or achievement... [and] most of us, unless faced with emotional illness do not give our inner scripts a fraction of the attention we give to the plots of movies or TV specials about some person of prominence. Yet the need to examine our inherited scripts is just below the surface of consciousness, so what really grips us is the inner reflections of our lives the auto-biographer sets in motion (Ker Conway, 1998, p. 6).

Rowe (1983) also describes the process of inner reflection as an “essential part of our sense of self”. She writes that our lives must have:

A beginning, a middle and an end. The beginning is where we come from - our family’s history, the history of our nation/race/religion as we learn it

from our teachers, our personal history as told to us by our family and increasingly our memories. The middle of our story is present time. From the present we see the future which stretches before us simply passing the time where anything can happen, we create expectations and predictions for ourselves. . . The sense of self evolves with the sense of passing time, and our life story is the essential part of our sense of self and arises out of the conclusions we have drawn from our experiences (Rowe, 1983, p 47).

Pipher (1999, p. 270) writes that “the last goal of the aged is realization or the growth of the soul”. She believes that “this realization brings both sorrow and self-acceptance [and] each old person needs wisdom, philosophy, poetry and a sense of being connected to something meaningful”. To begin and complete this task, the propelling motivation for almost every individual is the decoding of an inner script. This process of growth can most ably be assisted by reminiscence elicited through positive and empathetic conversation.

Understanding the “inner script” of individuals living with dementia

Research (Bowlby, 1979) has indicated that key characteristics within our family structure establish our inherited attachment patterns. They lay the first significant foundations stones on which we construct our emotional life. These patterns determine not only our identity, but also our ability to face and overcome challenges. This in turn affects our wellbeing. It should be noted, that aspects of Bowlby’s perspective have been challenged by some scholars. But, McFadden and McFadden (2011, p. 48) say, “despite some disagreement about how to measure it and how to describe different forms of insecure attachment, there is solid consensus about the fundamental precepts of the idea”.

Attachment, Kitwood (1997) points out, is one of the most basic needs common to all humans. When combined with what Camp *et al.* (2002) describe as “the interaction of lifelong habits and personality”, both must be considered key contributing factors when considering the needs and emotional responses of individuals living with dementia (Camp *et al.* 2002, p. 1397).

Browne and Shlosberg (2005 & 2006) cite and explore John Bowlby's description of attachment theory and then apply the theory to dementia-specific care. Bowlby (1980, p. 39) defines attachment behaviour as "any form of behaviour that results in a person attaining or retaining proximity to some other differentiated and preferred individual". Bowlby (1969 & 1979) maintains that the need of human beings to establish strong emotional attachments, particularly for security and protection, remains a key element of relationship building throughout adult life. When human beings experience feelings of insecurity, the reaction to such circumstances may be manifested in different forms of emotional distress. These may include anxiety, anger, depression, and emotional detachment - responses not unfamiliar to carers in most dementia-specific care settings.

Browne and Shlosberg's (2005) recent work explores the role of cognitive functioning and pre-morbid attachment style. Their comprehensive literature review (Browne & Shlosberg, 2006) outlines research into the nature of relationships between infants and caregivers, and then relates these patterns of attachment to ageing individuals who exhibit psychological symptoms associated with dementia. They comment that the "common occurrence of attachment behaviours and parent fixation", amongst individuals living with dementia in residential care, highlights the need to introduce strategies that foster feelings of security and safety (Browne & Shlosberg, 2005, p. 160). It is common in many aged care and dementia specific settings for individuals to search for and call out for a lost attachment figure. Bowlby (1979, p. 103) describes these urges as a "regular feature of grief and in no sense abnormal" in cognitively functioning individuals. However, such behaviour in cognitively impaired individuals is almost always seen as abnormal, and is almost always controlled with medication.

Browne and Shlosberg (2005) acknowledge the value of a growing number of non-pharmacological interventions such as “doll therapy” (Bryant & Foster, 2002; Moore, 2001) and “simulated presence therapy” (Woods & Ashley, 1995), designed to address this not uncommon phenomenon. Further exploration of memories and associated connections, through a life-story and reminiscence, holds real promise and further acknowledges what Waller (2002) has described as an all-pervasive feeling of terror and abandonment experienced by many of those living with dementia.

Dissanayake (1995, p. 37) also makes an interesting point that may have relevance when considering the use of art-based research to evaluate the psychological wellbeing needs of those living in dementia-specific care. She says that although “we cannot say that the need for attachment is the reason for artistic behaviour”, but “the phenomena of attachment and mutuality help to explain why we find art to be affecting”. This seems to this writer to be a very good reason to conduct art-based research with those living with dementia.

Preserved skill and preserved motivation

Cohen (2000, p. 144) contends that older people want to tell their story because it is a normal developmental tendency that draws on their preserved skills, and preserved motivation. He believes it is of utmost importance to provide those with significant memory loss, particularly those who tend to repeat the same story, with the opportunity to tell their story. Working with preserved pockets of memory, the exploration of memories and associated connections to these stories can create bridges between family members and, not insignificantly, the prospect of increasing the interest of care staff. These memories can be creatively translated into visual images for art as therapy, or through memory cards and photo images in life-story books. These images can be used to elicit greater detail and memory recall during the reminiscence

process, thus preserving the individual's self-worth and identity, while increasing enjoyment and meaning for the individual.

The development of memory and life-story programs

The recent development, in the USA, of memory and life-story programs (Isey, 2007) and those specifically designed for those living with dementia heralds an important new direction and approach to person-centred care. Incorporated into the creative arts therapies, such programs as created by Cohen, Basting, Friedman, and Levine-Madori and those directed by Heinly and Isey and others is discussed at greater length in Chapter Three - the *History of dementia* - and could be said to set new benchmarks.

Trauma and life-story

Ker Conway (1999) expounds on the enduring legacy that Dachau and Bergen-Belsen has left. She describes these two concentration camps as representative of the converging trends that have had a profound effect on our society. This period of history and its legacy is of particular significance to those individuals born in the first three decades of the 20th century, many of whom now live in aged care. The trauma associated with war, including concentration camp survival, and other experiences associated with 20th century conditions and conflicts are not uncommon, but are often hidden within this cohort. Three authors discuss this hidden trauma. It is worth considering their research in the context of reminiscence and life-story as it relates to the care of those in aged care, now and in the future. Awareness of the extreme cases of genocide can assist in the assessment of traumatic experience generally, even though most trauma does not carry with it the dramatic horror of the worst moments of modern history.

Frankl (1985) and Valent (1994) both recognize that the resolution of emotional issues, linked to particular traumatic events, is important to the emotional wellbeing of both the individual and his or her family. Frankl's work developed directly as a result of his experiences in concentration camps during the Second World War. The Holocaust, as has been persuasively argued over the past sixty-five years, represents the nadir of evil in the 20th century. Frankl (1985), who survived four concentration camps, describes the development of his unique psychological approach called "logotherapy" in his widely influential book *Man's Search for Meaning*. Logotherapy, he writes, is based on the principle that human beings must find meaning in life if they are to progress toward a peaceful resolution of life's traumas. This extraordinary book was written in nine successive days in 1945 after the war ended. He describes how his exploration of his logotherapy concept was based on his own survival, and how he wrote his thoughts down on scraps of paper within Auschwitz.

Frankl, as well as Elie Cohen (1953) and Primo Levi (1961 & Levi & De Benedetti, 2006), and to a lesser extent Bruno Bettelheim (1960), shared comparable wartime experiences in the camps and remind us that the years 1939 to 1945 in occupied Europe were a time in which the "abnormal" became "normal". Robert Jay Lifton (1971 & 1986) has been particularly interested in the psychology of genocide, the study of the Holocaust and Hiroshima and other extreme historical tragedies. His body of work focuses on the relationship between individual psychology and historically induced trauma.

Most human beings can understand and anticipate death but European Holocaust survivors, and for that matter survivors of other genocides, struggle not only with the concept of systematic extermination, but also with the memory that such acts became everyday occurrences.

Langer (1991) writes that one of the most powerful themes to emerge from the stories of Holocaust survivors is the difficulty survivors have when telling their

story, managing the contrast with what is normal in the present. The very nature of the abnormal conditions that existed surge into the present to further remind the survivor of their overwhelming and potent influence.

Reflecting on this difficulty, Langer puts forward the view that the experience of recalling the memory of trauma is not always predictable. He says that memories can flow like a spring from a well deep in the past, and memory can also become entombed and cling like “withered ivy” in the mind. Langer is convinced that this conflict divides the individual between the need to recover from the loss and at the same time a seeming inability to recover. He thinks this is because the memories are inseparably identified with victims who did not survive and few, if any, survivors escape emotionally unscathed from the death of others. Langer contends that, as a result, the memory of survivors grows more intractable as they age and troublesome memories re-emerge as they approach or enter retirement. At the successful completion of a career, and the raising of a family, frequently more time and space is filled with anguished memories that cannot be silenced.

Valent (1994) focuses on the courage that child and adult Holocaust survivors display when talking and writing about their experiences. Valent, himself a child survivor of the Holocaust, believes that recording such experiences can have a positive impact, an impact not only on the emotional health of these individuals, but also the process can provide useful insights for healthcare professionals to adapt and use in their work with victims of child abuse and with survivors from other 20th century genocides, such as those in Cambodia, Bosnia and Rwanda.

Valent (1994) considers writing and remembering central to the therapeutic process for child survivors, whose experiences are frequently moulded in the pre-verbal stage of life. He writes:

One is one's memories. One cannot exist without memories. Memories connect the past with the present, they connect oneself to the world. Without memories there is a nothingness, an irrational deadness. . . It is a tribute to the human capacity for creativity and the need for order that child survivors have attempted to place the Holocaust into a wider world vision (Valent, 1994, p. 281).

Valent explains that as child survivors begin to remember, they gain self-esteem, meaning, and purpose for themselves.

Conclusion

Reminiscence is the one element that is integral to the story and theme of the collaborative, communal artwork that is the subject of the art activity in this research project. Trust built through reminiscence enabled the facilitator to introduce the art activity and his or her personal images on the artwork surface to each participant. The aim of this chapter was then to present a brief background to the rise and use of arts-based reminiscence in dementia-specific care to understand why stories matter so much to residents living in long term care.

This chapter began with Jill Ker Conway's thoughts on life-story and the "inner script" and the impact it has on the lived experience of us all. Ker Conway noted that since the end of World War 2 autobiography has become an increasingly popular genre and, in explaining the art of biography writing, she describes leading biographers and autobiographers as having highlighted the importance of documenting an "inner script". The art activity in this research project, through the use of easily recognizable images and graphic symbolism, documents the lived experience of the participants who contributed.

The notion that we all look back and reflect is married to the need to review our experiences from our own perspective. This is a concept that Butler popularised. Robert Butler, described as the "father of modern gerontology" died in 2010. Butler was undoubtedly someone who made a very significant

contribution to cultural attitudes toward ageing and his legacy should not be underestimated. Not only did he coin the term “ageism” but he was also the co-founder of what is now the American Alzheimer’s Association and the American Federation of Ageing Research. Increasingly, the relevance of each person’s “inner script” as being an essential part of our sense of self is becoming accepted, and our human need to connect to something that has meaning is no less for those whose sense of self is stripped away by dementia.

As memory slowly fades for an individual on the long slow progression through Alzheimer’s disease, it can sometimes appear to leave behind an apparent “nothingness” an “irrational deadness”. This is what Bayley (1999) so aptly describes as the “lion mask of Alzheimer’s”. Whalley (2001, p. 116) refers to this demeanor as “the confusion” and apart from the natural attrition of the disease, he also attributes it to the “ill-effects of poisoning by sedative drugs” and/or the affect that withdrawal of chemical substances has on the individual. This chapter has argued that making a connection with the outside world, through reminiscence and creativity, for those living with progressive memory loss can be possible for most individuals. The capacity to temporarily shed this mask and engage in fulfilling reminiscence activity has been demonstrated time and time again in programs such as *TTAPS* and *The Spark of Life* and *Timeslips*. Engagement in reminiscence is also a way for such individuals to relate to the past and come to terms with trauma and find meaning in life.

Furthermore, the study of holocaust survivors, and those of other historical horrors, provides unique insights into the role of memory and reminiscence in the area of dementia care and for those struggling with other more limited traumas. It provides valuable clues to aid in the challenge of processing the multi-faceted dynamics of modern dementia care - once again a case possibly of the prism of the extreme case shedding light on the more commonplace.

This chapter ends Part One of this thesis. It is immediately followed by an overall summary of the five chapters that have made up Part One. Part Two begins with an exploration of Lifton's (1971) concept of 'symbolic immortality'. Put simply this is when an individual makes and leaves a mark - in this case through painting part of a permanent artwork - that is an integral part of fulfilling his or her existence through the lived experience.

SUMMARY OF THE FIRST FIVE CHAPTERS OF PART ONE

It is fitting that the introduction chapter that made up Part One of this thesis began with a quote by Alois Alzheimer. In 1908, Alzheimer had little idea that the disease that now bears his name would have such an impact on the world stage when he stressed the importance of searching to find new ways to advance scientific research. At the dawn of not only another century, but a new millennium, the Baroness Greenfield has picked up Alzheimer's mantle by challenging scientists and researchers to set new parameters for dementia research for the 21st century.

The debate on ageing has been raging since ancient times and public conceptions of dementia have changed over time. The end of World War 2 heralded a new era as it saw the birth and introduction of creative arts therapies into hospitals and institutions and the evolution of a new person-centred approach to therapy and, by extension, the care of those living with dementia influenced by the ideas and theories of the humanist philosophers of the 1950s. Robert Butler, described as the "father of modern gerontology" made a very significant contribution to cultural attitudes toward ageing by championing the rights of older citizens including those living with dementia in the 1960s. We know that dementia is not a normal part of ageing, but instead it comprised of as many as eighty different diseases and syndromes. An umbrella or magic cure for dementia is unlikely and as a consequence, dementia is set to become the biggest disability burden in Australia and other first world nation's

history. The impact that this will have on the economy of these nations will be devastating.

Even though governments around the world are aware of this impact they have yet to recognise the importance of building stock resources for the wellbeing of the baby boomer generation, and are falling far short of addressing many of the vexed issues surrounding dementia and its research. As a result, researchers, other than medical researchers, face funding shortages and obstacles including the perceived “gap” between scientific and art-based research, which is driven by a “traditional dogma” that operates within the biomedical organizational structure and dominates the aged care sector and dementia-specific research.

The impetus for cultural change today however must come through the redefinition of dementia and may be achieved with a new dementia/disability approach and the widespread implementation of a person-centred approach to dementia care. Leading healthcare professionals and dementia specialists maintain that one way for the aged care sector to understand the concepts and values of person-centred care, and its relation to the individual’s emotional wellbeing is to broaden the scope of research by conducting and publishing research that investigates the natural synergy between dementia and creativity.

Recently, leading neurologists have studied artists living with dementia and have for the first time isolated idiosyncratic art techniques and skills relating to different forms of dementias. Parallel to these discoveries, colour and vision experts, point to the many possibilities and new directions for the use and application of colour and art, not only to strengthen individual engagement with the world, but also to add colour to an environment that is likely to positively influence wellbeing and the quality of lived experience of those in care.

Leading experts have also identified that the neuropsychology of art is in its infancy. With the exception of one or two scientists, no one yet seems to have explored the neuropsychological stages and steps of an art activity beyond a few basic steps. There are few original dementia-specific creative art activity programs in existence and, as a result, research into the role and use of the art or how the arts relate to wellbeing in dementia-specific care is rare. In addition, the role that the facilitator plays in dementia-specific art activity would appear not to have been explored in any great depth or detail.

Since the end of World War 2 autobiography has become an increasingly popular genre. The importance of documenting an “inner script” through the role and use of reminiscence highlights a way for individuals to relate to the past and come to terms with trauma and find meaning in life. If we are to meet the challenges of the next four decades in healthcare, reminiscence and life story provide valuable clues to aid in the delivery of best practice person-centred care. And, many believe that person-centred care is both the key and the most effective way to face the challenges of processing the multi-faceted dynamics of modern dementia care.

The concept of dementia-specific wellbeing and the identification of the functions and role of art and the role that an art facilitator performs in this process, are critically important to understand, as is the relationship between art and dementia and wellbeing during an art activity. PART ONE has identified a gap in research knowledge to further the research questions and thesis.

PART TWO

CHAPTER SIX

Making a mark: The individual and an art activity

You don't need a prescription to buy a box of crayons

Barbara Fish (Ramm, 2005)

The first five chapters that made up Part One of this thesis spoke to the historical background and lived experience of individuals with dementia in the past. The role of colour and vision and art-based reminiscence and how they relate to the creative arts was identified. The aim of this chapter is to explore the motivational drive and subliminal human desires that contribute to the lived experience of individuals during their involvement in the creation of an original artwork. This chapter also aims to detail some of the organizational obstacles experienced by art activity practitioners in the field.

Here I have left my mark: a unique creative thumbprint

Professor Geoffrey Blainey (2003), commenting on the motivation to paint of residents living in aged care, makes the observation that humans wish to paint because the emotional and aesthetic rewards of painting are so powerful they become overwhelmed by the desire to create. They hope to pin down or capture something of beauty, or just to escape, but most of all humans paint because of their need to proclaim here I have left my mark (Blainey, 2003)

Warren (1996) too explores the universal human desire to leave a mark. He asserts it is the birthright of every human being "to make his or her own 'unique creative thumbprint' - one that no one else could make". Warren laments that "over the centuries we have created the concept that artistic creation is the responsibility of a few gifted individuals"; on the contrary he

maintains, “we all need to make this ‘mark’” because each creative mark reaffirms and represents an individual spark and are expression of our humanity. Each mark says ‘I am here’ (Warren, 1996, pp. 3-4).

Symbolic immortality and the need to make a mark

Throughout his work, Robert Jay Lifton (1971) has explored time and the emotional motivation in each of us to make our mark and create “works” that live on after us. He writes that the evolution of his unique “thematic and formative approach” to the ‘big’ issues of time and death facing individuals, springs from his study of Erikson’s “imprint” and his own observations of each person’s unique response to survival, death and immortality. He is of the opinion that “generally speaking man has avoided systematic investigation of his feelings about time” (Lifton, 1971, p. 15). He thinks this is due to a conscious or unconscious avoidance of death and/or the realization that we are running out of time. By placing an interpretative emphasis on death and “death imagery” Lifton developed the concept of “symbolic immortality” - a concept he now describes as being “central to his work” (Lifton, 1971, pp. 156-157). He describes each individual’s “quest for symbolic immortality, for living on through larger groups and images to which one is attached, [as] part of a compelling universal urge, and in fact man’s only way of coping with the fact of death” (Lifton, 1971, p. 204).

In his later book, *The Broken Connection*, Lifton (1979), expands this philosophy, and in doing so identifies five working models that best describe his idea of ‘symbolic immortality’. He argues that a psychological need for a sense of immortality or ‘an assurance of eternal survival of self’ motivates our actions.

One of Lifton’s models in particular - the creation of “works” that live on after us - is significant to the creative arts therapies and particularly relevant in

meeting the emotional wellbeing needs of residents in care. Lifton (1971) writes, “man’s quest for ‘eternal survival’ can be seen as symbolically realized by artistic and other cultural ‘works’ he transmits to future generations” (Lifton, 1971, p. 253). For many individuals these “works” are of special significance, particularly for those who for whatever reason have little or no spiritual faith or have not been parents and cannot “live on” through their biological offspring. For these individuals the act of contemplation and participation may result in an immersion or a “losing of oneself” in what Lifton describes as a state of ‘experiential transcendence’. Artistic works, in particular group artworks and permanent community murals, ensure that at least each individual has an opportunity, whatever the circumstances, to make his or her mark.

“I can’t draw a straight line”

The perception that untrained artists “can’t draw a straight line” is one of the major obstacles that must be overcome when engaging individuals in care in creative pursuits. Over decades of professional practice working with clients of all ages, Kramer (2002) has heard many excuses when talking to her clients about drawing, painting and sculpture. She says “we are often confronted” by our patient’s and their feelings of inadequacy and familiar statements such as, “I can’t draw a straight line” and “I have not done any artwork since I was six years old”. Kramer says much of an art facilitator’s time is spent in the effort to “reassure them again and again that it doesn’t matter how they draw” (Kramer, 2002, p. 219).

Stott and Males (2004) speculate, that comments such as “but I can’t draw” stem from the memory of “struggling with perspective in the school classroom”. Their experience is that able-bodied adults in residential aged care are actually more likely to have inhibitions, when presented with art materials

during creative arts therapy activity, than those living with dementia (Stott & Males, 2004, p. 116).

Hubalek (1997) has found participants often say “I don’t know why I am here, I can’t draw a straight line” when introduced to an art activity for the first time. She confirms first timers are often “initially fearful” and most “tend to judge their attempts to draw and paint under two misconceptions”. The misconceptions are, firstly, “an artist must be able to draw a straight line” and, secondly, “art must be realistic or identifiable”. As a result, many “participants come into an art [activity] expecting to fail” (Hubalek, 1997, p. 1). Lane (2010, p. 75) adds, “another widespread and ingrained assumption is that we lack the talent to do anything of significance”.

Edwards (2008) believes individuals often abandon art in childhood because “unthinking people sometimes make sarcastic or derogatory remarks” about their efforts. She says many adults relayed their “painfully clear memories of someone ridiculing their attempts to draw [and] they seldom attempt to draw again” (Edwards, 2008, pp. 68-69). Lane (2010, p. 74) has observed that “nearly every child [is] capable of producing visually exciting work to their native abilities”. He also believes that although many creative talents may seem to be extinguished in childhood, adults nonetheless have “general hidden abilities” that almost always go under mined.

Burton (2007) contends the acquisition of skills is largely determined by teacher’s attitudes and parental reinforcement. She too is of the opinion that negative comments can have a profound and lasting effect on engagement and creativity. As a result of negative conditioning, Edwards (2008) has observed “the majority of adults in the Western world do not progress their art skills beyond the level of development they reached at nine or ten”. She believes some adults draw childlike stick figures because they are convinced they have

never been able to draw, not even a straight line, and they “simply could not learn how to draw” (Edwards, 2008, p. 69).

Allen (1992) thinks “many individuals harbour mistaken ideas about how artists work, or have no idea about how an art piece comes to look the way it does when finished”, and untrained artists probably do not develop a “reference for visual representation, or skills for translating complex inner experiences into satisfying images” (Allen, 1992, p. 26).

Edwards (2008) goes some way to explain this phenomenon by saying most mental and physical skills, like speech and reading and writing, develop and change in adulthood, but because our survival is not dependent on drawing, we cut off our artistic development prematurely. Dissanayake (1998) also links the demise of the arts with the acquisition of literacy. She writes, “ability to read and write and the division between history and prehistory is based on whether or not there are written records”. She is also of the opinion that literacy above all other acquired skills is commonly considered necessary for participation in modern life, and of unquestionable benefit to the individual (Dissanayake, 1998, pp. 172-173).

In the 1930s, Buhler (1879-1963) observed that children by the age of three or four already have “a well formed body of conceptual knowledge formulated in language” and images dominate memory because verbal language processes are not fully controlled in very young children. Warner (1989) remarks that children “quickly develop many drawn symbols” that undergo “changes over time”. She says symbols have “more to do with thinking than specific observations” and every child “will come up with symbols that are important” to them and will use them until words take over (Warner, 1989, p. 9).

The five components that combined to create the skill of drawing

Edwards (2008) explains that important and significant symbols are preserved and embedded in long-term memory along with five component skills, which make up the “global” skill of drawing. She describes the five skills in some detail. The first skill is the ability to conceive and draw edges. The second skill is the ability to understand the concept of space. Edwards argues the third skill, is the concept of perspective. This concept includes the ability to place objects in relationship to one another in space. The fourth skill is the ability to perceive and draw, light and shadow. And, the fifth and final component is the combination of the first four skills. This combination creates the “gestalt” or beginning of each individual’s particular skill in drawing.

Art is a natural activity

Many people express lack of confidence in their ability to draw and paint. Warner (1989) admits drawing “scares more adults than any other art activity”, but says art is a natural activity that “isn’t something that should be done in the corner, at a certain time, wearing special clothes” (Warner, 1989, p. 7). Kramer’s (2002) personal view is that individual life experience, and the cultural environments in which we function, largely determine such constraints. She maintains an art facilitator should be mindful of such considerations, but be ready to promote spontaneity by helping individuals overcome inhibitions. A professional approach should not focus on the quality of a participant’s work, but instead the goal should be to free each artist from constraints and artificial standards.

In nursing homes, Stewart (2004) encourages residents to participate in art by describing enjoyable aspects of the activity. She says most people living in aged care are intimidated by the prospect of “doing art”, but an emphasis on the enjoyable aspects of the process, not the end product, is what is important to

relieve stress. Stewart writes, “most of us have been told we are no good at art and have no creative ability, so we stopped ages ago”. Stewart begins the art activity by encouraging residents to watch the process, and before long many “can’t resist the colour and the feel of the various materials” and they become actively involved (Stewart, 2004, p. 150). McNiff (2007) supports the kind of creative and intuitive process that Stewart implements, when he recommends that the facilitator must learn how to “create a supportive environment that inspires creative thoughts [by] realizing that nothing happens in creative expression unless we show up and start working on a project, even [if we have] little sense of where we might ultimately go with it” (McNiff, 2007, p. 32).

Group artworks and murals in a therapeutic setting

Adamson (1984) records irresistible excitement when hospital patients worked together for about eight hours, on the production of a very large, collaborative communal artwork. A depiction of Noah’s Ark, collaged on scrap pieces of wallboard, “resulted in an unusually integrated picture of a fishing scene”. He writes this was “surprising” given the group of twelve artists were from “a closed ward where the residents were regarded as very anti-social and would not communicate”. Adamson says “each participant drew a pair of animals on sheets of an old wallpaper pattern book, [then] cut them out”, and pasted them on the mural. Adamson says he had a hard time keeping up with the demand for art supplies but it was worth it because many nurses remarked that they had never seen the patients “working together in such harmony”. In the project postscript, Adamson details the reaction of the management committee who made the decision not to continue to fund his initiative or the cost of the art materials. The sad result was the patient’s retreat “back into their shells of non-communication” (Adamson, 1984, p. 84).

Johnson and Sullivan-Marx (2006, p. 312) write, “Working together on a group project, such as a mural, can link people together, giving a sense of ownership

and belonging. The artwork is a visual reminder for participants that they can still accomplish and learn new things despite limited mobility or cognition”. Although the benefits of communal art are obvious (VicHealth, 2002), unfortunately Adamson’s experience is not uncommon. There is a widespread assumption that ongoing art activity is too expensive to finance and that art is linked to the supposedly “messy aesthetic” of art, or the misconception that individuals who are no longer able to verbally communicate will spend their time trying to eat the art materials or destroy their surroundings. Allen (1992) thinks this may explain why some management and staff may be resistant to proposals that fund time for artists-in-residence.

The role of modern folk art

Peterson (2006, p. 113) contends that as a “precursor and to adjust to the use and cultivation of the spoken word, from caveman to subway graffiti artist humans have made meaning of their lives through images and symbols”. Just as prehistoric man used his hands as stencils to make his mark 22,000 thousand years ago, graffiti and stencil artworks and participatory institutional art and community art today can be seen as the modern equivalents of traditional folk art. Kramer (2000, p. 60) believes the “pictorial productions” created by graffiti “have filled the void left by the demise of folk art”. She continues by adding:

Throughout our pre-industrial history, the object of daily life was made by hand. A kind of overflow of joy and pride in making things and in possessing them led people to embellish their handiworks with countless variations (on innumerable surfaces) of imagery drawn from the imaginative and spiritual storehouse of their culture. Thus, folk art linked everyday life with the enduring and transcendent values of culture, and the effect of confirming the existence of the everyday world and our place in it, lending reassurance and stability to life. Folk art has now all but disappeared. Instead the persisting appetite for imagery is being exploited by the packaging industry... [In] the cacophony of visual noises issuing from boxes, cans and plastic wrappers (Kramer, 2000, p. 58)

Both graffiti and institutional art are art forms emanating from a similar urge in two stratas of society to create culture by making a mark and giving voice to their concerns. In the first instance, spurred on by peer group enthusiasts, and mixed with the added frisson of illegality, the mostly illiterate and dispossessed adolescent male, and very occasionally a female, are able to voice anger and dislocation by creating illicit social commentary and by making new “in the raw” art. Kramer (2000) thinks, “the inclination to decorate is perverted into the impulse to deface”. She contends, “graffiti-making attracts the artistically endowed among the population that lacks the opportunity to cultivate such gifts in other ways” (Kramer, 2000, p. 61). For the elderly the urge to participate in communal works is driven by the need to express loss of identity and loss of social position.

As already mentioned, folklorists (Kirshenblatt-Gimblett, *et al.* 2006) have long understood the place of reminiscence, story telling and memory painting in the lives of those who were born at the same time and navigate the course of history together. The creation and recording of the inclusive reinforcement of the best qualities of a common heritage helps ease the loss for older members of a community who no longer hold the revered position of custodians of the culture they once enjoyed. If custodians, through life-story interviews, are given the opportunity to shape and develop a unique theme that represents their shared history it can, in effect, provide each individual with the means to share their life experiences and to see his and her collective history valued and preserved.

For all generations, if there was one defining characteristic of folk art, and the ancient communal custom of community storytelling, it was location. The demise of traditional arts and expression in our society is due to the fragmentation of traditional cultures, primarily as a result of industrialization, mass communication and an atomization of what were communal ponds of communication.

The value of community art projects and the link between participation and wellbeing are well documented (Elliott, Grant & Morison, 2010; Commonwealth of Australia, 2004; Marsden, 1993; VicHealth, 2002). There is a valid argument for the expansion of art activities and the production of communal artworks in dementia-specific settings, if only to rekindle a common cultural experience and connection.

Rekindling a common cultural experience: An argument for the expansion of art activities and the production of communal artworks in dementia-specific settings

Those born in Australia and educated in the 1920s and 1930s are mostly characterized by a common cultural experience. For those now living in care, Stewart (2004) comments, “most older adults have little or no experience in using art materials or in expressing themselves visually. For the most part, the generation now in their 80s and 90s placed a high value on work and family and little value on hobbies” (Stewart, 2004, p. 150).

Tomlinson, in his classic book, *Children as Artists* (1947), offers us another reasonable explanation as to why Australians living in aged care today may place little value on art and may be reluctant to engage in creative art activities. One reason might be found in the legacy of British art education and teaching traditions, and the influence of this legacy on the Australian public school curriculum and educational framework. Tomlinson explains that after 1850, there was a marked increase in interest in art education, inspired by the Great Exhibition. As a consequence, art as a subject in British government schools was increasingly seen as an integral part of a liberal education. He writes, “until the time of the new movement and modern methods, the aim of the teacher was to develop the children under his care [to acquire] technical skills with adult standards in mind” (Tomlinson, 1947, p. 14). Under the banner “skill of hand and eye”, systematic, technical art training in schools was

fuelled above all by the need to constantly replenish skilled workers in industry.

Tomlinson (1947) describes the significant worldwide contribution made by Franz Cizek (1865-1946) in art teaching and art education. Cizek's response to systematic and industrial focused art teaching is encapsulated in his child-centred credo, "let the children grow, develop and mature". Tomlinson outlines Cizek's philosophy and details his recommendations:

No child should be subjected to a rigid course of technical education. Ideas and methods of expression of adults should never be imposed upon children. Children should be given a choice of material with which to express and create. Their expression in the chosen material should be allowed to mature according to their innate laws of development. It should not be hastened artificially or altered to satisfy adult ideas. Above all, children's efforts should never be ridiculed and criticism should always be sympathetically given. Care should be taken not to praise skill at the expense of creative ideas (Tomlinson, 1947, p. 20).

Cizek began his revolutionary work in the last decade of the 19th century. Unfortunately, his enlightened philosophy had not reached Australian schools in the 1920s and 1930s. Even in the late 1930's the Victorian public schools system continued to practice and institute a very technical approach to art education.

Examples of the application of this philosophy in the classroom are found in the prescribed drawing exercises of the day. Through attempts to draw straight lines of different lengths and thicknesses, proportion and perspective were mastered. An appreciation of the contrast between thick and thin lines for instance had a dual purpose as it was thought to be a necessary preparation leading to good penmanship. Only when these exercises were mastered was the "skilled" child allowed to draw freehand renderings of symmetrical architectural features, such as the linear Ionic volute, and nature drawings

such as the Acanthus leaf. So for people educated to think of art as linear and mechanical, it is hardly surprising that an invitation to participate in “creative” art is often met with surprise, and almost always accompanied by the retort - “but I can’t draw a straight line”.

Art and handwriting are taught very differently in schools today. In terms of tapping into the hidden skills of those who are now in care, and received formal schooling more than seventy years ago, one must appreciate that the five components necessary to draw effectively were learned and embedded in long term memory as each individual worked toward mastering the prescribed drawing exercises of the day. Most individuals in care today can recall being put through the rigors of learning penmanship. In particular, they can recall being told to use every “skill of hand and eye”, when attempting to render the straight line edges of the linear Ionic volute and to take care when applying pressure to the paper whilst shading the Acanthus leaves.

Conclusion

This chapter explored the motivational drive and subliminal human desires that contribute to the lived experience of individuals during their involvement in the creation of an original artwork. This chapter detailed some of the organizational obstacles experienced by art activity practitioners in the field

This chapter documented the thoughts and theories and lived experiences of practitioners as they relate to the physical skills and strategies necessary to draw and paint and it has outlined the role and purpose of modern folk art in residential aged care. Although misconceptions of art may momentarily limit individuals from trying creative arts activity, it is not because they are not creative or capable. Many are too fearful to attempt art or are overcome with inhibitions caused by past negative experiences. Predominantly it is management and organizational policies that stifle innovation and opportunity.

Drawing and painting skills are a primal heritage. New skills are learned and strengthened during imaginative play and experimentation in early life (Erikson, 1959; Winnicott, 1971). They became embedded in long-term memory, particularly in those who received the instruction to use every “skill of hand and eye” during their formal education and contribute to each individual’s lived experience during an art activity. Invariably, the lure of colour and paint sparks a subliminal human desire for symbolic immortality - to create a unique thumbprint by making a mark.

When served by a capable facilitator those who live in institutional care seem to relish the opportunity and they deserve no less. And, now that the motivations of the participant have been thoroughly examined, it is time to turn our attention, in the next chapter, to the role and motivation and special skills of the facilitator in dementia-specific art activities.

CHAPTER SEVEN

The role of the facilitator in a dementia-specific art activity

In the previous chapters of this thesis it has been established that research into the neuropsychology of art is in its infancy. The previous chapters give an indication that the creative process involves a complex combination of cognitive skills. And, the motivational and subliminal human desire of individuals to leave their mark and, to fully participate in the lived experience, was thoroughly canvassed and acknowledged in the last chapter.

The role of the facilitator is critical to the success of a dementia-specific art activity. This is because loss of cognitive skills due to dementia limits the ability of individuals living in care to participate. Therefore the aim of this chapter is to identify what special skills the facilitator must bring to a dementia-specific art activity. This will be achieved by documenting the thoughts of leading practitioners and art activity facilitators in this field. Identifying the skills needed to facilitate the dementia-specific art activity under investigation will produce a fuller and more comprehensive understanding of aspects of the design and development of the phenomenological research methodology and the tools being applied in this research project.

A humanistic perspective and person-centred approach to dementia-specific wellbeing

Perrin and May (2001) have written extensively on wellbeing and dementia and the role of the facilitator in care. They write that any facilitator working in dementia-specific care “needs to learn to recognize and foster the innate creativity within an individual, and trust that they will, aided or unaided, bring to birth the solution that is right for them alone” (Perrin & May, 2001, p. 27). They are convinced that creativity is the “essence of human life” and wellbeing lies “in action and doing”. Even though the facilitator may be “an ordinary

person, doing what comes naturally and intuitively”, he or she plays a critically important role by encouraging a participant to relax, join in and embrace the “here and now” in an expression of “unique creativity”. They remind us that facilitation is critical to the “wellbeing of the severely impaired person”, given that such individuals are “not able to engage in occupations without [the] intervention of another”. They also confirm that “high levels of wellbeing can be experienced in the context of occupation with another” (Perrin & May, 2001, p. 52)

In Tasmania, Australia, Dr Pat Baines (2007) approaches wellbeing and dementia-specific care from a humanist perspective whilst embracing a person-centred approach. Baines (2007, p. 7) notes that “art therapy is becoming increasingly recognized as having a contribution to make in the area of quality dementia care”. She believes that “art therapy, which grew out of psychotherapy, engages with a person’s creativity to initiate a process - whether through painting or drawing, sculpting or writing - that is healing and whole-making”. Baines maintains that art as therapy in dementia care today need no longer be “an adjunct to psychotherapy but [instead] is becoming important in enabling those living with various kinds of dementia to remain creative”. Her experience has convinced her that the use of art as therapy and creative self-expression “raises self-esteem and enables individuals with various kinds of memory loss to express their feelings”.

The desired qualities of an art facilitator in person-centred, dementia-specific care

At the conclusion of *Healing Art Therapies and Person-Centred Dementia Care* Kasayka, Hatfield and Inness (2001), speak directly to the importance of the role of the art facilitator, in dementia-specific activities. The authors’ stress that all art facilitators, from whatever discipline, need to be fully aware of the necessary skills required to achieve professional standing. They also stress that, art facilitators should be “practicing artists in the art form they use in

therapy”, because the “discipline one gains through practicing one’s art gives validity to the therapy” (Hatfield & Innes, 2001, p. 121).

Lokon (2007) thinks such a person should have aged care training and the skills necessary to adapt an art activity to meet individual needs. She writes to be “efficient artist facilitators of people with dementia, both artists and gerontologists need to have some ‘school knowledge’ about the diseases that cause dementia and about art materials” (Lokon, 2007, p. 27). Kelly (2007) is more philosophical after spending more than ten years working with individuals living with dementia in the long-term wards of Scottish hospitals. She writes:

The facilitator must provide a climate in which external evaluations is absent, where the facilitator does not form judgments from his/her locus of evaluation. The facilitator must engage in empathetic understanding in which he/she truly sees the person and what the person is feeling, in which he/she enters the person’s private world and sees it as it appears to him/her. Finally, the facilitator must allow psychological freedom for symbolic expression. By these means, a safe environment is created for creative expression to emerge (Kelly, 2007, p. 70).

Adamson (1984) is certain anyone who wishes to work, as an art facilitator in institutional care, should first and foremost be an artist. Reminiscing on a long and fruitful career, like Kelly above, he describes the role of art in clinical healthcare settings as “opening a non-judgmental space” in a safe psychological environment. Adamson believes that artists carry “the great authority of their vocation”, and that skilled and empathetic art facilitators hold a sacred trust to “give a professional welcome to individual expression”. He likens the primary role of an art facilitator to that of “a catalyst [that] allows the healing arts to emerge” (Adamson, 1984, p. 4). When Dr. Dax appointed Adamson, in 1946 making him one of the world’s first “art therapist”, he envisaged the role of the artist as a facilitator not a clinician.

In an exploration of the role of art and artist in healthcare, Woodhams (1995) offers an historical insight on the art therapist’s professional contribution to

Australian healthcare. She documents the role and use of art, as it was perceived at that time. She makes the point that, before the aged care reforms in the late 1990s, although art facilitators working in healthcare were often described as being part of a “multidisciplinary team”, they did not always fit readily into either a biomedical model of care or into an art establishment model. As a consequence, artists did not usually enjoy the rights and privileges of either group and the validity of their work was not always fully appreciated. Woodhams’ points out that, some professionals from other disciplines, i.e. within the “multidisciplinary team”, compounded this lack of recognition by denying art as a “proper healthcare practice”. She documents that art therapists were often criticized for “wasting time playing with paint when they should be doing proper work” (Woodhams, 1995, p. 25).

Dissanayake (1998) sheds light on Woodhams’ experience when she writes, “even though it may not be consciously articulated [as it was in Woodhams’ experience above], it is usual today to consider capital ‘A’ art as ‘useless’ in the sense that it does not contribute directly to physical vital needs and processes”. She explains, “if one then claims that Art satisfies a psychological need, it is discomfoting to admit that many people seem quite able to live without the benefits of at least the more refined arts” (Dissanayake, 1988, p. 34). Revisiting the same issue thirty years later, Dissanayake (2008) sadly expresses the follow observation:

The subject of art is of particular and commanding interest and consequence within humanistic studies *and to human life itself*. The current postulate that art has no biological or functional importance has real-world implications outside academic theory. It echoes the traditional Western elitist assumption of ‘art for art’s sake’ and contributes to the broader cultural atmosphere that increasingly reduces support for art programs in schools and communities (Dissanayake, 2008, p. 25).

An assumption that art has no biological or functional importance stands in the way of the progression of specific art activities tailored to meet the emotional

wellbeing needs of those living with dementia in care. Woodhams (1995) found this attitude is almost invariably linked to a view that creative art activity is “only a diversion, to keep people occupied [and] only ‘therapists’ should work in health care settings”. Although some multidisciplinary team members are willing to consider the merit of having art programming, they still believe the only value of art, apart from keeping people quiet, is “to interpret and use for diagnosis and other therapy regimes” (Woodhams, 1995, p. 30). Judith-Kate Friedman, the author of *Songwriting Works*, objects to the view that music therapy is little more than what she describes as “maintenance entertainment” and she believes this attitude is probably symptomatic of a much wider malaise that she refers to as “institutional think” (Basting, 2009, p. 105). This ‘malaise’ and a possible cause in relation to art activities is discussed further in the conclusion to this thesis.

Webster (2002) argues that most challenges arise because individuals within a multidisciplinary team have “little understanding of each other’s roles” and few actually acknowledge each other’s “expertise and professional contribution to the team”. He maintains the functionality of a multidisciplinary team depends primarily on individual members who work together well as a team with a clear understanding of the “different methods” that each discipline employs. Webster thinks that effective collaboration can only really occur in a climate where individuals work uncompetitively together towards a common goal.

Abraham’s (2004) experience in Israel appears to confirm the prominence of many of the worst characteristics associated with competitiveness. It would seem antipathy to the role and value of art in many healthcare settings is still problematic. Woodhams (1995) convincingly argues that the way “these tensions are resolved will have a great impact on the ways in which art might be made an integral part of healthcare practice” (Woodhams, 1995, p. 25). By placing the resident at the centre of the care, as Kitwood argued and Luther

Manor, a residential aged care facility in Wisconsin, USA, demonstrated, institutions can diffuse competitiveness and produce quality integrated care that meets the needs of residents and care partners.

The concept of “the third hand” and small changes

Exclusive definitions of what an art facilitator is in healthcare settings, and the level at which that person should help each participant to engage in art is contentious and varies from culture to culture (Ulman, 2001). Kramer (2000), writing in *The Art Therapist’s Third Hand: Reflections on art, art therapy and society at large*, describes how she developed the concept of the “third hand” as an extension of Theodore Reich’s (1938-2003) metaphor for the cultivation of the psychoanalyst’s third ear and eye. Kramer says she coined the phrase “to describe an area of the art therapist’s functioning wherein artistic competence and imagination are employed in the empathetic service of others”(Kramer, 2000, p. 27), and she claims uses the “third hand” to promote artistic skill, pictorial imagination, ingenuity and improvisation in order to help participants engage in the creative process. She believes that an awareness of the psychosocial “forces” which may affect an individual’s sense of autonomy and selfhood is as essential to understanding as being aware of that person’s physical limitations and capacity to engage.

In relation to aged care, Stephenson (2006, pp. 25-26) adds, facilitators should “understand the way in which elders think about and make art” which, she maintains, is different from younger people and occurs on a “physical, creative and psychological level”. She advocates “adapting an art technique for a physically impaired client [because it] gives the person the experience of tapping into the senses [and] encourages the life review process”. For Stephenson the great value of art activities is the opportunity for the facilitator to give “the client an audience” and to make adaptations that encourage participation. She believes understanding and anticipating the participant’s

needs in an art activity fosters “exploration and emotional growth”, and knowledge that has the capacity to “empower older men and women through creative expression and to encourage them to draw on their wisdom and experience as valued members of society”. Not unlike Stephenson, Kramer (2000) believes assisting individuals to participate can bring about “small changes” which nonetheless can, enable the participant to achieve a new level of engagement that would otherwise be out of reach. Knill *et al.* (2005, p. 87) add, an experienced facilitator “can enable people who are not artists and usually have a sense of ‘not being talented’ to engage in art disciplines of some sort and to find satisfaction in them”. Blatner’s (1992, p. 407) view is similar too, he believes that helping participants “develop their creativity...involves not only fostering their creative ability, but also building their sense of themselves as creators and their attitude toward life as a creative challenge”.

The value of traced images and drawn outlines and technical props

The painting process demands sight, dexterity and both gross and fine motor skills to coordinate hand-eye movements in unison and every individual is clearly influenced by the extent that he or she can remember steps in sequence (Zaidel, 2006). Klammer (2010) and Stephenson (2006) recommend a beginning or starting point in an art activity within a clearly defined area, because “elderly clients are often unable to fully execute their creative ideas, so they require the use of the therapist’s mobility, imagination, or technical knowledge” (Stephenson, 2006, p. 25).

Cave paintings some 22,000 years old (see below) indicate the first artists used their hands imaginatively as stencils to create art (Dissanayake, 2008). It has been a common practice since at least the 16th century for artists to transfer works using master “cartoon” drawings on paper as templates. Some artists use pinpricks to transfer drawn outlines onto different surfaces, and a medieval

technique known as “inking up” is still used by weavers to transfer designs onto the warp in the production of tapestry artworks (Phillips, 1994).



Pre-historic cave paintings, Rio de las Pinturas, Patagonia (Chatwin, 1995).

Professional artists today use a vast variety of “tools” and aids, including overhead projectors and light boxes and computers, to trace and print images onto different surfaces. Many individuals living with dementia are overwhelmed by the prospect of creating something original and may harbor personal doubts and uncertainty about the technicalities of painting, or are simply daunted by the prospect of a blank canvas. As detailed in Chapter Four of this thesis, the abstract impressionist painter, Willem de Kooning in his later years, had his assistants transferred outlines onto canvas to relieve him of pressure and anxiety and so “free him up” to capitalize on his remaining strengths and abilities (Stevens & Swan, 2004). The de Kooning example and experience suggests, that facilitators might achieve greater levels of participation by using traced images and outlines.

The value of one-on-one participation in a dementia-specific activity

One-on-one participation is considered not only appropriate, but often preferable by leading professionals experienced in dementia-specific care (Perrin & May, 2009; Baines, 2007). The one-on-one experience is regarded as the optimal person-centred approach to the creative process because it ensures each individual receives the facilitator's full and undivided attention. A highly individualized audience allows the facilitator to accommodate each person's unique and specific needs. Under these circumstances the trust developed in a reciprocating partnership is more conducive to the establishment of confidence and security. Most importantly, it negates the all too familiar plea, "but I can't paint".

The value of the art facilitator assisting individuals who cannot initiate an activity

Dementia affects memory, in particular, the ability to remember steps in sequence and can reduce the participant's ability to independently initiate an activity. Without assistance from the facilitator engagement in creative activity is more likely to be limited. Baines (2007) speaks directly to this problem when she writes, "dementia, in its many forms, can affect individuals in various ways. A common effect is to make starting something creative difficult... it means that writing the first words or making the initial strokes of a pencil or paint brush may be a prohibitively difficult act" (Baines, 2007, p. 24). Baines has observed that often a person "may sit with their hand holding the oil pastel suspended in space above the paper" in a frozen gesture awaiting a prompt. Then, "once 'the switch' in the brain has been 'flipped'", the person can begin or continue to create art independently. Baines comments, "I am simply assisting the part of the brain that needs to be reminded to begin by modelling a few strokes". The essayist and poet, Ralph Waldo Emerson (1803-1882), who

died of Alzheimer's disease, describes how memory is jogged by having, "all sorts of mysterious hooks and eyes to catch and hold, and contrivances for giving a hint", at hand (cited in Harvey Wood & Byatt, 2008, p. 173). Baines employs such contrivances to great effect. She equates her role as scribe and art facilitator to "turning on switches or finding hooks", and confirms that modelling a step in an art activity is often necessary when assisting individuals with advanced dementia.

Adapting the creative space as a precursor to the art activity

Baines' comments and observations demonstrate that the facilitator must employ not only skill and capacity, but imagination. Baines (2011, p. 112) believes that "all human beings are creative and that being creatively engaged is a human need". She adds that part of the facilitator's role is to provide support and this is best achieved by the creation of a "judgement free space" (Baines, 2011, p. 124). The absence of these critical factors, she finds, has the potential to create frustration and render the activity counterproductive. When conducting any dementia-specific activity, a facilitator must be ready to adapt the creative space to accommodate and provide support to every individual according to his or her needs. This may mean moving the artwork project from room to room to accommodate more socially isolated participants, or even accommodate painting in bed, or draping the work over wheelchairs and walking frames; in short, careful consideration must always be given to the selection and implementation of an appropriate and "safe psychological space".

Dalley (Case & Dalley, 1992) details ways in which facilitators, whether in a clinical or community setting, might devise a controlled working environment and "safe psychological space" by employing methods that are balanced and relaxing for both parties. McNiff (2004) writes that, "creative powers are exercised when people are safe" and the facilitator, when anticipating the

needs of another person, must first listen, be observant, and then attentive and non-judgmental. He stresses that an appropriate response from a facilitator often has the “power to allay fears” (McNiff, 2004, p. 29). A facilitator must also carefully prepare for the activity with good forward planning, not least because such planning, can dissipate distractions and environmental intrusions.

Keep it simple

Johnson and Sullivan-Marx (2006) emphasize that the steps of an art activity must be explained simply, as only then is the participant likely to achieve a positive outcome. They write: “art tasks need to use client’s strengths to provide success in art making. Whereas some clients respond well to a multi-step task, such as painting and rinsing the brush between colours, other clients need an approach that requires only one step, such as receiving a paintbrush already dipped in paint” (Johnson and Sullivan-Marx, 2006, p. 312).

Conclusion

The aim of this chapter was to identify the necessary skills and the role of the facilitator in dementia-specific activities, so as to provide a better understanding of aspects of the research design methodology detailed in the next chapter. This chapter documented the recommendations of leading practitioners in this field and identified the special requirements and circumstances unique to dementia-specific art activity facilitation, as well as highlighting some of the obstacles art facilitators can face working in a multidisciplinary team. From this exploration, a key concept to emerge is that of the “third hand” and its applicability to dementia-specific activities. This chapter also identified the critical role that any facilitator plays in dementia-specific activity. Primarily, that role is to assist individuals with varying levels of ability to initiate and sustain an activity.

This chapter identified the special set of skills that a dementia-specific art activity facilitator must bring to the art activity. This chapter is followed by a summary of Part Two. This chapter set the scene for the next chapter, where the research project methodology is explained in detail.

The first chapter in Part Two begins by identifying the sequence of stages to be initiated by the facilitator when implementing this research project's dementia-specific art activity. That chapter sets out the key elements of the art activity and clarifies the facilitator's role as it relates to the 'how' and 'what' of this research project's phenomenological research methodology.

SUMMARY OF TWO CHAPTERS THAT FORM PART TWO

The aim of the two chapters that comprise PART TWO of this thesis was two fold. Firstly, the aim was to identify the motivational drive that contributes to the creation of an original artwork and to highlight some of the obstacles that limit creative involvement. The second aim was to identify the skills and role of the facilitator in dementia-specific art activities, so that a better understanding of aspects of this research project's design methodology might be achieved.

Drawing and painting are part of the human primal inheritance and even though some participants may at first be reluctant to take part, invariably, the lure of colour and paint sparks the desire to create a unique thumbprint and to make a mark, wins out. The role the facilitator plays in assisting individuals with varying levels of ability to initiate and sustain an activity in a dementia-specific art activity is critical.

PART TWO documented the many thoughts and recommendations that leading art facilitators and practitioners have on this subject. It has been shown that

management and organizational policies may stifle innovation, and some preconceived ideas about art that momentarily limit individuals from embarking on creative arts opportunities must be overcome by the actions of skilled facilitators.

PART TWO sets the scene to ensure that key elements of the art activity and the facilitator's role detailed in the chapters on the research methodology and discussion in PART THREE can be better understood.

PART THREE

CHAPTER EIGHT

The research methodology: The creation of the dementia-specific art activity holon.

A picture is a window, an expression of the inner self. Here there is no right or wrong.
There are no mistakes in our art and everything is beautiful. This is a safe place.
Nothing profound is expected, yet that is exactly what occurs.
Holly Queen-Daugherty (2001)

Emotionally and intellectually everyone “knows” how good creative expression is for people, but few really know or have been able to explain what it is about an art activity that is so good and valuable. Like wellbeing it is elusive. It stands to reason then to understand how and why an art activity might be good for an individual living with dementia one must begin by understanding the mechanics of the art activity process as a whole, from top to bottom. To achieve this we must first understand the process and then develop a methodology and unique set of tools to do the job.

The last chapter identified the special set of skills that the facilitator must bring to a dementia-specific art activity. This first chapter in Part Tree begins by identifying the sequence of stages to be initiated by the facilitator when implementing this research project’s dementia-specific art activity. This chapter then sets out the key elements of the art activity and clarifies the facilitator’s role as it relates to the ‘how’ and ‘what’ of this research project’s phenomenological research methodology.

As already indicated this research project is a phenomenological exploration of the lived experiences of a group of individuals living with dementia in an aged care facility in Australia as they participate in an art activity. The overarching aim of this project is to examine and document ‘what’ each individual experienced during the art activity, and then assess ‘how’ each individual experienced that phenomenon. (For a further elaboration on the nature and

uses of a phenomenological approach, see pages 50 to 56 in the introduction of this thesis).

Understanding the process

An understanding of the mechanics of the whole process addressed in this thesis begins by considering the reasons why an activity is designed in a particular way. In addition, to fully appreciate what good is gained by this design one needs to understand the subtle and trusting relationship that must be built between the facilitator and the participant. Each facilitator has a responsibility to fully appreciate and accommodate the physical ability of the participant, and take into consideration the psychosocial circumstances of that person. Only then can a facilitator be reasonably well equipped to implement the critical elements that enable him or her to professionally fulfil the role and responsibilities of a facilitator.

The relationship between the facilitator and the participant has been identified as one of the key elements in dementia-specific facilitation (Kitwood, 1997; Perrin & May, 2001). With due consideration of the published material and the role of the facilitator detailed in previous chapters, there is a strong indication that structure and empathetic facilitation are the key to the success of an art activity. There are some who disagree; Kim (2007), for example, thinks that the participant's "interaction" with the materials might be the most important element and the catalyst that leads to the success of the art activity. Tyler's (2002) case study illustrates what happens when the facilitator stands back and leaves an individual to sort the art materials and start the art activity by himself.

An overview of the art activity process

An overview of what is involved in an art activity, so that the methodology is designed and created to allow observers to make observations of the lived experience of the research participants, is set out directly below. In ideal circumstances:

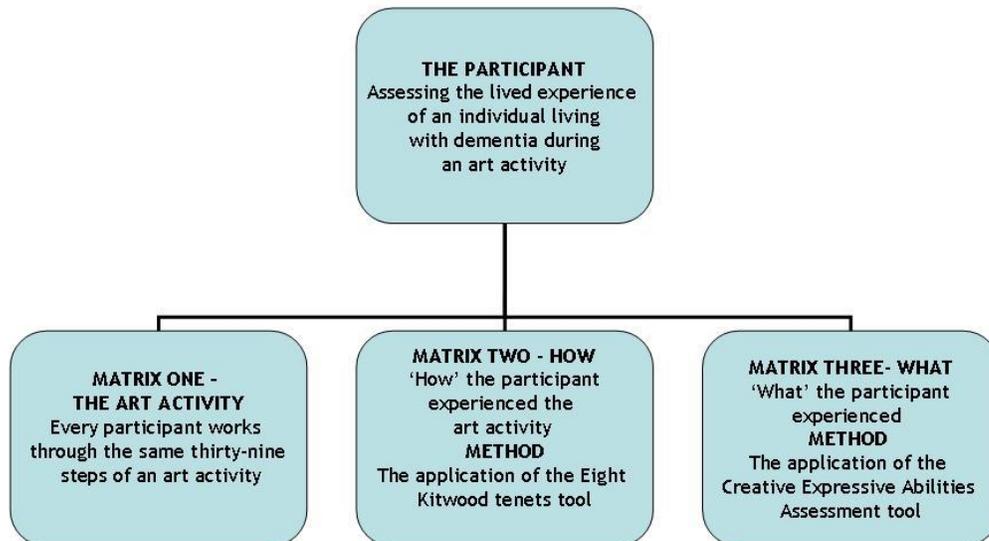
The facilitator brings and introduces the participant to the activity. The facilitator establishes a safe psychological space and holding container within the first moments of the activity. Trust is quickly established and inhibitions are overcome. The facilitator follows a structure that is the same for each participant, that is designed to relieve performance pressure on both individuals and they both relax. In a relaxed and equitable environment the participant begins the activity and is soon involved or even consumed by the creative “flow” (Csikszentmihalyi, 1990 & 1996). The facilitator observes the participant closely and offers encouragement and positive reinforcement of individual colour selection, and validates each choice and comment. The facilitator assists if and when necessary in the creative process. This is when a wellbeing opportunity, embedded within the activity, is manifest. It is also an opportunity to access wellbeing outcomes by what and how each individual experiences this phenomenon using the assessment tools. The skills and the lived experience of each participant may be noted in order to later create individually tailored activities that best suit his or her needs.

The activity is un-pressured and proceeds through the same stages and steps of the overarching art activity structure for each participant. The art activity goes on for as long as the participant determines. At the end of the art activity, an opportunity to express gratitude is presented to both participant and facilitator, in an equal and reciprocal relationship.

To follow the above process, a set of tools and a structure must be designed so that the facilitator and observers are able to access how and what the participant experiences the art activity. This is necessary to determine if the pre-determined performance criteria, expectation and outcomes are met. The following explanation of the design of these tools creates the appropriate phenomenological methodological framework for this research project.

The design of a set of tools necessary to implement the research methodology

The aim of this chapter is to fully explain the design of the methodology employed in this research. The structure of the methodological framework, using the basic assumptions of the phenomenological approach as set out in the introduction, begins with the creation of an original and new dementia-specific art activity matrix. This new design is achieved by combining together the Tom Kitwood person-centred “wellbeing metaphors”, and his “positive person work” tenets, with the multiple stages and steps of an art activity, the result is the creation of MATRIX ONE - the art activity. This matrix makes it possible to present the same art activity following the same process to all the participants. MATRIX TWO - the eight Kitwood tenets - makes it possible to explore ‘how’ the art activity is experienced by each of the participants. MATRIX THREE, uses the CEAA tool, a quantitative research tool, specifically designed to document ‘what’ each participant experiences whilst engaged in the same phenomenon. It needs to be stressed that the published literature suggests what is being measured in this study has never been measured before. The tools mobilised for this study provide multiple layers of assessment as they relate to the participants’ lived experience during the art activity.



This chapter will begin with a brief outline of Kitwood’s (1997) five “wellbeing metaphors” and his twelve “positive person work” tenets. Kitwood argued that this person-centred care model, contains essential elements critical in maintaining wellbeing in individuals living with dementia. After this description, the specific stages and steps involved in a dementia-specific art activity will be identified.

In the previous chapter, the role and the skills of an art facilitator, as they apply to dementia-specific activities, were identified. The term ‘holon’ and ‘matrix’ as described in the introduction of this thesis are used throughout this chapter and the next to describe the three matrices - the critical elements of the phenomenological research methodology - that make it possible to assess what and how each participant experiences during the art activity.

The Kitwood person-centred care model

The Kitwood person-centred care model encapsulates the importance of wellbeing in those living with dementia. Kitwood (1997) links wellbeing with the psychosocial “needs” of residents in care when he recognizes and celebrates each person’s capacity for enjoyment of life and self-expression. The combination of Kitwood’s person-centred “wellbeing metaphors” and the twelve “positive person work tenets”, with an art activity, offer an ideal framework to observe the often hidden creative skills of those living in dementia-specific care and to document each participant’s lived experience.

In his book *Dementia Reconsidered: The Person Comes First* (1997), Kitwood lays out his person-centred approach to care which he constructs using two parallel concepts. On the one hand he believes this approach presents the best and most useful guideline for person-centred care models, even though the validity of his methodology has subsequently come under criticism (Epp, 2003 & Adams, 1996). In a more recent appraisal, Baldwin and Capstick (2007) analyse Kitwood’s contribution and they put his legacy into perspective by convincingly countering the most common criticisms levelled against him, i.e. that Kitwood could not back up his theories with sufficient empirical evidence. Baldwin & Capstick, (2007, p. 15) comment that Kitwood simply “did not have empirical data to draw on” when he was developing his theories and model of care in the 1980s and 90s, and they make the point that Kitwood himself challenged many of his critics to “falsify his theory through empirical research”. Baldwin and Capstick (2007 p. 16) convincingly argue that now, a decade after Kitwood’s death, there is “enough empirical evidence to... lend credence to Kitwood’s theories [and] regardless of his own methodological failings” Kitwood’s theories “have generated questions, research programs and activities and data that contribute greatly to our understanding of dementia” and wellbeing. They further argue Kitwood’s “Dementia Care Mapping” tool is just one example of Kitwood’s legacy that has “provided a wealth of data on wellbeing and ill-being among people with dementia in institutional settings”.

Kitwood's primary motivation was to improve conditions in institutional care and the wellbeing of those living and working there. He strongly advocated a wider understanding of the psychosocial needs of residents. He maintained that the fulfilment of individual needs are inextricably linked to wellbeing, and firmly believed that care partners and program directors have a paramount responsibility to firstly, understand the wellbeing and psychosocial needs of those in their care and, secondly, to design interventions to better accommodate each person's individual needs.

Kitwood believed to create a "culture of care", where these two themes work in parallel harmony, management and staff must first practice a person-centred approach by integrating the following concepts.

Kitwood's "wellbeing metaphor"

Kitwood's first concept, the "wellbeing metaphor", uses a flower as a metaphor to illustrate the five primary psychological "needs" he identified in his model of care. Kitwood believes that individuals living with dementia need comfort, attachment, inclusion, occupation and identity, and if these needs go unmet, the individual cannot sustain wellbeing.

Kitwood's five "wellbeing metaphors" in more detail

COMFORT (COM)

Kitwood (1997, p. 81) describes comfort using traditional meanings and associations. He uses words such as "warmth and strength" and "tenderness and closeness". He associates comfort with dementia and a person-centred approach, by describing it as "the calming of anxiety and the feeling of security which comes from being close to another".

ATTACHMENT (ATT)

Kitwood (1997, p. 82) outlines John Bowlby's (1979) attachment theory and refers to the "safety net" it provides for infants in the first years of life. Kitwood sees this theory as particularly relevant to those living with dementia and believes the need for attachment "may be as strong as in early childhood". He maintains that, "when the world is full of uncertainty...the loss of primary attachment undermines a sense of security". Even though Bowlby's theory has fallen from favour in some quarters, Browne and Schlosberg's (2006) dementia-specific literature review of Bowlby's theory and dementia points to recent research into the relevance of attachment theory with this cohort.

INCLUSION (INC)

Kitwood (1997, p. 83) makes the point that "to be part of a group is essential for survival", but dementia causes social life "to dwindle away" and, regrettably, "it is still very rare for people with mental impairment to be included with ease". Kitwood maintains when this need is rarely met, although individuals may appear to be part of a group they may also be profoundly alone and, in such circumstances, individuals tend to withdraw into what Perrin and May (2000) describe as a "bubble of isolation". Kitwood strongly believed that inclusion in purposeful activities is essential to sustain wellbeing.

OCCUPATION (OCC)

Kitwood (1997, p. 83) advocates the inclusion of individuals in activities that are "personally significant and [draw] on a person's abilities and powers". He makes the observation that when individuals are not fully occupied, or deprived of the opportunity to use and exercise their abilities, limited as they might be, these abilities "atrophy and self-esteem drains away". This can lead to "a state of boredom, apathy and futility". Kitwood argues that when an individual's

past history and activities are appreciated and absorbed into purposeful activity solutions, wellbeing is enhanced.

IDENTITY (ID)

Kitwood (1997, p. 83-84) describes identity as a way of knowing “who one is, in cognition and in feeling”, and adds that every individual has a “story” and a “sense of continuity” with the past. He maintains empathy, and the reinforcement of each individual’s “life story”, leads to a “global sense of self-worth, of being valuable and valued” and this, above all, forms the solid base of his person-centred care model.

The central core of the “wellbeing metaphor” is love

In Kitwood’s wellbeing metaphor the five overlapping “needs” form the petals attached to the flower’s central core. This core is symbolic of unconditional love. Kitwood (1997, p. 82) maintains that love, and no matter how elusive it might seem at times, is above all the essential emotion at the core of every individual and that unconditional love enables him or her to “remain in one piece” when uncertain emotional circumstances are present and individuals find themselves “in danger of falling apart”.

Kitwood’s twelve “positive person work tenets”

Kitwood’s other concept is based on twelve “positive person work tenets”. These tenets are central to both developing an understanding of the individual in care and his or her needs, and the creation of a “culture of care” that involves everyone who forms part of the care hierarchy. Kitwood developed these tenets under the following headings: recognition, negotiation,

collaboration, play, timalation¹, celebration, relaxation, validation, holding, facilitation, creation and giving. Kitwood's "culture of care" acknowledges the special talents and unique abilities inherent in every care partner and resident alike, whilst "positive person work" relies on the innate integrity of care partners to recognize the dignity and worth of each human being.

Like beads on a string, applying Kitwood's "positive person work tenets" to an art activity.

Kitwood, throughout his career encouraged his critics and others to conduct detailed research of his "positive person work tenets" (Baldwin & Capstick, 2007). Kitwood explained (Kitwood, 1997, p. 90) that collectively the tenets form a sequence of actions each designed to enhance personhood in a different way. Ralph Waldo Emerson described memory as "the thread on which the beads of man are strung" (cited by Harvey Wood & Byatt, 2008, p. 172), and, in an equally powerful analogy, Kitwood likened the actions of the tenets to "beads on a string", each fits together and "provides a higher level of detail". This detail leads in turn to a greater understanding of the individual living with dementia and their wellbeing needs.

A description of Kitwood's twelve "positive person work tenets"

RECOGNITION (REC)

Positive person work tenet number 1

Recognition is made up of two parts. Firstly, recognition acknowledges that each person living with dementia is unique. Secondly, recognition acknowledges that each person is still a person worthy of respect irrespective of his or her level of cognitive impairment.

¹ Kitwood used the term timalation to describe sensory stimulation such as massage or aromatherapy

NEGOTIATION (NEG)

Positive person work tenet number 2

Negotiation and consultation with each individual on his or her preferences, desires and needs creates a degree of personal control.

COLLABORATION (COL)

Positive person work tenet number 3

The facilitator and the participant are “aligned in a shared task with a definite aim in view” (Kitwood, 1997, p. 90).

PLAY (PL)

Positive person work tenet number 4

The primary aim of the activity is participation, allowing the activity to be spontaneous and self-expressive.

TIMALATION (TIM)

Positive person work tenet number 5

Usually a form of sensory and/or sensual contact such as aromatherapy or massage but, in the context of an art activity, it can be used to describe sitting close to each other combined with discussion and explanation, including physical contact with the art materials and props (including stencils and photographs) to provide the participant with “reassurance and pleasure, whilst making few demands” (Kitwood, 1997, p. 90).

CELEBRATION (CEL)

Positive person work tenet number 6

Kitwood (1997, p. 90) describes celebration as an “expansive and convivial ambience experienced by those living with dementia when engaged in a form of interaction where fear and responsibilities disappear”.

RELAXATION (REL)

Positive person work tenet number 7

Many living with dementia have “particularly strong social needs [and] are only able to relax when others are near them or in actual bodily contact”(Kitwood, 1997, p. 91).

VALIDATION (VAL)

Positive person work tenet number 8

Validation acknowledges the reality of each individual’s emotions and feelings and promotes better understanding and acceptance of the individual.

HOLDING (HLD)

Positive person work tenet number 9

With this tenet Kitwood draws on a substantial body of work developed by the psychoanalyst D.W. Winnicott. Winnicott (1971) was convinced of the importance of a “safe” emotional environment, and he coined the term “safe container” to describe his concept. Knill, Levine and Levine (2005, p. 50) describe the role the therapist/facilitator plays in creating this environment and where “the patient feels free to be himself without constraints”. Kitwood (1997, p. 91) emphasizes that providing a holding “container” in a “safe psychological space” is important and must be carefully developed.

FACILITATION (FAC)

Positive person work tenet number 10

Some individuals living with dementia have difficulty organizing their thoughts and activities in sequence. Facilitation fills in the missing gaps and enables the participant to “get started” in the art activity and/or complete each stage in sequence.

Kitwood added the final two tenets, “creation” and “giving”, explaining that in most situations the participant is nearly always “at the receiving end” of care. These tenets allow the participant to take the leading role and express gratitude, whilst the facilitator is offered the role of empathetic respondent.

CREATION (CRT)

Positive person work tenet number 11

The participant brings a spontaneous offering of skill and ability to the activity.

GIVING (GIV)

Positive person work tenet number 12

Giving is described as the expression of warmth and sincerity - combined with concern, affection and gratitude - demonstrated by the participant.

The above tenets clearly outline the important and crucial role the facilitator has to play in dementia-specific activity. The following directions outline the basic steps involved in the creation of an artwork.

The basic steps involved in creating an artwork

As mentioned in the previous chapter, the study of the neuroscience of art is in its infancy, and Zaidel's (2005) book provides an umbrella coverage that is a good and useful initial exploration into a very complex and detailed subject. Franz (2006, p. 302) correctly describes Zaidel (2005) as "a very skilled scientist and author who plants the seeds for a whole host of scientific studies", and points out that Zaidel makes a tentative start by only putting forward workable and understandable neuropsychological explanations for the most basic and obvious steps in the painting process. Franz makes the further observation that it will probably be other studies that will eventually "unveil" our intimate and "extraordinary ability to persevere in creative skills". However, the basic steps that Zaidel does outline are a starting point for an exploration into the neuropsychological processes an individual must undertake when beginning an original piece of art.

The following paragraphs detail the processes and steps that an able-bodied participant must negotiate to commence an activity and take it through to completion.

A plain description of the neurological processes involved in art creation

Zaidel's research (2006) outlines the neuropsychological processes an individual undertakes when thinking about and visualizing an idea or concept in detail. Put simply, she explains that the process progresses through the following sequence: when the artist has a basic conceptual understanding of the activity sufficient to see the process in its creative context, the activity that follows a logical progression in sequence toward a conclusion. This sequence uses procedural memory and may be repeated several times. The process requires the active participation of a functional long and short-term memory and considerable skill to place these events in sequence and repeat them in order.

As Zaidel explains, whether the process is conscious or not, the development of a theme and placement of images is carefully planned. An artist draws on long-term memories, reminiscences and imagination. Skills learned during drawing and writing exercises at school, and practiced over a lifetime, involve visual thinking and spatial differentiation, and combine together to place visual images into perspective. These images can often be subliminally influenced by iconography and pictorial symbolism. Each individual's appreciation of colour, including a sense of the tonal values of each colour and their relationship to one another and their integration, is influenced by sight and personal preferences. Choice and decision making is closely linked with an artist's confidence, and this plays a crucial role enabling the artist to relax and fully engage in the process. A combination of all these influences provides each artist with the skill necessary to construct and "paint" the picture.

The basic steps in an able-bodied participant's contribution:

Excluding the pre-activity preparation, such as the mandatory occupational health and safety (OH&S) responsibilities involved in maintaining a secure and safe therapeutic environment, most able-bodied individuals automatically process the steps in logical sequence, even skipping steps as necessary.

Look at a blank painting surface

Look at the instruments

Feel the surface

Look at colours

Think about an idea

Visualize an idea

Look at colours

Choose colours

Choose an instrument

Pick up an instrument
Focus on the idea
Look at the blank painting surface
Visualize the image in proportion
Pick up a pencil and/or draw an outline (optional)
Construct the elements of the composition
Transfer the image onto the painting surface
Choose a starting point
Pick up the paintbrush
Wet the paintbrush (optional)
Dip the paintbrush
Apply the paint - note the texture and “brush drag”* etc
Remember the sequence and idea
Dip the paintbrush and continue
Concentrate on task
Wash the brush
Change colours

*Zaidel (2006) illustrates how neurologically complex the physical act of painting is by analysing the unconscious mind’s influence on brush strokes. She refers to both the influence and the flow of the brush across the surface of a painting and describes this phenomenon as “brush drag”. She explains:

Brush strokes have a trajectory, a surface curvature, are broad and thin; influenced by granulations of the surface, flow of the brush, degree of pigment absorbed, shape of the brush itself and size of the brush. Also, path of previous marks and strokes are adjusted to begin and end relative to the whole illustration. The artist’s decision to place the first mark in a specific spot on the drawing surface reflects knowledge of scaling, approximation and context and cannot be simply measured. In addition to the issue of skill and preservation, post-damage effects on art reflect not only influence of damaged tissue over healthy tissue but also functions of healthy tissue. Both interact with each other in the production of art (Zaidel, 2006, p. 24)

Fortunately, this complex process is automatic for most able-bodied artists as is the action of sweeping a brush across a smooth surface whilst observing the colours as they glisten and merge into a recognizable shape. The drive to “go with the flow” is powerful and the unconscious desire to build up an image on the surface takes over. The steps in the above process use procedural memory and require the active participation of functional long and short-term memory. In addition, most able-bodied individuals will have a conceptual understanding of the activity and be able to see the process in a creative context and understand how the activity follows a logical progression toward its conclusion.

Zaidel’s observations highlight that the facilitator, when assisting an individual living with dementia to participate in an art activity, has a crucial role to play in this process. Understandably, for an individual living with dementia there are many more than the twenty four aforementioned steps that an able-bodied participant might work through, and the facilitator, in Australia at least, has both a legislative and a duty of care responsibility to adapt the process to meet the individual needs of each individual.

The following paragraphs briefly outline the dementia-specific art activity that participants will engage in. Whilst the larger exercise and process are not under investigation or observation or evaluation in this research project, an understanding of how the images that are painted by the participants in the art activity are created, and how the theme of the work is developed, is essential. To maintain the reliability and the validity of the research outcomes, every participant comes to an art activity that is the same for everyone and is conducted under the same conditions.

The structure of the matrix that creates the dementia-specific art activity

The stages and steps that make up the dementia-specific art activity form the first matrix, MATRIX ONE - the art activity. This matrix has been developed to

ensure each participant's experience in the art activity is the same. This matrix reflects the minimum contribution a facilitator must bring to a dementia-specific activity, in terms of discipline and skill.

Kitwood's twelve "positive person work tenets" and the "wellbeing metaphors" are applied to the stages and steps of MATRIX ONE - the art activity. This process identifies eight tenets that form the second matrix, MATRIX TWO - the eight Kitwood tenets. This is the instrument that is used by the facilitator of the art activity to observe 'how' the participant experiences the art activity phenomenon.

The stages and steps in an art activity for an individual living with dementia:

The following explanation describes in more detail the processes involved when an individual living with dementia participates in a dementia-specific art activity. For simplicity's sake, the art activity process has been divided into five stages and thirty-nine basic steps have been identified. In addition, what is involved in terms of the facilitator's contribution to each step of the dementia-specific art activity has been carefully considered using the five Kitwood "wellbeing metaphors" and the twelve "positive person work tenets" as a guide. The actual contribution made by the facilitator will vary between individuals and some steps will require more of a contribution from the facilitator than others. This is because each individual is unique and has had different life experiences and each lives with a different level of cognitive impairment and physical ability. The tenets are linked to each of the stages and steps of the art activity using the following legend:

Comfort (COM), Attachment (ATT), Inclusion (INC), Occupation (OCC), Identity (ID), Recognition (REC), Negotiation (NEG), Collaboration (COL), Play (PLY), Timalation (TIM), Celebration (CEL), Relaxation (REL), Validation (VAL), Holding (HLD), Facilitation (FAC), Creation (CRT), Giving (GIV). The stages and steps

that form MATRIX ONE - the art activity, and the tenets that are involved in each step are set out below:

MATRIX ONE - The art activity
PRE-ART ACTIVITY STAGE:
Prepare a safe physical and psychological space
1. Room temperature - check and adjust (OH&S, PLY, HLD)
2. Prepare a secure room and workspace (PLY, HLD, FAC)
3. No distractions and/or background noise (REC, HLD, FAC)
4. Prepare and arrange the materials (PLY, FAC)
5. Read social profile - know the participant (INC, OCC, ID, REC, NEG, VAL, COL, FAC)
6. Care provision - Toileting etc (INC, REC, VAL)
7. Check and include glasses and walking frame/stick (INC, REC)
THE ART ACTIVITY - STAGE ONE: Establish trust and rapport
8. Locate participant and make introductions (INC, OCC, ID, REC, COL, VAL, FAC)
9. Invite participant to activity (INC, OCC, ID, REC, NEG, COL, VAL, FAC)
10. Escort and converse with participant on way to activity (OH&S, COM, ATT, ID, REC, COL, VAL, FAC)
11. Seat participant in comfort (OH&S, ID, HOL)
12. Thank the individual for attending (COM, INC, OCC, ID, REC, VAL)
13. Remind the individual of the last meeting and contribution to the theme (COM, ATT, INC, OCC, ID, REC, NEG, VAL)
14. Explain the overall activity (INC OCC, ID, REC, NEG, PLY, VAL, FAC)
15. Introduce specific painting activity (INC, OCC, ID, NEG, COL, PLY, HLD, CEL, FAC)
16. Reassure participant (COM, ATT, ID, REC, NEG, VAL, HLD, FAC)
STAGE TWO: The preamble to painting
17. Encourage participant to feel the canvas (COM, INC, OCC, ID, COLL, PLY, TIM, CEL, HLD, FAC)

18. Introduce the materials - brushes and paint (INC, OCC, ID, REC, COL, PLY, TIM, FAC)
19. Encourage participant to choose brush/feel surface (COM, INC, OCC, ID, REC, COL, TIM, PLY, FAC)
20. Explain and offer aides to creativity - stencils, photos etc (INC, OCC, ID, REC, PLY, TIM, FAC)
21. Indicate individual area of work to participant (INC, OCC, ID, REC, NEG, COL, PLY, FAC)
22. Discuss outlines and work area in greater detail in context of surrounding design (INC, OCC, ID, REC, TIM, VAL, FAC)
STAGE THREE: The process of painting
23. Invite participant to choose starting colour (COM, INC, OCC, ID, REC, NEG, COL, PLY, CEL, VAL, FAC)
24. Indicate the outline and starting point (INC, OCC, ID, REC, NEG, COL, PLY, VAL, FAC)
25. Mix colours and hand brush to participant (INC, OCC, ID, REC, NEG, FAC)
26. Demonstrate aides if chosen (INC, OCC, ID, FAC)
27. Tape or hold aide in place for participant (COM, ATT, INC, OCC, ID, REC)
28. Encourage each achievement (COM, ATT, INC, OCC, ID, REC, VAL, FAC)
29. Recharge brush as appropriate (INC, OCC, ID, REC, NEG, FAC)
30. Offer colour change and variety (INC, OCC, ID, REC, NEG, FAC)
31. Offer choice i.e alternate and different area to paint (INC, OCC, ID, REC, NEG, FAC)
32. Continue repeating steps 22-30 until end of activity (INC, OCC, ID, REC, NEG, FAC)
33. Offer opportunity and choice to continue or end participation (INC, OCC, ID, REC, NEG, FAC)
STAGE FOUR: The art activity conclusion
34. Thank the participant for contribution (COM, ATT, INC, OCC, ID, REC, COL, VAL, GIV)
35. Escort participant to another safe physical and psychological space (OH&S, COM, INC, ID, REC, VAL)

36. On arrival thank the participant for contribution again (COM, INC, ID, REC, COL, VAL, GIV)
37. Ensure participant is settled in new environment (OH&S, COM, ATT, INC, ID, REC, COL, HLD, VAL, FAC)
38. Say goodbye (COM, ATT, ID, REC, COL, REL, VAL, FAC)
39. Document the activity (INC, ID, REC, VAL)

An analysis of the stages and steps

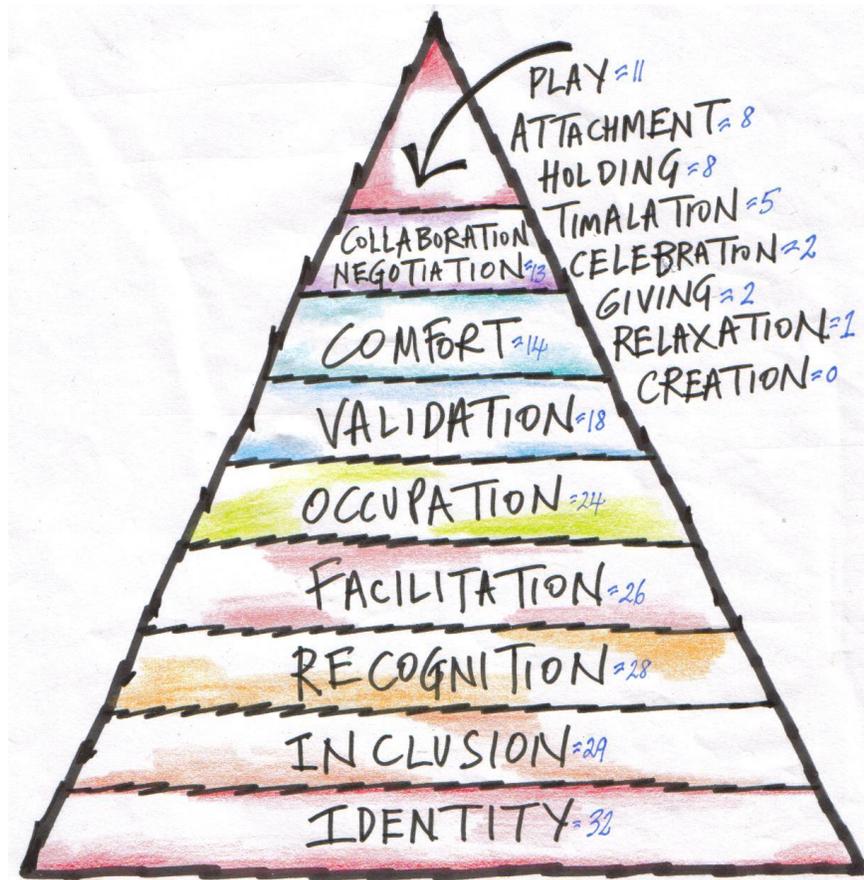
An analysis of the above thirty-nine steps of a dementia-specific art activity reveals that the identity of the participant is the most important “wellbeing metaphor” overall and it is an integral part of thirty-two of the thirty-nine steps listed in the matrix.

Inclusion is the second most important factor in the successful facilitation of an art activity. Inclusion is an integral part of twenty-nine of the activity steps. Inclusion is closely followed by recognition, an integral part of twenty-eight steps. Facilitation, the only “positive person work” tenet in the top most important factors, appeared integral to twenty-six steps of the art activity and was only slightly above occupation that appears to be integral to twenty-four steps. With four out of five of the “wellbeing metaphors” in the top group, the analysis appears to indicate that identity and the psychosocial factors, encompassed in inclusion, recognition and occupation, seem to be critical contributing factors at every stage in the successful facilitation of a dementia-specific art activity.

The next most important factor is validation, it is an integral part of eighteen of the art activity steps. Validation is followed by comfort, the remaining wellbeing metaphor that is integral to fourteen steps. Collaboration and negotiation appear equally important to thirteen steps.

The final eight tenets:

A final grouping of eight tenets appeared in the following order of importance to the facilitation of an art activity, and because they are linked to the participant's contribution to the activity and as such they can probably only be assessed by close observation by the facilitator during the art activity. In order of importance, play is integral to eleven steps. Play is followed by attachment and holding, integral to eight steps. Finally, stimulation is integral to five steps, celebration and giving are integral to two, and relaxation is integral to one. Creation at zero can only be assessed during the art activity. The many parts of the art activity matrix form the dementia-specific art activity holon immediately below.



The dementia-specific art activity holon

How the remaining tenets fit together

As has been identified, over the entire art activity inclusion, identity and recognition are clearly central to the personhood of every individual. They have emerged as the three most important elements for the facilitator to establish at the start of the art activity. They are the essential ingredients to guarantee the success of this particular dementia-specific art activity. Basting (2009, p. 145) writes, “identity is a rich blend of personality and the people, places and things [we] encounter. These are the elements that shape our identity”. She thinks “we never are ourselves, [but] we are always becoming ourselves - even in the depths of dementia”. In terms of Kitwood’s wellbeing outcomes, inclusion in any activity that culminates in individual personal achievement for the participant can be seen as an important step toward “becoming ourselves”. The holon indicates that identity, inclusion and recognition are fundamental to establish when attempting to create an environment conducive to a sense of wellbeing, in this case achieved during the accomplishment of a creative and fulfilling experience for the participant.

To understand how the remaining tenets fit together it is best to examine them in more detail and identify their dependence on one another and their inter-connecting relationship.

Another critical element of the art activity is the establishment of trust between the facilitator and the participant. Trust is critical, and must be established before there can be any real expectation of achieving the most productive outcome from the experience.

It naturally follows that attachment and holding are fully dependent on the facilitator’s ability to create an environment under which the participant can experience a sense of safety and comfort (Holding). If a genuine rapport between the facilitator and the participant can be established over the

preceding weeks, and renewed within the first few minutes before the art activity begins, then a productive outcome may be achieved. If the facilitator then fully engages in gentle conversation with the participant, whilst attentively assisting the person to sit comfortably in front of the activity, and if the facilitator then sits closely next to the participant (Attachment and Timalation) everything is then in place and the activity may commence. With gentle encouragement, the participant has the opportunity to be in physical and undemanding contact with the art materials and the facilitator, and to fully engage in each of the experiences inherent in the activity without time limitations, and for as long as the participant wants. This creates an opportunity for the art activity experience to continue for extended periods of time.

To recap, after an emotional “safety net” created by trust is established, and a gentle and affectionate conversation underway in which the art activity is slowly explained and discussed in simple language by the undemanding facilitator, then the perceived expectation or need to please the facilitator in the participant’s mind quickly dissipates. Along with this, the possible fear in the participant that his or her performance may fall below expectation, and the fears that this might generate, also disappears (Relaxation). Under such conditions the activity can proceed and fully develop into a relaxing, spontaneous and self-expressive experience (Relaxation and Play), where the participant can express enjoyment and satisfaction, articulate spontaneous thoughts about the activity, and, at the end of the activity express personal gratitude for his or her participation (Celebration and Giving and Creation).

The matrices to be examined during the art activity

To summarise, by a process of elimination, one “wellbeing metaphor” and seven “positive person work” tenets were identified during the creation of the dementia-specific art activity holon. Together these tenets form the holon that

is MATRIX TWO. This assesses ‘how’ the participant experiences the art activity. As already indicated, Kitwood (1997) believed that the presence of the “wellbeing metaphor”, along with the other “positive person work tenets”, are necessary to maintain wellbeing in those living with dementia in care. Perrin and May (2003) make the important observation that those living with dementia are reliant on the professionalism of all care partners to help maintain wellbeing. And, in this case in particular, it is incumbent on the art facilitator to set the scene and create an environment conducive to creating and/or maintaining wellbeing.

To reiterate, MATRIX TWO - the eight Kitwood tenets, creates an instrument to document ‘how’ the participant experiences the art activity phenomenon. The eight tenets, to observe ‘how’ the participant experiences the art activity, emerged as follows:

PLAY: The tenet relating to participation, self-expression and spontaneity. The observation will determine if and how the participant joins in the art activity and/or is seen to work independently of the facilitator.

ATTACHMENT: The “wellbeing metaphor” relating to the participant’s ability to relate to, and place trust in another. The observation will determine if and how a rapport between facilitator and participant is present and how the participant responds.

HOLDING: The tenet relating to the environment in which the activity is conducted. The observation will determine if and how the facilitator has been able to establish a holding “container” and/or a “safe psychological space” and how the participant responds.

TIMALATION: The tenet relating to the presentation of “reassurance and pleasure whilst making few demands”. The observation will determine if and

how the participant is able to tolerate the facilitator’s closeness and how well the participant is able to touch and/or interact with the materials during the activity.

CELEBRATION: The tenet relating to “expansive and convivial ambience” that is “free of fear and responsibility”. The observation will determine if and how the participant displays evidence of happiness or other signs of being free of fear and responsibility.

GIVING: The tenet relating to expressions of “warmth and sincerity”. The observation will determine and record if and how the participant expresses gratitude or makes verbal comments about his or her participation.

RELAXATION: The tenet relating to relaxation in another’s presence. The observation will determine if and how the participant shows signs of comfort and relaxation in the facilitator’s presence and the art activity.

CREATION: The tenet relating to a “spontaneous offering of skill or ability”. The observation will determine if and how the participant uses his or her skill and ability during the activity.

MATRIX TWO - the eight Kitwood tenets

Participant’s name	
Attachment	
Holding	
Timalation	
Relaxation	
Celebration	
Play	
Creation	
Giving	
Wellbeing outcomes	

After the observations of each individual's lived experience has been documented on MATRIX TWO - the eight Kitwood tenets, the questions below will be addressed under the heading "wellbeing outcomes" to determine how the participant experienced the phenomenon.

The questions are:

1. Was a "holding container" in a "safe psychological space" established at the start of the activity? (Holding)
2. Was a rapport established between the participant and the facilitator? (Attachment)
3. How closely did the facilitator sit to the participant and could that individual tolerate touching the art materials? (Timalation)
4. Were there signs of relaxation and comfort for the participant in the facilitator's presence and the activity? (Relaxation).
5. Did the participant become involved in the activity and then work independently? (Play).
6. What sort of skills and ability did the participant display during the activity? (Creation).
7. Did the participant express happiness or joy and/or appear to be free of fear and responsibility? (Celebration).
8. Did the participant express gratitude or any spontaneous comments about the activity and/or his or her participation? (Giving).

And finally, taking into consideration all of the above questions the researcher will be in a position to determine an overall assessment of how the participant experienced the art activity.

To determine 'what' each participant experienced during the art activity is to be assessed using another assessment tool - The Creative Expressive Ability Assessment (CEAA) tool

MATRIX THREE - the CEAA tool and the art activity evaluation

The CEAA tool is the third and final matrix to be applied in the research project to evaluate ‘what’ the participant experienced during the art activity. The CEAA tool was specifically designed by its authors to “answer important questions” as to ‘what’ the participant experiences during a creative expressive activity and to discover why “the value of creative expression and related programs [continue] to be underestimated”. The authors believe this stems from “the lack of an easy-to-read instrument for collecting comprehensive, compelling, solid quantitative evidence” concerning many existing creative arts programs and activities despite “the numerous and diverse and positive effects” such programs and activities can have on those living in care (Gottlieb-Tanaka, Lee & Graf, 2008, p. 5).

The seven ability domains

The CEAA assessments cover seven different lived experience ability domains (memory, language, psychosocial, reasoning/problem solving, emotions and culture) and each domain has a number of “core items” that an assessor might observe during an expressive activity. If the item occurs during the activity the assessor records its frequency, i.e. one tick for every observance of the particular core item, using a tick box system. At the end of the activity the tick scores are added together.

MATRIX THREE - the CEAA tool immediately below itemizes the CEAA lived experience domains and core items under investigation and lists what the participant might experience during the art activity.

MATRIX THREE - the CEAA tool
Memory
M1. Reminisces
M2. Recites
M3. Invents memories
Attention
A4. Levels of attention
Language
L5. Produces complete written sentences
L6. Produces complete spoken sentences
L7. Uses key words/simple sentences/body language
L8. Uses humour when writing
L9. Uses humour when speaking
L10. Uses elaborate/informative descriptions
L11. Uses facial expressions to communicate understanding
L12. Makes vocal responses to music
Psychosocial
P13. Attracts/holds attention telling a story
P14. Attracts/holds attention singing a song
P15. Attracts/holds attention dancing/performing/playing an instrument
P16. Responds to comments - shows compassion and/or reflections
P17. Shows self-esteem/confidence
P18. Shows interest in grooming/clothing
Reasoning/Problem solving
R19. Shows insight/solves problems
R20. Makes clear decisions and choices
Emotions
E21. Uses facial expressions to express moods and emotions
E22. Expresses mood in visual display
E23. Expresses mood in music
E24. Expresses mood in anecdotes and stories
E25. Shares thoughts and speaks from the heart
E26. Shares wisdom/life experiences
E27. Discusses religion and tradition and cultural/spiritual/customs

A more detailed explanation of the seven CEAA ability domains and twenty-seven core items

Domain one: Memory.

Domain one has three core items (1, 2 and 3) that relate to what a participant might reminisce about during the art activity. It includes people, events and

personal experiences, and documents whether the participant can recite poems, sing songs or tell jokes. This domain will also assess what the participant contributes that is relevant to a topic during conversation.

Domain two: Attention

Domain two has one core element (4) and will be used to measure the length of time the participant is able to concentrate and stay focused during the art activity.

Domain three: Language

Domain three has eight core items (5, 6, 7, 8, 9, 10, 11 and 12) that measure what language skills the participant possesses and whether or not the participant is able to use key words to complete a simple grammatical sentence. This domain also measures what body language and facial expressions the participant exhibits and notes what the participant can convey using humour and/or informative and descriptive language.

Domain four: Psychosocial

Domain four has six core items (13, 14, 15, 16, 17 and 18) that measure what methods the participant might use to attract and hold the attention of others in a group activity and whether or not the participant can respond with compassion to others. Two core items measure self-esteem and confidence, and notes the participant's interest in grooming and clothes.

Domain five: Reasoning/Problem solving

Domain five has two core items (19 and 20) that measure what ability the participant has to make clear choices and show insight into problem solving. In this case, during an art activity, the participant might be able to show insight by making comments about the images within the artwork, and/or by offering colour solutions and explanations to compliment the spatial arrangement within the design.

Domain six: Emotions

Domain six has four core items (21, 22, 23 and 24) that measure what each participant's response is to music and the emotional content of stories. In this case, facial expressions will be noted during the activity to indicate what mood and/or satisfaction the participant may experience during the art activity.

Domain seven: Culture

Domain seven has three core items (25, 26 and 27) concerned with what each participant's cultural connection is to others and what the individual might share about his or her spiritual beliefs with the facilitator.

For the purposes of this research project not all of the "core items" in each domain are relevant, for example, the assessor of the art activity will not be looking for evidence of what writing or singing or performance skills the participant may exhibit (Items 5, 8, 12, 14, 15 and 23); the activity under evaluation is an art activity and therefore writing and singing and performing are not necessarily relevant to all participants. Nor will the assessor evaluate what the participant's interest is in grooming or clothes (Item 18), as these domains are also not relevant to the one-on-one painting activity under evaluation.

What the assessor collects

The assessor will collect evidence on 'what' each participant experienced over twenty "core items" during the art activity. These are items number: 1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 16, 17, 19, 20, 21, 22, 24, 25, 26 and 27. As mentioned, the remaining seven items (5, 8, 12, 14, 15, 18 and 23) relate to singing and writing and personal grooming and are not necessarily relevant when researching an art activity. These items are struck through on MATRIX THREE.

The wellbeing evaluation process

An evaluation to determine both the lived experience and the wellbeing of individuals living with dementia during an art activity was conducted by...

- Implementing the stages and steps in the art activity process as set out in MATRIX ONE - the art activity, to ensure the research is conducted under the same conditions for each participant.
- Evaluating how and what each participant experienced whilst contributing to the art activity by using both MATRIX TWO - the eight Kitwood tenets, and MATRIX THREE - the CEAA tool.
- Drawing conclusions on the lived experience and the wellbeing of the participant during the art activity by compiling and joining together the observations on how the individual experienced the activity from MATRIX TWO - the eight Kitwood tenets, with what the participant experienced as recorded in MATRIX THREE - the CEAA tool. This leads to the formulation of an assessment and future recommendations.

The art activity has been conducted with every research participant under the same circumstances, following, stages and steps of an art activity as set out in MATRIX ONE - the art activity. The minimum attributes of this replicable experiment are:

- The establishment of a “safe psychological space” from the beginning of the art activity
- The same facilitator works one-on-one with each participant
- The facilitator anticipates individual need and facilitates practical solutions
- The facilitator allows each participant to explore the activity without hindrance and to freely express comments

Each participant's case study interview, and his or her contribution to the art activity, as they relate to both MATRIX TWO - the eight Kitwood tenets, and MATRIX THREE - the CEAA tool, has been collected and appears along with each individual's accompanying case study analysis in the Appendix of this thesis.

One model example of how the observational information and data that was gathered with reference to MATRIX ONE - the art activity, and MATRIX TWO - the eight Kitwood tenets, and how that information was compiled and joined together is presented in an individual the case study sample. This is followed by a thorough summary and discussion of the overall research findings and outcomes, reflecting both the individual and collective outcomes.

Conclusion

Wellbeing, both as a concept and a reality, is an elusive term. If one is to research it in relation to an art activity one must first understand the process and mechanics of the art activity as a whole, from top to bottom, and then develop a unique set of tools and methodology to do the job. An assessment of relevant publications reveals that few if any researchers conducting art research itemize or properly explain what they do to set up an art activity and why they do it. Nor do they fully explain the facilitation process. Details relating to the physical processes involved in the implementation of a dementia-specific art activity are rare and no publication, with the exception of Zaidel (2005), explores dementia-specific neuropsychology and art creation beyond a few basic steps.

The aim of this chapter has been to detail this research project's methodology by explaining the design and development of its dementia-specific research assessment tools. The introduction began by indicating why it was necessary to

create an original dementia-specific matrix for use during a dementia-specific art activity and for this project in particular.

The chapter then identified Kitwood's five "wellbeing metaphors" and twelve "positive person work tenets". Kitwood (1997) argued that these seventeen elements are essential to wellbeing in a person-centred approach to dementia care. Together they constitute the core theoretical framework of this research project.

To understand the top to bottom processes, i.e. the mechanics of a dementia-specific art activity as a whole, a matrix detailing the five stages and the thirty-nine steps that make up an art activity was constructed. This formed MATRIX ONE - the art activity. Kitwood's "wellbeing metaphors" and his "positive person work tenets" were applied to each of the stages and steps of the art activity. This created a workable and informative dementia-specific matrix that separated and identified eight Kitwood tenets for special investigation during the art activity. The most logical step was to create a separate instrument to collect information relating to the eight tenets that could be compared and juxtaposed with the data collected from the other sources. A second matrix, MATRIX TWO - the eight Kitwood tenets, based on Kitwood's theoretical framework, detailing 'how' the participant experienced the art activity across eight areas of investigation during the art activity, was constructed as a separate and independent lived experience and wellbeing assessment tool.

Finally, the CEAA quantitative research tool, MATRIX THREE - the CEAA tool, designed to assess 'what' the participant experienced during the art activity across seven lived experience and wellbeing domains, completes the data collection assessment tools.

The research process and methodology

The research process and methodology is as follows:

- With assistance from the art facilitator (JGM), each participant works through thirty-nine steps in the art activity through to completion.
- The participant is observed and videotaped during the art activity and the CEAA wellbeing tool is tick scored live by an independent observer (LS). ('What' they experienced).
- On completion of the art activity, the facilitator (JGM) immediately documents impressions of the activity and details the participant's skills.
- The facilitator (JGM), using MATRIX TWO - the eight Kitwood tenets, then writes an assessment of the eight wellbeing tenets for each participant. ('How' they experienced it).
- After the activity, a staff member (CB) who knows each participant well, tick scores in a single setting the art activity from videotape footage using the CEAA wellbeing tool
- After the activity, the facilitator (JGM), tick scores in a single sitting the art activity from videotape footage using the CEAA wellbeing tool
- Three sets of CEAA wellbeing tool data generated by LS, CB and JGM are combined to validate the overall assessment for each participant
- The individual score generated by the CEAA wellbeing tool is then compared with the wellbeing information from MATRIX TWO - the eight Kitwood tenets, and an overall art activity lived experience and wellbeing outcome of low, moderate or high is recorded in a final collective wellbeing assessment.

This phenomenological methodology and process creates the necessary structure to enable a study of each participant's lived experience of the art activity. This process sets achievable working parameters. The following chapter, the Discussion Chapter, will draw together all the data and evidence,

providing an assessment of the lived experience and wellbeing of individuals living with dementia as they participate in an art activity.

CHAPTER NINE

The research project discussion

In chapter eight, the design and construction of three matrices to examine the lived experience of the research participants was detailed and explained. The overarching purpose of this research project is to explore the relationship between art, dementia and wellbeing to gather and gain information on the lived experience of individuals living with dementia, and to ascertain both the wellbeing of the participants and the skills they utilise as they participate in an art activity.

This chapter begins with an overview of the term wellbeing, as society perceives it. The chapter then goes on to define how experts in the field, as well as peak body organizations, relate the concept of wellbeing to those living with dementia. The research project outcomes are then documented and a distillation of the “universal essence” of the lived experiences of the research participants is presented. Finally, the chapter ends with a small stock resource of new knowledge in the form of a practical list of facilitation techniques and recommendations for use by recreation and art activity facilitators that have emerged from the research project.

What is society’s concept and understanding of wellbeing?

Vernon (2008, p. 44-45) informs us that “wellbeing is a useful term because it is relatively unfamiliar”. He adds, “*The Oxford Dictionary of Quotations* has dozens of entries for happiness and happy [but] there is not a single one for wellbeing”. And, even the dictionary editors are not clear on how to spell the word and they ask, “Is it wellbeing or well-being?” Vernon points out that wellbeing “embraces notions of health, contentment and flourishing, it includes psychological growth as well as physical welfare [and] it has an

individual and community aspect”. Vernon believes the concept is so elusive that “our wellbeing depends in some way on that which is beyond us”, and for most people the concept is “by definition in large part unfamiliar, unusual and unknown. It emerges as something shown or revealed, not told or made. It is an experience not a rule; although informed by reason it outstrips rationality” (Vernon, 2008, p. 12). While much of our media links wellbeing with wealth and body image, the notion of wellbeing expands beyond this. Vernon believes wellbeing is based on meaning, he writes; “pleasure matters [but] meaning matters more and the transcendent good underpins it” (Vernon, 2008, p. 99).

Beginning with Kitwood’s wellbeing and “ill-being” model, the concept of wellbeing is explored in the context of the dementia-specific lived experience.

Kitwood’s dementia-specific concept of wellbeing

As explained throughout this thesis, Tom Kitwood was the first to develop a dementia-specific wellbeing and personhood model (Brooker, 2007). Kitwood came to his conclusions by careful observation and by marrying neurology and psychology together. Baldwin and Capstick (2007) document the progression of Kitwood’s theory, explaining that it developed in three stages over a ten-year period between 1987 and was well formulated by 1998, the year of Kitwood’s death. In essence, Kitwood’s theory rejected the biomedical notion that ill-being is an inevitable and normal part of the “pathology” of dementia, rather he vigorously argued that memory is only one aspect of personhood and that ill-being is primarily a manifestation of an individual’s unmet psychological needs. Since then other scholars, including Cohen-Mansfield (date) and Zeisel (2009) to name two, have explored this theme. Kitwood believed the challenge, in both residential care and the community, was and is to equip care providers and care partners with skills to identify and meet these needs. In the previous chapter identity emerged as a key factor in maintaining wellbeing. And, if the individual’s psychological needs are met, then the identity or personhood of

the individual is not compromised.

Baldwin and Capstick (2007, p. 106) write, the “essential quality of good person-centre care [and positive person work] is interpretation, reflection and informed response”. Consultation, and informed response in particular, allows the individual living with dementia an opportunity to “remain in a relatively high state of wellbeing” throughout each stage of the progression of dementia (Baldwin and Capstick, 2007, p. 92).

In 1992, the Bradford Dementia Group in the United Kingdom published the “Dementia Care Mapping” tool (Kitwood and Bredin, 1992). This tool outlined the group’s dementia-specific indicators of wellbeing and ill-being (below) for the first time.

Wellbeing indicators	Ill-being indicators
Making wishes known (non-destructively)	Distress
Initiating social contact	Depression or despair
Warmth and affection	Intense anger
Self-respect	Anxiety
Being helpful	Fear
Humour	Boredom
Bodily relaxation	Bodily tension
Creative self-expression	Agitation
Showing pleasure or enjoyment	Apathy and withdrawal
Responding appropriately to others	Cultural isolation
Expressing appropriate emotions	Physical discomfort/pain
Holding his/her own socially	Difficulty withstanding powerful others
Alertness, responsiveness	
Being active	
Being purposeful	

Since then, Dementia Care Mapping has become internationally recognized and Kitwood's concept of wellbeing is widely respected.

The Dementia Care Mapping indicators were designed, developed and published in response to the ethical questions and challenges created by the wellbeing debate, surrounding those living with dementia, in the mid 1990s. Another person to take up this challenge at that time was Stephen Post, an ethicist at Johns Hopkins University in Baltimore. Even today Post's book, *The Moral Challenge of Alzheimer Disease* (Post, 1995), poses pressing ethical questions and sets benchmark challenges for care providers involved in the ongoing worldwide wellbeing debate surrounding those living with dementia.

Post (1995, p. 95) makes an astute observation when he writes that few topics have been "more contentious in biomedical ethics than quality of life", and he places the debate in historical context when he says the issue of wellbeing and quality of life has been "fuelled" since the 1960s by "philosophical, theological, anthropological and clinical" disagreement.

Post (1995) demonstrates that wellbeing and quality of life cannot be easily separated, in any best care practice debate, when he writes "quality of life is partly contingent on the extent to which a supportive environment is created to enhance wellbeing, and this is thus a self-fulfilling prophecy, since quality of life is dependent in crucial ways on the attitudes and actions of caregivers" (Post, 1995, p. 100). He further adds, "the hope for people with dementia rests almost entirely in the commitment of family members, professional caregivers and society to their wellbeing" (Post, 1995, p. 126).

Throughout the book, Post puts forward a convincing moral argument for dementia-specific rights and he is convinced that sustainable wellbeing is only possible when the autonomy of the individual is respected in the decision making process. Post writes (Post, 1995, p. 16), "the fundamental

moral commitment of a good society is to protect all human beings, based not on their varied and unreliable capacities but on radically human equity". He also makes the point that our culture puts too great an emphasis on the values of "rationality and productivity" and "wrongly excludes people with dementia from the sphere of human dignity" (Post, 1995, p. 2). He contends that "the veneer of respect for people with dementia is always thin" and the "socio-cultural assessment of worth is notoriously exclusionary" (Post, 1995, pp. 32-35).

Post believes that in our society, "people with dementia are victims of metaphorical dehumanisation and de-equalisation" generated by "excessively rationalistic prerequisites for moral inclusion". He expresses his concern over what he describes as the "dominance of biomedical data in our culture which has imposed a medical model of reality on the journey into old age" (Post, 1995, p. 82). He clearly states his commitment to the ethics of "respect to treatment" and believes a medical model imposition has resulted in the over-medicalization of individuals living in aged care. He documents his concern that "drug use for custodial reasons is a serious problem in long-term care facilities for the elderly", and is particularly serious in situations governed by "understaffing and other institutional inadequacies" (Post, 1995, pp. 59-61). Post is of the opinion that healthcare professionals often impose a "passive sick role" on elderly individuals living in care and that resident wellbeing is compromised when overmedication occurs. Healthcare professionals further place the individual at a disadvantage by failing to consult with the individual directly. Other researchers (Bird *et al.*, 2003) support Post when he contends it is not uncommon for healthcare professionals to ignore effective non-pharmacological interventions in favour of medication because it is an easy option.

Post is an advocate for individual human rights, particularly when he suggests that the wellbeing of individuals living with dementia is contingent on a commitment that demands that individuals know how they will be

treated in the future. They need to know that everything will be done by society to ensure a life free of pain and suffering when they can no longer make such decisions.

Post argues that individuals must be afforded moral and legal protection and treated with dignity and respect. Unfortunately, such rights and concepts are largely contingent on an "interpretation" of the Alzheimer's disease "experience" made by health care professionals in a medical context and by family members and society in general. Post believes it is essential that all individuals be consulted in the preparation of advanced care directives and then provided with access to and the benefits of support groups. Post argues that society's "moral task is to always enhance the person with Alzheimer's disease" and that "enhancing wellbeing and making the most of what strengths are still present is central to the ethics of dementia" (Post, 1995, pp. 27-29). He is certain that an individual should not be "pressed into a medical focused concept of caregiving"; instead, if a continuing belief in the potential of each person is linked with the opportunity to engage in "meaningful activities" in "creative ways", then the elements that are critical to each individual's sense of continuity and self-worth can help create and maintain an individual's wellbeing.

Post implicitly supports Kitwood's idea that creative activities can help restore wellbeing when he argues that "activity-focused care" supports each individual's need for creativity, self-expression and acceptance and that these wellbeing outcomes are often achieved through the creative arts. He is of the opinion that emotional adjustment to the environment can be made with the implementation of such affirming care practices. Post, although not entirely convinced by Kitwood's theories of personhood, does however acknowledge Kitwood and Bredin's (1992) work in developing Dementia Care Mapping when he makes the observation that "the goal of dementia ethics is to enhance wellbeing through facilitating a sense of personal worth, a sense of agency, social confidence and a basic trust or security in the environment and others" (Post, 1995, p. 24). And, if these

conditions are combined with the "process of helpful interaction" by care partners this can "enhance wellbeing" and each individual's lived experience which in turn "helps mitigate the progression of dementia". Post again cites Kitwood (Post, 1995, p. 25) when he warns against underestimating "what those with dementia can do with proper facilitation".

Post discusses at length the difficulty those living with dementia and their family members face when striving to attain respect and a free and fulfilling lived experience in a biomedical context. His book is particularly valuable when one assesses the debate surrounding the concept of dementia-specific wellbeing and quality of life over the last decade and a half, i.e. since his book was published. Not least there are some interesting parallels to be drawn between the debate over quality of life and the aged care industry's therapeutic pessimism as exemplified by the slow introduction and acceptance of the creative arts into aged care.

Perrin and May (2000) describe "dementia care or 'psychogeriatrics' as it was once called, [as being] perceived at best as rather dull and boring, [and] at worst hopeless and futile" (Perrin & May, 2000, p. 11). They describe therapeutic pessimism, emanating as it does from an "old culture of care", as failing to value or respect both the liberty of an individual living with dementia and that individual's basic human right to know the truth. They credit Kitwood as the person who made "the first really significant challenge to the dominance of the medical model" in dementia care (Perrin & May, 2000, p. 11). The authors also argue that wellbeing in dementia terms is best understood "in the context of novel and varied experience" (Perrin & May, 2000, p. 27-28). They further argue that "seat of wellbeing" cannot be understood except in the context of "an active engagement with the world" and is reliant on "critical partnerships". And, they claim, this critical partnership "can only be understood in the context of the interface between therapist [or facilitator] and client" (Perrin & May, 2000, p. 28).

Commenting on Kitwood's contribution, Perrin and May (2000) write that his "work in dementia care has provided a sound argument for placing

wellbeing at the centre of dementia care...[and they argue] the person who has dementia has it within his or her capacity to experience wellbeing in the face of advancing dementia” (Perrin & May, 2000, p. 126). They also believe mounting evidence strongly suggests there is a “positive correlation between engagement and wellbeing” and this correlation has risen directly from Kitwood’s theory on wellbeing and ill-being.

Cohen’s notion of wellbeing

The late Dr Gene Cohen’s (1944-2009) notion that an individual’s creative abilities act as critical keys in determining wellbeing and the quality of each individual’s lived experience is relevant to this research project in one very important way. The authors of the CEAA tool, one of the assessment methods used to access ‘what’ the individual experiences in this research study acknowledge that their tool is predicated on Cohen’s principles and wellbeing research (Cohen, 2001 & 2006a). Inspired by Einstein’s $E=mc^2$ equation on the encapsulation of energy, Cohen formulated his theory of creativity and came up with his own equation to describe the nature of creativity and the encapsulation of creative energy. His formulae is as follows:

$$C=me^2$$

C refers to “*creative* expression” such as an idea or accomplishment. M refers to a “*mass* of knowledge” an individual accumulates before “mastering a particular field” or technique that leads to creative expression, and e^2 represents “two dimensions”. The two dimensions refer to the way in which our “external and internal lives interact to produce new insights and energy for self-expression” and this in turn contributes to each person’s overall wellbeing and the quality of their lived experience (Cohen, 2001, pp 35-37).

Years of research experience with older Americans has taught Cohen that productivity and creativity in old age “is a catalyst for change of the best kind, with benefits that are immediate, long-lasting and within the reach of

every person” (Cohen, 2001, p. 10). Cohen’s ideas were the catalyst for the development of the Creative Discovery Corp, set up to encourage participation in the arts and other cultural activities for older Americans living in the community. And, Cohen’s long-time interest in creativity culminated in America’s first major research study into creativity and ageing, in which older Americans, including many living with dementia, were asked to evaluate their wellbeing and the quality of their lived experience through creativity (Cohen, 2006).

Similarly, and more recently, individuals living with dementia in the United Kingdom have been asked to evaluate and comment on their personal wellbeing and lived experience. The results have been published by the Alzheimer’s Society UK (AS UK) in a 2010 research project report entitled *“My Name Is Not Dementia”*: People with dementia discuss quality of life indicators (Alzheimer’s Society, 2010a) and in the accompanying literature review *My Name Is Not Dementia: Literature Review* (Alzheimer’s Society, 2010b). These reports fully explore the concepts of wellbeing and lived experience as they relate to individuals living with dementia; and it has the distinction of being the first and most comprehensive research project and report of its kind worldwide. The AS UK report, we are informed, is the result of a project “carried out in 2009 and early 2010” and is a follow up to the AS UK 2008 publication *“Dementia Out of the Shadows”* (Alzheimer’s Society, 2008).

A brief analysis of the AS UK report *“My Name Is Not Dementia”* and its accompanying literature review

In the preface to the 2010 report, Ruth Sutherland, Acting Chief Executive of AS UK writes, “this piece of work begins to bring together what they [individuals living with dementia] think is important” from across all sections of British society (Alzheimer’s Society, 2010a p. vii). Toby Williamson, the report’s author makes some very important observations and findings and calls into question the biomedical reliance on proxy interpretations of the dementia experience. Williamson notes that whilst

wellbeing and the quality of lived experience are extremely hard to quantify, he believes the description provided by Bowling and Gabriel (2004) is helpful:

Quality of life is a multidimensional collection of objective and subjective areas of life, the parts of which can effect each other as well as the sum. It is also a dynamic concept, reflecting values as they change with life experience and the process of ageing (Bowling & Gabriel, 2004, p. 30)

In addition, the report offers recommendations that are pertinent to all nations struggling with the enormity of future dementia care forecasts. Of the many useful findings in this report there are several points that are perhaps more salient than others, such as the basic observation that “the perspective of the person with dementia has for too long been omitted or ignored”. Williamson comments (Alzheimer’s Society, 2010a, p. 46) health related assessments of the quality of the lived experience of those living with dementia are dominated by “disease-oriented measures” that are “not as helpful as once thought”. He cites Trigg *et al.* (2007) who write:

Implicit in the medical model is the notion that there is an optimum level of functioning to which all people should aspire to, whereby those who are impaired or disabled have by definition a poorer quality of life. This leads to the questionable assumption that one cannot achieve positive quality of life in the presence of physical deficits (Trigg *et al.*, 2007, p. 790)

Based on the UK research findings, Williamson (Alzheimer’s Society, 2010a) is certain “the assumption that dementia inevitably results in poor quality of life from the perspective of the person with dementia is faulty” (Alzheimer’s Society, 2010a, p. 46).

Williamson then directs us to recent research by Thompson and Kingston (2004) and Ashley and Savitch (2009) and informs us that these authors maintain that the only individuals who are “expert” in assessing wellbeing and the lived experience in those living with dementia are the individuals themselves. It should be understood that until the very recent past, few

appropriate and sensitive wellbeing assessment tools, such as the Talking Mats (pictorial images designed especially for this AS UK research project), that enable an individual with advanced dementia to reliably express an opinion on his or her wellbeing and the lived experience have been developed or implemented (Murphy, *et al.*, 2010). The failure of the aged care industry to take the time to develop, and/or use appropriate and sensitive tools to obtain an informed response, has not only restricted the introduction of the creative arts and limited access by residents to purposeful activities, but this failure has limited choice, capacity for self-determination and by extension the wellbeing and the quality of the lived experience for those living in care.

Williamson (Alzheimer's Society, 2010a), points out that the literature review (Alzheimer's Society, 2010b) reveals that wellbeing and "quality of life is not just multi-dimensional, it is multi-perspectival" and dependent on "where you are looking from" (Alzheimer's Society, 2010a, p. 47). The literature review also documents that "the dominant biomedical approach to dementia in its traditional form, allows for little scope for a holistic view of the individual" (Alzheimer's Society, 2010b, p. 36). More importantly, although mentioned but not specifically singled out, the "perspective and knowledge base" of the researcher or clinician, and what component he or she is looking for and seeking to measure, is critical to the outcome. Williamson writes that different researchers emphasize different things and staff assessment of wellbeing and the lived experience is often associated with assessing "dependency" and so called "challenging behaviours" (Alzheimer's Society, 2010a, p. 37). As a result, proxy assessments of wellbeing by care provider and care partners are often found to be unreliable. In addition, "agreement between proxies and the person with dementia is often rated as poor to moderate, and the gap widens as dementia becomes more advanced. Quality of life is generally rated as being lower by carers than by the person with dementia themselves" (Alzheimer's Society, 2010a, p. 44). In fact, the report indicates that proxy assessments are shown to be skewed and influenced by, and a reflection of, the care

partner's emotional wellbeing and his or her ability to adjust to care responsibility and what care providers think the individual should be experiencing. Snowdon's (2001, p. 34) "Nun study" revealed that nurses' reports are invariably "unreliable" because "they tend to underestimate their older patients' competence". Nonetheless, such assessments gathered from "proxy respondents often replace self-reports" by those living with dementia.

Williamson adds, "the idea that a single instrument [can] be used to assess [wellbeing and] quality of life at each stage of development of an illness such as dementia is almost certainly redundant and much more dynamic approaches [and methodologies to address] the task are required" (Alzheimer's Society, 2010, p. 47).

Sharing the same needs and experiences

Research shows that once an individual is diagnosed with dementia "all too quickly [the disease is] perceived to be the all-consuming feature of a person's identity" (Alzheimer's Society, 2010, p. 45) by society. Nonetheless, individuals living with dementia "remain complex and multi-faceted and their quality of life is no less complex" than anyone else's (Alzheimer's Society, 2010, p. 45); indeed, they share the same psychological needs and experiences, many of the same fears and aspirations. In fact, the top ten wellbeing indicators are "similar, or even the same" as those shared by the general population (Alzheimer's Society, 2010a, p. 23). Almost two decades ago, the Alzheimer's Society of Canada encapsulated the basic psychosocial needs of those in care when they published the following guidelines:

In addition to physical needs such as the need for security, nutrition and good health, people with Alzheimer's disease have the same psychosocial needs as other individuals. They need stimulation and companionship, they need to feel secure, to feel they are unique and valued individuals, and so feel a sense of self-esteem (Alzheimer's Society of Canada, 1992, p, 3).

Not surprisingly, the key wellbeing indicators and priorities as identified by the UK research participants in 2010 are little different. In order of importance, the UK participant's indicated that their wellbeing is anchored by the hope of good health and companionship and close sharing relationships, the comfort and reassurance of a friendly voice and human touch, within a safe and secure, emotionally supportive environment - in short a lived experience that has meaning, exceeding what Vernon (2000) describes as "wellbeing beyond quality of life that revolves around bodies and pleasure" (Vernon, 2000,p. 46).

The research participants identified the following top three fundamental *wellbeing needs*, numbered 1, 2 and 3 below, which are followed by seven *wellbeing aspirations* (Alzheimer's Society, 2010a, p. ix). They are listed below in order of priority:

1. Relationships or someone to talk to
2. Environment
3. Physical health
4. Sense of humour
5. Independence
6. Ability to communicate
7. Sense of personal identity
8. Ability or opportunity to engage in activities
9. Ability to practice faith or religion
10. Experience of stigma

The first three fundamental wellbeing needs and the seven wellbeing aspirations require little further explanation except for number ten which confronts the issue of stigma and discrimination and societal attitudes. Not surprisingly, the overall experience of discrimination was found to be of particular importance to the research participants.

Stigma and societal attitudes

Price (2008) makes the following observation in a study on stigma and discrimination within the dementia-specific environment. He writes:

Once a person has dementia, the diagnosis and its personal and public consequences somehow becomes a person's chief defining characteristic. Other social identities are perceived as less important, or at least less pressing and are thus extinguished in the observer's eye - a response, perhaps, to the power of the stereotypes, stigma and discrimination that surrounds the condition (Price, 2008, p. 1,341).

The taboo that is dementia

At the beginning of the dementia journey, many living with dementia are all too aware of the power of the "taboo nature" of society's attitude toward dementia. Dementia is often perceived as a "personal tragedy" because unlike cancer, dementia is an "incurable disease" that affects the mind. Many individuals and their care partners are vocal in expressing their "desire to be treated fairly" and lament the "loss of friends" and their "marginalisation" in society. The AS UK research records that the priority concerns in the mind of each individual are the fundamental right to "self-determination and freedom" and "security and privacy" (Alzheimer's Society, 2010b. p. 24).

Now that the concept of dementia-specific wellbeing has been clarified by leading researchers, and by individuals who live with the dementia, the following paragraphs address the research project and its parameters and detail the method by which the three assessment tools have been applied to determine wellbeing and the lived experience of the participants and how the outcomes have been formulated.

The research project parameters begin with a research project theory

The theory behind this research project is that individuals living in dementia-specific care are able to actively engage in an art activity, and that engagement in a one-on-one art activity has the possibility of making a discernable difference to the wellbeing and lived experience of the individual at the time. Perrin and May (2000) argue above that “the seat of wellbeing” in dementia is reliant on “critical partnerships” and “can only be understood in the context of the interface between therapist [or facilitator] and client” (Perrin & May, 2000, p. 28). This statement will be considered in the discussion.

Testing the research project theory

To test the theory directly above, it will be argued in the discussion below that:

Firstly, an art activity, applied under the same conditions and delivered uniformly by an experienced facilitator to each participant, can significantly and measurably contribute, during the activity in question, to the lived experience and the emotional wellbeing of the participant.

Secondly, that art as an activity, when conducted by an experienced and appropriately qualified facilitator, can offer the possibility of both a novel and varied experience for the participant, as well as providing a unique opportunity for the facilitator to gain scientifically valuable insights into how individuals living with dementia engage in and respond to an art activity.

With data gathered from MARTIX TWO on ‘how’ the individual experienced the art activity, and ‘what’ they experienced gathered from MATRIX THREE, through the tick scoring of the CEAA tool - by the art activity facilitator, a staff member and an independent observer, and case studies observation - it may be possible to ascertain if inclusion and participation in an art activity contributes towards a sense of wellbeing, ownership and

achievement during the artwork's creation. Furthermore, individuals living in dementia-specific care, although experiencing different and varying levels of impairment, may still successfully and actively participate and use skills to engage in and enjoy the experience of a one-on-one art activity.

It has already been demonstrated in the AS UK report that individuals living with dementia are more than capable of expressing their thoughts on wellbeing and their lived experience. The potential contribution that this particular research project holds is the prospect for not only a deeper understanding of the use of art in dementia care, but also a greater understanding of the role of art and its relationship to wellbeing and how the two complement each other. And, with particular reference to the place of creative participation through art in aged care, new knowledge may be gained as to how those living with dementia respond to the challenges posed by art.

The research project discussion

In this discussion it is implicit in the decision to take on this research challenge that the outcomes of this research have the potential to identify new areas for NPI program development for the betterment of those living in dementia-specific care. In addition, these techniques and discoveries have been identified and clearly set out in the recommendations section so that such a resource, no matter how small, may be added to the universal knowledge pool to be adapted for general use by art activity facilitators worldwide.

The overall research objectives

The research objective was to document the relationship between art and dementia and wellbeing. The art activity was documented from three different perspectives with the specific aim of investigating the lived experience of individuals with dementia engage in a one-on-one art activity, following the stages and steps of an art activity process set out on MATRIX ONE - the art activity. The information was gathered during the production

of a large-scale collaboratively produced, permanent artwork measuring approximately 2.5 metre by 1.5 metre. The research, firstly, documented 'how' the participant experienced the art activity and how it contributed to an individual's wellbeing during an art activity using MATRIX TWO - the eight Kitwood tenets. MATRIX THREE - the CEEA tool documented 'what' the participant experienced. Both tools enabled the researchers to assess individual levels of wellbeing during the art activity. And, secondly, the researcher/facilitator made observations to determine how individuals living with dementia were able to use their skills during the art activity.

The artwork

The communal artwork is now known as the "*Getting to Know You*" artwork. Pre-drawn images were painted by each participant on a single piece of professional quality canvas approximately 2.5 metres wide by 1.5 metres deep. A list of art materials used during the art activity is detailed in Appendix C. The images were pre-drawn on the canvas by the facilitator. They consist of the illustrative interpretations of the diverse thoughts and ideas contributed by each participant in personal life-story interviews conducted before the art activity. The facilitator, using a variety of paint materials, aids, props and brushes (Appendix C), worked one-on-one through the same thirty-nine steps of the art activity with each individual as they painted their section of the work. The artwork remains on permanent display at the participating aged care facility.

The research methodology

The methodology that has been used in this research project is a phenomenological methodology. This research study is about the lived experience of human beings, many of whom are no longer able to fully articulate their feelings or experiences. Therefore a phenomenological observational methodology arguably best fits the research questions and the participant's specific and unique difficulties, not least cognitive impairment and memory loss, and the scientific rubric of replication of the test.

The concerns regarding the specific difficulties of conducting research with those living with dementia is well documented (Bernfeld and Fritsch, 2006) and Gottlieb-Tanaka and Graf's (2011) meta-analysis of current literature highlights the paucity of published documentary evidence. As mentioned in the introduction to this thesis Zeisel (2011) believes there are many reasons why so few studies have been conducted and why the existing evidence into non-pharmacological interventions is not readily accepted. He thinks that the prevailing biomedical orthodoxy assumes that randomised controlled trials (RCT) are the highest level of research "proof", no matter what the research question, and that statistical significance is the only true measure of the value of any research finding. Zeisel (2011) believes individual researchers and analysts with this mindset relegate other methodologies, often much more suitable to dementia-specific research and capable of providing more reliable outcomes with this cohort, to the lower end of the research continuum.

A dementia-specific wellbeing assessment

When it comes to making a decision on what methodology to use to enable a definite assessment of wellbeing in individuals living with dementia Williamson (Alzheimer's Society, 2010) makes a salient point: "the idea that a single instrument [can] be used to assess [wellbeing and] quality of life at each stage of development of an illness such as dementia is almost certainly redundant and much more dynamic approaches [and methodologies to address] the task are required" (Alzheimer's Society, 2010, p. 47). In search of the most appropriate instrument for this project, the author carefully examined a selection of research instruments that measure quality of life and wellbeing in dementia. The instruments included Brod and colleague's *Conceptualisation and measurement of quality of life in dementia: The dementia quality of life instrument* (Brod et, al. 1999), and Lodgson's (1996) *Quality of life - AD instrument*, and *The Greater Cincinnati Chapter Wellbeing Observational Tool*, used by Kinney and Rentz (2005) to evaluate the *Memories in the Making* program. And, whilst it is true that a much

more dynamic approach to dementia-specific wellbeing research is long overdue, each of these instruments contained very useful component elements but none was exactly right for this project. The author of this project finally settled on the CEAA tool primarily because of its relative simplicity to use and because it was thought to be sensitive enough to capture and record elements of wellbeing and the lived experience of those living with varying and different levels of dementia. The two other instruments used in this research project were developed to complement it.

Post's wellbeing concept is perhaps the most useful when considering the mechanics of an art activity. Post (1995) asserts that wellbeing can only flourish in a "supportive environment", and the quality of the lived experience of those living with dementia is almost entirely "dependent in crucial ways on the attitudes and actions" of care partners and the commitment of family members. Perrin and May (2000) also emphasize the "critical partnership" role that individual care partners play in creating and sustaining a supportive environment. They add, there is a "positive correlation between engagement and wellbeing" and, they argue, that "active engagement in the world" is the "seat of wellbeing" for individuals living with dementia. In particular, they argue, "the person who has dementia has it within his or her capacity to experience wellbeing in the face of advancing dementia"; and active engagement rests primarily on the nature of the relationship and critical partnership that has been established between the care partner and/or facilitator and participant. This is arguably best achieved in a Kitwoodian and person-centred approach to care.

Post (1995) is one of many who is convinced that activities "help mitigate the progression of dementia", and Cohen's (2006) research indicates that an individual's creative abilities act as critical keys in determining wellbeing and productivity. Creativity in old age, Cohen maintains, "is a catalyst for change of the best kind, with benefits that are immediate, long-lasting and within the reach of every person" (Cohen, 2001, p. 10). The art activity in this research project is designed, in line with Australian legislation, to be a 'here and now' activity. It is an art activity that McFadden, Frank and

Dysert (2008, p. 138) might describe as one in which the participant is presented with an opportunity to enter “into the ‘now’ of the creative moment”. And, whether or not the wellbeing benefits are long-lasting is not the purpose of the art activity or this project.

As indicated above, Vernon believes wellbeing is based on meaning, and that “transcendent good underpins it” (Vernon, 2008, p. 99). Most professionals working in the dementia-specific care would argue that wellbeing and finding meaning in life is no less important for those living with dementia than any other person in society.

Meeting the scientific rubric of replication in this research project

Three major problems had to be faced at the outset of this research project. The first was to source and/or design elements suitable to use in a phenomenological methodology to assess the lived experience participants with dementia and memory loss. It is logical to assert that RCT’s cannot always be successfully implemented in a research project where individuals must rely on memory to participate in follow up assessments. In such circumstances, where a person often cannot remember participating in the original activity, the research data is not always reliable. The second challenge was to measure wellbeing. The views expressed by the writers above demonstrate that wellbeing was and is an illusive and subjective concept and extremely hard to quantify. The third problem was to address the scientific rubric of replication, not least to satisfy a biomedically imposed, but not unreasonable expectation of competency. To meet these challenges the art activity had to be replicated with a strict adherence to precise guidelines. It was determined that the minimum attributes of a replicable dementia-specific art activity are the following:

- The establishment of a safe psychological space at the beginning of the activity
- A facilitator who works one-on-one with every participant

- A facilitator who anticipates each participant's need and facilitates practical solutions
- A participant who is encouraged to creatively explore the art activity without hindrance
- A measurement/methodological mix that enables a facilitator and independent observers to determine, with a level of objectivity, the effects of involvement in an art activity on the state of wellbeing of the participants

The process was to facilitate the art activity under the same conditions for every participant using MATRIX ONE - the art activity. The lived experience and wellbeing assessments are achieved through the use of MATRIX TWO - the eight Kitwood tenets that documented 'how' the participant experienced the art activity and MATRIX THREE - the CEAA tool that documented 'what' the individual experienced during that phenomenon. The CEAA tool was tick scored by three different people, once in a live setting during the art activity, and twice by videotape in a single sitting, post activity assessment.

MATRIX THREE - the CEAA tool

The CEAA tool is, according to its inventors, based on "solid quantitative research" and designed specifically to "obtain in-depth information about the expressive abilities" of individuals living with dementia. The tool was used to determine 'what' the individual experienced because it is predicated on Cohen's (2001) notion (above) that an individual's creative abilities act as critical keys in determining wellbeing and the quality of each individual's lived experience (Cohen, 2001). Existing trials of the CEAA tool, conducted by Gottlieb-Tanaka and Graf in Canada and by Lee in Australia, indicate that this assessment tool has "good internal consistency (Cronbach's alpha = .89) and rater reliability (Kappa = .83) in its use with those living with dementia in care.

The CEAA tool's function in this research project was to access a wide range of abilities including 'what' each individual experiences whilst they were engaged in a one-on-one art activity. The CEAA tool uses a tick score method, in which an assessor ticks in a box the number of times a clearly defined behaviour or action occurs during the activity. Each box relates to a wellbeing domain, and the domains include memory, attention, language, psychosocial, reasoning, problem solving, and emotion. Also, the facilitator of the art activity observes eight outcomes to determine 'how' the individual experiences the art activity.

The observational research data were gathered in three ways. Firstly, an independent assessor, identified as LS, tick scored MATRIX THREE - the CEAA tool - during each individual's live participation in the activity. During the art activity the participant was videotaped.

Secondly, the facilitator of the art activity, identified as JGM, conducted the activity and observed how individuals living with dementia used their skills during the art activity and then documented these observations immediately afterwards. In addition, JGM tick scored MATRIX THREE - the CEAA tool, in a single sitting, post-activity videotape assessment.

And, thirdly, a staff member, identified as CB, who knows and is familiar with each individual participant, tick scored MATRIX THREE - the CEAA tool, in a single sitting, post-activity videotape assessment.

The research participants

All thirty-five individuals who permanently reside at Nixon Hostel were invited to participate in the art activity that resulted in the creation of the "*Getting to Know You*" communal artwork. Although, each family was notified twice of the research project by mail (see Appendix D), and the facilitator addressed resident and family meetings as well as an afternoon tea information session, where the risks and benefits of the project were fully outlined, only twelve residents joined the research study. In addition,

staff members were fully briefed on the project during a staff meeting presentation preceding the project's commencement.

The legal guardians of the twelve permanent residents gave permission for them to participate in every aspect of the wellbeing study, including the CEAA assessment and videotaping of the participants during the art activity. Each guardian signed the Victoria University Ethics Committee approved consent forms (see Appendix D). The final group in the research study is comprised of seven females and five males. Eight participants are Australian born (four males and four females), three participants are English born (one male and two females), and one female participant was born in Italy. Eleven out of twelve participants are native English speakers. All twelve participants are living with some form of non-specific dementia, and all are affected by dementia in different ways.

The procedure

The painting and resident participation component of "*Getting to Know You*" artwork project began on August 6, 2010 and ended five weeks later on 8, September 2010. The facilitator worked with each of the thirty-five permanent Nixon Hostel residents individually over an eighteen-day period. Each participant received varying degrees of assistance from the facilitator. The facilitator worked one-on-one with each research participant so that the actions and/or painting style of another artist did not influence the activity. It ensured that another participant's painting style or colour preference could not be copied and an independent appreciation of each research participant's skills could be ascertained. None of the research participants had worked previously on any other project or art activity with the facilitator. All participants were asked permission for photographs to be taken.

The art activity was permanently set up in an alcove off the main C Wing lounge room at Nixon Hostel, and whilst a variety of different music styles were played on the CD player in the lounge room, and some research participants spontaneously hummed or sang along, a musical assessment of

the research participants was not part of the art activity or research performance criterion. Suffice to say the choice of music was generally compatible with the participants' taste, 'popular' by their standards, and the volume was maintained at a non-intrusive background level.

In line with Australian aged care legislation every participant was encouraged to exercise choice and self-determination when deciding whether or not to join the activity and/or be photographed. Every participant who chose to participate progressed through the stages and steps of the art activity outlined in MATRIX ONE - the art activity, to complete the art activity. There were no deaths and no research participant dropped out of the project for any reason during the eighteen-day art activity component of the project.

All twelve-research participants progressed through the same stages and steps of MATRIX ONE - the art activity - to complete the activity and were videotaped and observed. Each participant made his or her individual contributions over a four-day period, although two of the Australian male participants exercised choice and self-determination and did not paint, but both men fully engaged with the facilitator in a series of "passive" participation components inherent in the art activity, such as choosing colours and spotting mistakes to clean up.

The research observers

Three individuals made observations for this research project. The first member (JMG) is the primary researcher and is also the art activity facilitator. The second member (LS) is an independent assessor with more than thirty years experience working as a diversional therapist in aged care. She currently teaches tertiary level aged care and diversional therapy qualifications. This assessor tick scored MATRIX THREE - the CEAA tool - live. The third member (CB) is a Nixon Hostel staff member, and a fully qualified diversional therapist, who tick scored MATRIX THREE - the CEAA tool - in a single sitting, post-activity assessment of the videotape.

The research facility

The research project was conducted at Nixon Hostel in Mordialloc, Victoria, Australia, during August and the first two weeks of September 2010. Nixon Hostel was chosen for three important reasons. Firstly, the facility is a dementia-specific facility. In this case, dementia-specific means that every individual who lives there has some form of dementia. Secondly, Nixon Hostel actively practices a person-centred approach to care and this practice is reflected in the facility's management policies and procedures and its nursing philosophy. In addition, each staff member is individually trained in the "Spark of Life" program. This program was designed by Jane Verity, of Dementia Care Australia, who was educated and trained in the person-centred approach to dementia care by Tom Kitwood, at Bradford University in the 1990s.

The atmosphere generated by a human, loving, home-like environment is the third reason why Nixon Hostel was chosen. Kubler-Ross (1978, p. 125) believes that creativity comes to individuals as they start to live "life fully", and she writes that living life fully is "something which is possible in a human, loving environment, and not possible in a sterile, mechanized hospital setting". Nixon Hostel staff, furthermore, practice a minimalist medication policy which ensures that each resident can experience life to the full with the minimum of pharmacological intervention or interference. Residents are encouraged to participate in activities that are designed to promote wellbeing through a positive lived experience and the facility supports each resident to achieve this to the best of his or her ability.

In terms of this research project, Nixon Hostel's policies and procedures, its person-centred care philosophy and human and home-like environment, has ensured that the research findings are not overly influenced by external factors and that each response during the art activity has been recorded in as near to ideal conditions as possible.

The research questions

The primary researcher, who was also the art activity facilitator, observed each of the twelve research participants, whilst engaged in a one-on-one art activity, and asked the following two questions.

- What signs of wellbeing, if any, including engagement, concentration and emotional response, are observed during a one-on-one art activity?
- What skills do individuals living in dementia-specific care exhibit during the art activity?

To briefly answer the first question, every participant displayed evidence of engagement and concentration and, not surprisingly, each had a unique and different emotional response to the activity. With the information gathered from MATRIX TWO and MATRIX THREE, the twelve very detailed case study examples answer both questions fully. They demonstrate ‘how’ and ‘what’ each participant experienced during the phenomenon. The assessment tools also document the diverse and individual set of skills that each participant brings to the activity.

Three demonstration case study examples

Immediately below three case study examples are included in the body of the thesis text. In order, they demonstrate, firstly, a high, then a moderate and then a low wellbeing assessment. Nine other case study examples, documenting the diversity of each participant’s lived experience and response to the art activity in detail, and the supporting data for the research project, are included in full in Appendix 1.

The first demonstration case study

The first demonstration case study immediately below is of an individual (PB) living with advanced Alzheimer’s like dementia. This example documents PB’s lived experience responses and the data information

gathering process that resulted in the recording of a high wellbeing outcome.

Pamela (Pam) B. (PB)

Born in Clare, South Australia, on 19.09.1940

THE CASE STUDY INTERVIEW

Pam talked about her life as a pediatric nursing sister at Adelaide Hospital when we chatted on the afternoon of 22.03.10. Pam had been sitting singing a song selection from *The King and I* and the *Cole Porter Songbook* when I arrived and as we sat and had afternoon tea together she told me more about her life.

Pam was born in the village of Clare in South Australia where her father ran a family dairy and fruit-growing farm. Pam says life on the farm was hard and she had lots of chores to do, like milking cows and picking grapes in season, after coming home from the local Catholic school in Watervale. After leaving High School, Pam found herself working in a bank whilst she waited for a place at the Royal Adelaide Hospital to begin her nursing training.

Pam's real love is nursing, and it was whilst she was doing her rounds that she met Roger, one of the patients who had just come in after a very bad motorbike accident. Roger says he was "in hospital forever" whilst his leg healed and over the time the romance blossomed. The couple married a year later on his release.

After Pam finished her training her great love became pediatric nursing. She says, "I just love babies". And, her love of babies is just as well, as the couple had seven children, three girls and four boys. This large family travelled widely in Australia due to Roger's profession as a meteorological observer and, when her children were old enough, Pam returned to fulltime nursing.

Pam is an Alzheimer's "pin-up girl" and her image has appeared in lots of promotional material for Alzheimer's Australia to raise public awareness. The family thinks this is most appropriate as Pam's grandmother, her mother and father and her brother all died of dementia. Roger believes that Pam was probably living with dementia long before he first recognized it first about twelve years ago.

THE ART ACTIVITY

On 06.08.10, the first day of the artwork activity, Pam spent a considerable amount of time, about $\frac{1}{2}$ to $\frac{3}{4}$ of an hour, both in the morning and the afternoon, as an "active" passive observer. Pam contributed much to the conversation between participants, interjecting with appropriate comments and observations and she is particularly caring of other people's needs and comfort. When I enquired whether she would like to participate here and now, she said, "I'm sorry, but I cannot do this today because I want Roger here when I do it".

Over and over again during the course of the next three days, Pam made her intention and her willingness to be part of the project evident. On 09.08.10, Pam spent about six minutes painting some of the blue sea.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Pam was able to see the outlines clearly and grasped the concept of painting. She applied a few brush strokes, following the fine machine stitched hemline that runs across the bottom of the work, apparently using the stitches as a guide.

Pam was not able to dip her brush herself, but she cheerfully took up each

new brush and continued until she expressed “deep tiredness” and carefully laid down the paintbrush. We chatted on for some time about life and family, and particularly her contribution in the workplace because I have found that this conversation topic always seems to reassure her. Ten days later, Pam, using small deliberate strokes once again painted a series of clear straight lines following the black outlines. After about eight minutes, Pam once again expressed her feelings of deep tiredness and laid down her brush.

Post art activity observations of the lived experience

Pam spent quite a lot of time as an “active” passive observer during another resident’s engagement. Pam and this resident both observed quite delicate rules of etiquette and old-fashioned manners towards one another throughout this exchange and it was a delight to observe their interaction.

The value of Pam’s “active” passive engagement should not be underestimated. In this case, it taps into Pam’s vast professional career as a respected Director of Nursing and organizer of people and staff, and although Nixon Hostel has a welcoming home like atmosphere, it is nonetheless an aged care facility and not that far removed from a hospital like setting. It can be said that Pam “is in her element” in this environment. Her keen interest in the project has sparked many other residents’ curiosity. And, when such curiosity is combined with Pam’s encouragement to other participants and her positive comments and observations about the work, it produced the cumulative effect of drawing other less outgoing participants into the activity.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents ‘how’ PB experienced the art activity phenomenon.

Participant’s name: PB	Art activity = 8 minutes
Attachment	PB has a very outgoing personality and had spent considerable amounts of time as an “active”

	passive observer before she participated. As a result, the rapport between PB and the facilitator was established immediately.
Holding	A trusting and safe environment was established quickly because of the above factors.
Timalation	Although PB lives with advanced Alzheimer's like dementia it was not necessary for the facilitator to sit closely or even next to her.
Relaxation	PB appeared relaxed and comfortable with both the art activity and the facilitator, laughing and smiling as she worked.
Celebration	Smiling and laughing gave an indication that PB was free of fear and responsibility during the activity. This continued until she was overtaken by "deep tiredness".
Play	Although PB was able to paint in short strokes when directed, she was not able to dip her brush or initiate the activity without assistance.
Creation	PB was able to see the outlines, she understood the concept of painting and appeared to enjoy painting, with accuracy, along a stitched hemline.
Giving	PB expressed gratitude at the end of the art activity and passed positive comments about the activity and the artwork on numerous occasions and encouraged others to join in.

Wellbeing observations in MATRIX TWO - the eight Kitwood tenets:

A safe psychological space was soon established because of PB's keenness to be part of the activity. Although PB lives with very advanced Alzheimer's like dementia, and even though she required the assistance of the facilitator to direct her and charge her brush, she approached the activity with openness and enthusiasm. PB smiled often, indicating her happiness and she fully embraced the opportunity to participate. PB's painting technique was fluid and she seemed to be guided by the lines on the surface of the canvas. Her continued interest in the activity after her participation, and her encouragement of others to join, was a positive form of giving and reciprocation.

PB's optimistic and outgoing personality, her former occupation in a busy hospital and role as mother to seven children, undoubtedly played a big part in her acceptance and enjoyment of the activity. PB's natural desire to

include others in the activity mirrored her former lifestyle. Even though her actual participation time was relatively short it presented her with a rare opportunity to be productive and active and so regain a semblance of her former self, all essential in raising her self-esteem.

MATRIX THREE - the CEAA tool, incorporating the assessor tick scores

MATRIX THREE below documents ‘what’ PB experienced during the art activity phenomenon.

The three right hand columns of the matrix, record the three assessors’ tick score observations, as they relate to each domain. The numbers represent how many times the action was observed by an assessor during the art activity. In the previous chapter, the author indicated what each assessor would and would not collect during the art activity. This research project did not assess the participant’s writing, singing or musical ability, nor did it assess his or her interest in grooming. Although part of the CEAA tool design, these items were not assessed during the art activity and, as a result, they are struck through on the matrix below.

Participant name: PB	Length: 8 mins		
Assessors column tick scores and assessment method	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	3	2	3
M2. Recites			
M3. Invents memories	2	2	2
Attention			
A4. Levels of attention	2	2	2
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	6	5	6
L7. Uses key words/simple sentences/body language			
L8. Uses humour when writing			
L9. Uses humour when speaking			

L10. Uses elaborate/informative descriptions	3	2	2
L11. Uses facial expressions to communicate understanding	1	1	2
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections	2	3	3
P17. Shows self-esteem/confidence	1	2	1
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems		1	
R20. Makes clear decisions and choices	4	2	3
Emotions			
E21. Uses facial expressions to express moods and emotions	3		4
E22. Expresses mood in visual display	3		2
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories		2	
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL TICK SCORE	30	27	34

MATRIX THREE wellbeing outcomes:

The CEAA observation tick scores indicates that even though PB lives with advanced Alzheimer's like dementia she uses complete grammatical sentences and provides informative descriptions of the activity. When PB first looks at the colours already on the artwork's surface she comments "that's nice isn't it", and then remarks that black outlines are "easy to follow". When PB is handed the paintbrush she skillfully paints along a stitched seam with small brush strokes, adding "I love blue, it's beautiful".

The video images capture PB's facial expressions and her response to comments. The images indicate both her enjoyment in the activity and record her ability to make clear, if simple decisions and appropriate comments. Even though PB's care needs have increased to such a degree that she is to be admitted to 'high care' soon after the activity she nonetheless makes specific observations about the art activity. PB confides that, "some people don't like doing this but I love it". When invited by the facilitator to continue with the activity, PB's answers, "I'd like to do some more", and then adds "you should be able to use your hands".

PB's interest in the activity is ongoing and constructive. Each day, on numerous occasions, she sidles up and stands beside the work. Images of PB positively encouraging and complimenting other participants are captured on video.

The tick score totals between the three observers indicate each observer made similar observations across each of the designated wellbeing domains. The tick score records are almost even, JGM = 30, LS = 27 and CB = 34. This indicates there are no major discrepancies between the observations across all of the CEAA wellbeing domains.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

PB was born in rural South Australia and has been living with early onset Alzheimer's like dementia for more than a decade. PB has an open and generous personality and she enjoyed a long, productive and fulfilling career as a pediatric nursing sister, then Director of Nursing before entering care. PB's life partner and her large supportive family are instrumental in regularly meeting her immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO - the eight Kitwood tenets and MATRIX THREE - the CEAA tool, indicate that the facilitator was able to implement the activity, and the independent evaluators successfully documented multiple signs of wellbeing outcomes, demonstrating the efficacy and suitability of the assessment tools.

PB came to the activity with an optimistic attitude and her comments throughout indicate she freely entered the activity and took the opportunity to explore its possibilities and use her remaining skills to the best of her ability. PB's contribution to the activity is typified by her positive comments and her visible personal engagement and enjoyment in the activity. Given PB's level of cognitive impairment, and the fact that her care needs are such that she was transferred from Nixon Hostel to a 'high care' facility on 08.03.2011, her positive encouragement of others to join the activity is both unusual and noteworthy.

The wellbeing assessment

PB's overall participation demonstrates that the lived experience of the art activity, in terms of Kitwood's identity and personhood wellbeing indicators, contributed to her wellbeing at the time. And, as a result, she reached and maintained a relatively high state of wellbeing during the phenomenon.

The second demonstration case study

The second demonstration case study immediately below is of an individual (FB) living with dementia caused by a benign brain tumor. This example documents FB's lived experience responses and the data information gathering process that resulted in the recording of a moderate wellbeing outcome.

Fred B. (FB)

Born in Essendon, Melbourne, on 12.06.1931

THE CASE STUDY INTERVIEW

I spoke to Fred and his daughter Liz, when she was visiting with her golden Labrador dog, “Jarrah”, before lunch 22.03.2010. Liz is the first of Fred’s two daughters and she lives nearby and her daily visits seem to be of great comfort to him.

Fred says he was born in Essendon and lived his early life in the family home in Moonee Ponds. Not surprisingly, Fred is an ardent Essendon Football Club supporter. Fred went to the local Essendon Primary School and remembers not liking school much but he did enjoy doing standard drawing exercises whilst he was there.

After high school, Fred worked for the Victoria Railways and then entered an apprenticeship in carpentry at RMIT. After that, Fred entered the technical teaching profession through the Trades Induction Scheme and he then taught woodwork and technical geometry in the Victorian Technical College system - a system that taught “the trades”, such as carpentry and plumbing and car maintenance, to boys until the 1970s.

Fred’s love of wood sparked an interesting and detailed discussion about wood and he was suddenly transported back into the classroom when he carefully explained to me the different properties of wood and how to build specific things with different types of wood.

Fred was married to Lorna but they divorced more than fifteen years ago. During their married life together they lived in rural Upper Beaconsfield because of his daughter’s love of horses and Fred’s interest in Australian native birds. Fred and his family were lucky to survive the devastating Ash Wednesday bushfires in 1983, but their neighbours died in the inferno, and they moved back to the city after this experience. The family took a

caravan holiday every year to Noosa in Queensland and Fred was fortunate to travel overseas to England.

When asked what he would like to see on a painting, Fred replied that he has “two favourite things in life”, one is wood, so a scene with trees in it would be nice, and the other favourite is football, so a football ground with goal posts might also be appropriate.

THE ART ACTIVITY

Fred was happy to participate on the afternoon of 30.08.10 for about ten minutes after lunch. Much ashamed of his tremor, Fred nonetheless entered into the spirit of the project.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Initially, I supported Fred’s arm as he moved into the tremor and this movement propelled the brush and the paint across the surface. Whilst Fred painted the Yellow Brick Road scene from *The Wizard of Oz*, he expressed concern that his tremor would hold him back and then he honestly confessed that painting “is not really my thing”. Despite this, Fred was prepared to give it a go and used his left hand to support his right painting hand during the activity. Fred improvised by actually using his tremor to assist him to dab and sway the brush across the canvas.

As Fred gained more confidence he attempted the activity supporting his painting hand with his other hand. Fred was very open and honest about his experience and talked about the effect the background noise was having on his concentration. Fred was quite inventive in his attempts to steady his hand himself and he continued to participate in the activity although he

repeatedly stated that painting is not really “his thing”. Although very aware of his tremor, he nonetheless showed great respect to me as a facilitator by continuing despite his disability.

As Fred became more tired he required some intervention by me to steady his hand; it was not forceful, the gentle touch of my hand on his forearm seemed to lessen the tremor and focus him back onto the task.

Post art activity observations of the lived experience

The inherent skills that Fred has used over a lifetime as a woodworker and carpenter, and as a teacher, seemed to take over and it helped that he had an open response to work with the unsteady action of the tremor to drive the paintbrush across the canvas. Fred expressed grief at his condition and explained aspects of the impact of his disability on his life, and ended the activity saying he felt “cheated” because he could not participate as well as he would have done in the past.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents ‘how’ FB experienced the art activity phenomenon.

Participant’s name: FB	Art activity = 11 minutes
Attachment	A friendly ambience was established quickly because the facilitator had spent some time over the previous weeks gaining FB’s confidence. Also, FB said he was happy and willing to participate
Holding	Confidence in the facilitator and the activity were soon established because of the above factors
Timalation	It was necessary to initially assist FB by supporting his elbow until he gained more confidence in the activity and later when he showed signs of tiredness
Relaxation	FB appeared acutely aware of his disability but was comfortable and confident to discuss it at some length with the facilitator. Nonetheless, FB made every effort to relax and participate

Celebration	FB's fear of failure due, to his disability and his loss of skills, appeared to greatly influence his participation
Play	FB appeared to be pleased with his participation even if the outcome may have been less than he may have anticipated
Creation	FB appeared disappointed that he was not able to participate more fully because of his disability but showed ingenuity in finding a way to overcome it by supporting his arm himself and he improvised by using his tremor to propel the brush
Giving	FB expressed gratitude for his participation even though he did with honesty confide that the activity was "not really [his] thing" and he was at pains to apologise for what he perceived as his shortcomings saying he felt "cheated" in life because of them

MATRIX TWO wellbeing outcomes:

The facilitator made every effort to put in place all the necessary conditions to create a "holding container". The participation was successful in that FB participated for more than ten minutes despite his disability and his protestation that painting was "not really [his] thing" and, secondly, that FB independently came up with a creative solution to assist himself during the activity.

As with MP, (another research participant) wellbeing is very difficult to assess in an individual who is acutely aware of the shortcomings caused by his disability and who feels "cheated", and somewhat ashamed, that he can no longer participate at a level that he might wish to. This underscores the role and importance and the skill of the facilitator in creating a "holding container" that adequately meets the needs of each participant. That said, an indication of FB's wellbeing level is exemplified by his decision, given his disability, to actively participate in circumstances where a person with less self-esteem would probably have declined the opportunity

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents 'what' FB experienced during the art activity phenomenon.

Participant name: FB	Length: 11 mins		
Assessors and assessment method - tick scores	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	2	1	
M2. Recites			
M3. Invents memories			
Attention			
A4. Levels of attention	2	2	4
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	6	5	20
L7. Uses key words/simple sentences/body language	4	5	4
L8. Uses humour when writing			
L9. Uses humour when speaking	2	4	2
L10. Uses elaborate/informative descriptions			
L11. Uses facial expressions to communicate understanding	2	2	2
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections	1	2	
P17. Shows self-esteem/confidence	1	2	
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems	5	4	2
R20. Makes clear decisions and choices	4	4	5
Emotions			
E21. Uses facial expressions to express moods and emotions	4	4	5

E22. Expresses mood in visual display	4	2	1
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	37	37	43

MATRIX THREE wellbeing outcomes:

The CEAA tool and the video record documents that FB uses self-deprecating, humor such as “my benign tremor, not too bloody benign if you ask me”, complete grammatical sentences, and a wide range of facial expressions and body language to communicate aspects of his life and disability. FB shows great insight and emotion when sharing his story, but appears hampered in taking pride and satisfaction in his participation in the art activity by his self-perception and feeling of being “cheated” in some way. That said, he does actively take part in the activity even though he openly admits that, “painting is not really my thing”. He could have declined the opportunity, as others have done, but instead independently restarted the art activity after his tremor became too strong and displayed insight and ingenuity and perseverance when supporting his arm and finding ways to overcome his difficulties.

The tick score totals between the three observers indicate each observer made similar observations across each of the designated wellbeing domains. The tick score records are almost even, JGM = 37, LS = 37 and CB = 43. This indicates there are no major discrepancies between the observations across all of the CEAA wellbeing domains.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

FB was born in Essendon, in suburban Melbourne, and spent his early life in and around Moonee Ponds. FB says he has been living with a neurological tremor all of his life and non-specific dementia for some time. FB states that he enjoyed his long employment as a woodwork teacher and found his interest in environmental issues very fulfilling before entering care. FB's daughter and her dog and their daily visits are instrumental in meeting his immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: the facilitator was able to implement the activity and the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

FB was brought to the activity and he freely made the decision to stay even though he soon realised that painting is not really his thing. Nonetheless, FB took the opportunity to explore and enjoy its possibilities despite being hampered by tremors. FB appears to relax in the facilitator's company, but seems ashamed of his disability.

The wellbeing assessment

FB's overall participation demonstrates that the lived experience of the art activity, in terms of Kitwood's identity and personhood wellbeing indicators, contributed to his wellbeing at the time. And, as a result, he reached a moderate state of wellbeing during the art activity.

The third demonstration case study

The third demonstration case study immediately below is of an individual (LF) living with very advanced Alzheimer's like dementia. This example documents LF's lived experience responses and the data information gathering process that resulted in the recording of a low wellbeing outcome.

Louise F. (LF)

Born in Central Victoria, in 1937

THE CASE STUDY INTERVIEW

I had lunch with Louise and Kevin on 22.03.10 and collected Louise's life story information. Louise was born in 1937 and spent her school days at various schools in and around Victoria because her father was a stationmaster employed by Victoria Railway. Louise and Kevin met at a Gala Ball at Maryborough in Central Victoria and married two years later.

Kevin spent his working life as a furniture agent and travelled throughout country Victoria and N.S.W. Family life was and is a very important part of Louise's life - she has always been a homemaker. Louise cared for her mother who had a stroke at 38, and then, after she and Kevin married, and had six children together, she was happy to be at home caring for them. Kevin says the couple "saved for years" to take their six children to Disneyland and he and Louise took other trips to the USA to follow their shared love of country and western singers and music. Together the couple visited Nashville for the Grand Old Opry together, and they even made a special trip to Graceland in Memphis, Tennessee, to see Elvis' grave. Another of the highlights of the couple's travel life was a pilgrimage to Rome to be "blessed by the Holy Father".

Kevin says Louise was a "beautiful dressmaker" and could "knit very intricate patterns". He said that when the children had grown up Louise used to accompany him on his sales trips and she used to sit in the car knitting whilst he called on his clients to take orders.

As a lead up to Louise's contribution to the artwork, on the morning of 23.03.10, Louise had a cup of tea with me. Louise was sitting in the lounge room totally enthralled in the music of Elgar and Percy Grainger when I arrived in the unit that morning. Her eyes were clear and bright whilst we engaged in simple conversation.

THE ART ACTIVITY

Louise lives with advanced Alzheimer's like dementia and cannot walk unassisted and, as a consequence, she is difficult to transfer. To facilitate Louise's contribution to the project, on the morning of 29.08.10, she was brought to the art activity directly after breakfast by care staff. This gave me the opportunity to try out the hand-held squeeze sachet tubes of paint with her.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

The white piano keys were chosen because it is a broad area to cover and once seated and comfortable Louise's hand was gently maneuvered toward the canvas surface. This procedure worked really well with Louise as she was able to firmly grasp the tube and then, with assistance, she was able to sweep the colour across the canvas from right to left. Louise seemed to enjoy the activity, which lasted about ten minutes, until she showed signs of tiredness and was transferred by staff to an easy chair. Louise enjoyed the attention and was very definite in her comments. She remained focused on and continued to watch the activity and the other participants long after she was settled in the easy chair.

Post art activity observations of the lived experience

After the residents' meeting on 31.08.10, Kevin spoke of the couple's forthcoming golden wedding anniversary in two weeks. With deep regret, Kevin confided that it was a "real shame" that Louise would not be able to contribute to the art activity because of her disability. He was visibly shocked, and then overwhelmed with emotion, when I told him that Louise had indeed made a very real contribution to the work. Kevin seemed very gratified by this information.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents 'how' LF experienced the art activity phenomenon.

Participant's name: LF	Art activity = 11 minutes
Attachment	LF smiled and responded to the facilitator's conversation and seemed to enjoy the attention
Holding	LF facial expressions indicate that she appeared to be comfortable and secure in the art activity environment
Timalation	Because of advanced Alzheimer's like dementia, it was necessary for the facilitator to sit close up and right next to LF to physically assist her in every way during the art activity
Relaxation	LF smiled throughout the activity occasionally giving quite definite one or two word responses
Celebration	LF appeared to enjoy her interaction with the facilitator
Play	LF was unable to work independently
Creation	LF was unable to demonstrate any retained skills
Giving	After the activity LF watched the activity from close by. She smiled often and remained focused on the other participants' engagement for some time

MATRIX TWO wellbeing outcomes:

LF's advanced Alzheimer's like dementia made the activity very short, but nonetheless it was productive and positive. The facilitator had to facilitate all of the processes in LF's engagement. LF grasped the special squeeze tube of paint and was content to have her hand propelled across the canvas. During the activity, LF smiled often and gave one-word comments. When LF

was transferred to a comfortable easy chair in the lounge room after the art activity ended, she remained focused on the activity for some time. She sat about one and a half metres away, happily observing another participant at work with the facilitator.

Although the positive wellbeing outcomes of individuals with advanced Alzheimer’s like dementia can never be precisely accessed, particularly with an individual who can no longer fully articulate their thoughts and feelings, non-verbal clues and signs have proven in the past to be reasonably accurate indicators. If LF had not be content and happy with the process she would have verbally and non-verbally indicated her dissatisfaction. LF’s inclusion in the activity was greatly appreciated by her life partner. The effect that the wellbeing of a life partner has on the wellbeing of the individual living with dementia cannot be underestimated.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents ‘what’ LF experienced during the art activity phenomenon.

Participant name: LF	Length: 11 mins		
Assessors and assessment method - tick scores	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces			
M2. Recites			
M3. Invents memories			
Attention			
A4. Levels of attention	1	1	1
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	1	1	1
L7. Uses key words/simple sentences/body language	5	5	4
L8. Uses humour when writing			
L9. Uses humour when speaking			
L10. Uses elaborate/informative descriptions			

L11. Uses facial expressions to communicate understanding	2	3	4
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections			
P17. Shows self-esteem/confidence			
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems			
R20. Makes clear decisions and choices	1	1	1
Emotions			
E21. Uses facial expressions to express moods and emotions	2		
E22. Expresses mood in visual display			
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	12	11	11

MATRIX THREE wellbeing outcomes:

The CEAA tool and the video indicate that LF experiences significant word processing delays, and is not always able to respond and/or is limited to the use of simple one or two word sentences in response to questions. On one occasion however LF whole-heartedly responded to the facilitator exclaiming that it was a “good idea, a cup of tea” when asked if she would like some tea. Even though LF’s language skills are profoundly affected by Alzheimer’s like dementia, she nonetheless effectively uses facial expressions to indicate her mood - one of happiness and relaxation - during

the activity. LF was fully assisted by the facilitator during the activity and was not able to demonstrate any independent skills.

The tick score totals between the three observers indicate each observer made similar observations across each of the designated wellbeing domains. The tick score records are almost even, JGM = 12, LS = 11 and CB = 11. This indicates there are no major discrepancies between the observations across all of the CEEA wellbeing domains.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

LF was born in rural Victoria and has been living with early onset Alzheimer's like dementia for almost a decade. LF enjoyed a long, productive and fulfilling life as a mother and homemaker with her life partner and her big family before entering care. LF's life partner and her large supportive family are instrumental in regularly meeting her immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: even though the facilitator had to fully assist LF to implement the activity, the independent evaluators successfully documented some signs and wellbeing outcomes. The assessment tools proved sensitive enough to capture some useful information.

LF came to the activity and the facilitator had to aid and assist her at all stages of the activity. Irrespective of her cognitive impairment, and the fact that her care needs are such that she was transferred from Nixon Hostel to a high care facility on 06.09.2010, LF's contribution to the activity is perhaps best judged by her non-verbal communication and facial expressions that manifest in what appears to be a visible enjoyment in the activity.

The wellbeing assessment

LF's overall wellbeing outcomes are difficult to access. But, the art activity, in terms of LF's lived experience and Kitwood's identity and personhood wellbeing indicators, appeared to contribute something to her wellbeing at the time. And, as a result, she achieved an observable, if low, state of wellbeing during the phenomenon.

Postscript

LF's life partner, Kevin, died suddenly in December 2010.

The nine other case studies

As in the case studies of PB, FB and LF directly above, at the conclusion of each case study, the lived experience of each of the nine other participants who contributed to the research study was assessed. On completion of every individual case study and lived experience of the art activity a wellbeing assessment was made for each individual based on the researcher's definitions, video observations and methodical assessments of wellbeing based on 'how' and 'what' the participant experienced. The facilitator has made an allocation of a low, moderate or high wellbeing outcome for each participant based on the above assessments. The case studies for each individual and their wellbeing assessments can be found in Appendix 1.

As mentioned in the introduction to this chapter, the aim of the research study was to assess the individual lived experience of each participant during the art activity, to determine his or her wellbeing and to identify the skills the participant utilized at the time of the activity. Note: the art activity was not set up to gather data for a detailed wellbeing comparison **between** participants, or to determine if the wellbeing benefits of the art activity are long lasting.

The matrix below documents a final wellbeing outcome for each of the twelve research participants in this study. The matrix reflects a person-centred assessment of ‘how’ and ‘what’ each individual experienced during the art activity, taking into consideration all of the data collected by observational methods as detailed in the case study example above.

Participant name	Wellbeing outcome
DD	High
PB	High
JO	Moderate
JB	High
LF	Low
GW	High
MH	High
TMc	Moderate
MP	Moderate
FB	Moderate
LG	High
NA	High

Researcher bias

Although there is always potential for a confirmation research bias to exist in relation to the allocation of a wellbeing outcome, in this case the final results of the independent observer’s assessments of MATRIX THREE - the CEAA tool, for example, support the principle researcher/facilitator’s assessment of ‘what’ the participant experienced during the activity. ‘How’ the participants experienced the art activity is subjective, and as a result, the wellbeing evaluation for each participant has been based on the facilitator’s lived experience of the phenomenon.

A distillation of the “universal essence” of the lived experience of the art activity for the twelve research participants

Polkinghorne (2005, p. 141) notes that final function of qualitative research, such as a phenomenological study of the lived experiences of individuals engaged in an art activity, is to make evident the “characteristics of an experience” so as to “increase an understanding of the human life as lived”. Phenomenologists refer to this final function as distilling the “universal essence” of the phenomenon (Creswell, 2006).

Three major sources of data provided evidence to distill the “universal essence” of the lived experience of a dementia-specific art activity for the participants. The process began with a personal interview of each participant by the facilitator to enable the facilitator to create a “rich and inclusive” account of what the participant could remember about his or her life-story. This interview culminated in both a social profile - a case study of the participant’s life-story - and the ideas for the theme and composition of the graphic symbols and images that appear on the artwork’s surface. The second and third source of data was provided by live observations of the art activity and video recordings of the participants at work. The steps of the art activity and the two assessment tools and the video recording made the assessments straightforward and each individual’s lived experience relatively easy to document and independently validate.

To recap, the facilitator worked individually with each of the thirty-five permanent Nixon Hostel residents to create the communal artwork, but only twelve permissions were obtained from individuals and their guardians to enable those individuals to participate in the research project. The twelve participants in the research project are comprised of seven females and five males. Eight participants are Australian born (four males and four females). Of this group six grew up in rural surrounding and two began life in suburban Melbourne. Three participants are English born (one male and two females), and one female participant was born in Italy. This group shares the 1950s migrant experience in common - the ‘dream’ of a better life in Australia. The research project group is homogeneous, as eleven out of twelve

participants are Anglo-Celts and, as a result, are native English speakers. None of the participants, except one who studied architecture at university, and another, who taught woodwork and technical drawing, had received any formal art training beyond their school years. All twelve participants are living with some form of non-specific dementia, and all are affected by dementia in different ways.

This project is about the lived experience of individual people - the collective lived experience and the shared interest of the enjoyment of participating in the creation of the “*Getting to Know You*” artwork. Their participation in this experience is one thing all twelve participants shared in common and their lived experience has revealed that they share many things in common.

A short discussion of the “universal essence” of their shared and common experience begins firstly with what this research project revealed about two common *a priori* assumptions regarding individuals living with dementia. Those assumptions are the lack of ability of individuals living with dementia to concentrate on task for more than a moment and their so-called propensity to “eat the paint”.

It stands to reason that each individual’s type and level of dementia, and his or her physical health and stamina and ability to concentrate, determined the length of participation and because of these factors every participant’s engagement time was different. The facilitator left each individual contribution time to the art activity open ended and worked through the thirty-nine steps of the activity at the participant’s pace. As a result, each individual’s lived experience of the art activity spans a different length of time. Each individual freely chose when to end the activity.

The evidence gathered shows that participation times ranged between eight minutes duration through to seventy-two minutes. These times are validated by a video camera that was set up on a tripod to videotape record and document the length of every session. The legs of the tripod were partly

obscured behind the “Rubbermaid” art cart but the camera was in full view at all times. The video camera ran continuously for the art activity and the final videos that accompany this project are unedited and in the appendix. During the art activity the facilitator sat next to or near each participant and assisted him or her, as and when required. The independent assessor sat unobtrusively in a corner to tick score MATRIX THREE - the CEAA tool - and did not engage in conversation with the participant during the activity.

All participants stayed on task for more than a moment and are variously seen laughing and joking and even singing with the facilitator. The engagement of those living with more advanced Alzheimer’s like dementia has been shown in this project to be about eight minutes on average and not nearly as long as other participants living with non-specific dementia. This research project has shown that artists living with Alzheimer’s like dementia tend to engage in short and very concentrated bursts of activity, and they also appear to articulate feelings of tiredness more frequently than participants living with other forms of dementia.

Of twenty-three other individuals, who were art activity participants, but not officially part of the wellbeing research project, five worked industriously at the art activity for over forty-five minutes or more. When combined with the three participant’s from the official research project it means that eight out of thirty-five artists, that represents just under 25% of the overall combined total of overall participants, concentrated on the art activity for unprecedented periods of time. This outcome seriously challenges the first of the above *a priori* assumptions about the length of time individuals living with dementia can concentrate.

This research project has shown that individuals living with dementia can concentrate on tasks that are structured and novel and varied and that they can remain engaged in creative activity for extended periods of time. No participant attempted to “eat the paint”. If nothing else, the lived experience of the participants and the resultant artwork presents tangible evidence that, regardless of age and disability, individuals living with

dementia from all walks of life when having fun have the ability to concentrate during the creative process and they appear to revel in the sensory delights of colour and design.

With regard to the sensory delights of colour, overwhelmingly, each artist, with the exception of one who could not articulate her preferences, demonstrated intact colour sense and colour memory. With one exception, each participant appeared to appreciate the range and scope of colours in the painting and some even commented on the shades of such colours, in particular the colour blue. Attracted by the colours, the artwork soon became a focal point for more than one participant who regularly returned to observe its progress. One participant even noticeably and regularly encouraged other residents to participate in the shared experience of enjoying and creating the work.

Encouraged by the freedom of personal choice, and by the colours they liked or preferred, the majority of artists in this project painted multiple, complementary colour combinations and those who could, articulated their reasons when making clear colour choices and design decisions. Such articulations clearly reveal an expression of the participants' "life-world" and they indicate the retention of preference and choice. McFadden, Frank and Dysert (2008, pp. 140-141) note that, "significant components of selfhood are retained through the course of dementia and can be readily observed through the lens of phenomenological psychology [and that such] identifications of the life-world can lead to a greater appreciation of the unique personhood of the individual living with dementia".

Not only did the participants of this project appreciate and comment on the scope of colour within the artwork, with the exception of one participant living with advanced Alzheimer's like dementia, the artists in this project also displayed an enthusiastic appreciation of the artwork and the design idea. In other expressions of life-world, most participants revealed genuine interest in the human elements that make up the artwork's story and they

took pleasure in the idea that the finished artwork was a communal work that would be on permanent display.

With the exception of the above mentioned participant living with advanced Alzheimer's like dementia, all participants in this project said they could see the black outlines of the design, and most could identify the hand drawn images on the artwork surface without prompting. The artists seemed relieved when they came to the art activity that they were not confronted by a blank piece of paper. Instead the pre-drawn lines and images appeared to instil comfort and appeared in some ways to relieve the pressure to create something original from memory. On numerous occasions, the facilitator observed the participants slowly scan the black lines in search of recognizable images. Then a palpable release of pressure was noticed, after which the participant relaxed, and was soon gliding the brush across the smooth canvas surface. Painting in and between the black lines, seemed to produce a flow and soothing effect in the majority of participants.

With the exception of one participant, none of the other participants in this research project had experienced particularly positive artistic outcomes as children nor had they had the opportunity as adults to experiment with paint and art materials. No one had contributed to a large-scale communal artwork before. Once boredom and any other inhibitions were overcome, the positive effects of the art activity became noticeable and even noteworthy. Irrespective of age or disability the participants in this study are variously seen and frequently laughing, smiling, joking and singing or telling stories during the art activity. Novel and varied conditions inherent in the art activity enabled individuals to relax and have fun and begin to enjoy the lived experience presented by the phenomenon. This circumstance presented participants with a rare opportunity to experiment with colour and the art materials and, confident in their surroundings, each began the initial steps toward the realization of his or her inherent creative potential.

With regard to inherent creative potential, the ability to create art and crafts would appear to come naturally to humans. The lived experience of the participants in this research project supports Dissanayake's theory (1988, 1995 & 2000) that painting and creative expression appears to be a primal heritage. The ability to "know" what to do when handed a paintbrush was an automatic response in all participants, except one participant living with advanced Alzheimer's like dementia. This observation demonstrates that painting appears to be an embedded and automatic skill that is accessible until quite late in the dementia progression. Therefore, with the right kind of assistance from a facilitator, individuals living with varying levels of impairment and even quite advanced dementia can, given the opportunity, successfully participate in art activities that involve painting.

The video footage of the lived experiences of the participants demonstrates that the art activity invariably activated and motivated each individual and, this in turn, was followed by enjoyment and the realization of a palpable sense of accomplishment. These lived experiences document and demonstrate that inclusion and participation in a structured art activity has the ability to significantly contribute towards a sense of shared ownership and achievement during the artwork's creation. But, a sense of individual and shared ownership, accomplishment and achievement is probably best conveyed in the words of the participants themselves: JB ends her activity by announcing, "I helped a little bit"; NA's interest is sparked when he surveys the artwork for the first time and after he gains more confidence in his supervisory role, he asks "Who has done the work?" During the course of the activity, NA asks, when will the artwork "be finished" and "where is it going to go when it's finished?" Later, he appears so impressed by the images before him, that he wants to include and share the enjoyment of the project with his wife, and he asks the facilitator whether she has seen it yet. Later NA returns to the activity at regular intervals to check on progress. Another participant, LG, comes out with the comment "They just look like scribbles to me!" but any indifference is belied by her clear expression of pride and sense of achievement.

The video footage demonstrates that engagement in an art activity appears to significantly contribute to circumstances where positive aspects of the lived experience of dementia, including increased wellbeing, could and can be both observed and measured with appropriate assessment tools.

The responses of individuals with dementia, in particular what they say when actively engaged in an art activity is informative. The participants provide useful indicators of their lived experience and their comments are sometimes quite remarkable. For example, DD told the facilitator, “can’t you see I am busy doing this at the moment” when the facilitator tried to interrupt the “flow” of her painting experience. PB remarked that “it’s easy to follow” and “that’s nice isn’t it”, when she first looked at the lines on the surface of the artwork, and then she paints along the seam with small brush strokes, adding, “I love blue, it’s beautiful”. Sharing her thoughts on the activity in general, PB confides that, “some people don’t like doing this but I love it”. When invited by the facilitator to continue PB says, “I’d like to do some more”. FB actively takes part in the activity even though he openly admits that, “painting is not really my thing”.

THE DISCUSSION

To the author’s knowledge this is the first project of its kind to identify the steps of a dementia-specific art activity. It is also the first time that Kitwood’s tenets have been applied to an art activity in this way to test his wellbeing theory. This project explores the lived experiences of participants with dementia whilst they are engaged in an art activity in an attempt to draw some conclusion and put forward some findings on the relationship between art and dementia and wellbeing.

Many, many millions of individuals worldwide will be affected by dementia over the next four decades. This unprecedented circumstance presents a critical and fundamental challenge to our age that continues to be effectively ignored. Whilst the scientific community concentrates on the race to find a cure those living with dementia and their care partners

struggle daily with the reality, and will no doubt continue to struggle for the foreseeable future.

Allen (1995) has written that, “too often art making is being co-opted as just another treatment modality with prescribed goals and outcomes... This sanitized soulless version of art must be administered to others, [and] interpreted by professionals” (Allen, 1995, p. xvi). This project details the life-story and lived experience of real human beings. The mere assessment of yet another possible treatment modality was and is not the objective of this research exercise, nor is it motivated by the need to gather even more clinical data on a randomly chosen research subject for a thesis report. Rather, this research project has captured moments in time in the lived experience of the participants, when life and art were celebrated by real human beings in need of the stimulus, which art has the unique capacity to provide. Not least, this project culminated in the creation of a permanent communal artwork on which participants left their mark and a lasting legacy. The project also provides clear evidence that participation in an art activity positively contributes to the wellbeing and lived experience of vulnerable individuals in care in ways previously little regarded or ignored.

This research project began with two theoretical questions. Did observations of the lived experience during the art activity show any indication that art significantly and measurably contributed, to the emotional wellbeing of the participant during the activity in question? This question has been addressed above. As for the relevance and importance of a critical partnership between the facilitator and the participant to the success of the activity, the study indicates that it must be established at the outset of any dementia-specific activity because it is related to wellbeing in the following way.

Critical partnerships

Perrin and May (2000) describe the relationship between facilitator and participant as a “critical partnership”. They believe it is this special

element, an ambience that creates “the seat of wellbeing”, that those living with dementia are most dependent on to maintain wellbeing whilst living in care. To address the relevance and importance of a critical partnership between the facilitator and participant, perhaps the most practical outcome to emerge from this research project is the reinforcement of the importance of creating a “safe psychological space” and holding “container”. Kitwood (1997) and others (Perrin & May, 2000) have long stressed the importance of the establishment of the holding “container” at the outset of any dementia-specific activity.

This project has shown that the establishment of a trusting partnership between the facilitator and participant is dependent on implementing the concept of the holding “container” and the creation of the “safe psychological space” immediately and on commencement of the activity. London (1989, p. 103) writes that trust is built “upon favourable outcomes of preceding events” and it is not simply enough to “create a pleasant working atmosphere”. He maintains that, “creating an atmosphere within which trust is engendered permits the scope of imagination to be extended, [and] increases our range of risk-taking”. This research project demonstrated that the facilitator has a pivotal role to play in the activity from the outset. The atmosphere the facilitator creates then determines the success of the art activity in terms of the length of time the participant remains engaged and interested. This project reinforces the idea that facilitator must be relaxed, empathetic and very observant, and ready to adapt and anticipate each participant’s unique needs. This project reinforces the idea that such conditions are most effectively established and implemented in a person-centred, one-on-one approach to dementia-specific art activities.

In this project, the facilitator followed the steps of the art activity detailed in MATRIX ONE - the art activity, and paid particular attention to the creation of the “safe psychological space” at the outset of the art activity. In particular, the facilitator meticulously progressed through the steps of

stage one of the art activity, with every participant, to establish the holding “container”. A practical indication that the process clearly satisfied the participant’s psychological needs can be seen in the case of two male participants, who, even though they chose not to paint, did not walk away from the activity after it was explained, but instead remained engaged throughout the activity. This indicates that both individuals felt secure with the facilitator to remain seated and interested in the activity, and both actively engaged with the facilitator to contribute to the activity in other ways i.e. by assisting the facilitator to choose colours and by spotting mistakes.

There is a reasonable conclusion that can be drawn from such occurrences. From the outset, if an art activity is introduced with subtly and tact, a facilitator can more easily establish a “safe psychological space”. And, if a facilitator is observant and carefully considers the skill and ability of the participant, and assists that individual if and when necessary, then, under such ideal conditions, the participant is presented with choices to live the experience to the full and to maintain a sense of wellbeing and identity.

Did the art activity, offer the possibility of both a novel and varied lived experience to the participant?

This research project has shown that just under 25% of the participants remained engaged for a rarely documented and somewhat unexpected length of time. This demonstrates that when a novel and varied opportunity to participate in an interesting activity is extended to individuals living with dementia, they have the capacity to participate fully and to the best of their ability. In addition, this project demonstrates that individuals living with dementia can often remain relaxed and engaged and involved in an interesting activity. It indicates that they mostly have the desire to make full use of the opportunity and when they remain engaged in the activity for the length of time that is determined by the participant through his or her choice, the activity and lived experience is productive and fulfilling.

It is acknowledged that most art activities in residential aged care consist of group art activities of between six to ten participants. Most art activities are conducted within set time limits and within a busy lifestyle activity program. Few art activities are one-on-one because many facilitators are unclear about the creative process or indeed know what creativity means in a dementia setting (Gottlieb-Tanaka & Graf 2011). Most activities are based on loose structures because facilitators have little involvement in, or knowledge of, how to design art activities or budget for them, and most have no time to learn.

The findings of this project can be primarily attributed to the discipline of the structural elements of the steps of the art activity and on the luxury of being able to implement the activity on a one-on-one basis with no time restrictions. This project has documented that the lived experience in the art activity, for some individuals with dementia can be up to forty-five minutes and, in some cases, well over an hour. Such length of engagement and participation can primarily be attributed to the structure and predictability of the activity and to person-centred one-on-one facilitation.

Structure and predictability

Structure and predictability are critically important in dementia-specific activities for a number of reasons. Levine Madori (2011) presenting a paper on the importance of facilitating innovative programs in dementia-specific care argued that, “structure gives us the ability to be exceptionally creative”. In her experience, participants “liked the structure of coming in to do things” and she maintains that, “structure creates the freedom to facilitate an activity to a professional standard”. Structure, she says, “provides the opportunity to apply and deliver an art activity uniformly and under the same conditions”. This research project has shown that structure can relieve performance pressure on the participant and the facilitator alike. This allows the facilitator and participant to regulate the speed and pace and duration of the activity together.

A regulated pace and tailored art activities

Regulating the pace of an art activity is important to both productivity and to achieve positive and fulfilling activity outcomes for each participant. Creativity uses brainpower and brainpower appears to deplete physical energy very quickly in those living with Alzheimer's like dementia. This project identified that such participants are quickly over taken with tiredness and express their concerns.

The facilitator has a critical role to play when regulating the pace of the activity and must be mindful to structure it in such a way as to allow short bursts of creativity, and then rest spells for those living with Alzheimer's like dementia, in particular. A series of small tailored art activities where separate pre-drawn design components take less than five minutes each to complete, and interspersed with rest breaks, might best serve the needs of participant's living with more advanced dementia. Klammer (2010, p. 26) has found that pre-drawn designs offer quick alternatives. She writes there is a "vast amount of choice within a pre-drawn project such as colour and its placement". She has observed that pre-drawn projects for individuals with more advanced dementia must not be over complicated or include complex patterns, as this can cause confusion and feelings of helplessness; instead, Klammer notes, simple designs "invite people to grow creatively within comfortable structures [and] do not limit originality or imagination".

Supporting theories on colour and dementia

One hundred and fifty years ago, Florence Nightingale (2009) imputed rapid healing power to bright-colours emanating from a bunch of flowers. Although she conceded that we know little "about the way in which we are affected by form, by colour, and light, we do know this, that they have an actual physical effect" not only on the mind but the body too. Nightingale was convinced that a "variety of form and [the] brilliancy of colour in the objects" presented to fever patients created a necessary diversion to aid them in a "means of recovery" (Nightingale, 2009, p. 58).

Although we still do not know exactly how form and colour and light affect us, this research project has at least borne out Scandinavian research (Wijk, 1999 and Wijk *et al.*, 2001) on colour and the colour preferences of those individuals living with dementia. This research project's observations on the use and appreciation of colour by individuals living with dementia reinforce Whalley's (2001) findings that colour acuity remains intact during dementia and almost invariably remains until the end, or very near the end, of life. Whalley's explanation is that the parts of the brain that process colour remain largely unaffected, particularly with Alzheimer's disease.

The important role that design and colour can play in the participant's comfort and appreciation of his and her lived experience in the environment is too often ignored or underestimated (Gottlieb-Tanaka, 2006). If the correlation between the role and the use of colour and design can be applied to the living environment it has the potential to have a profound impact on both the environmental correlates of facility design and decoration and the creative possibilities of future activity and program design.

This research project has delivered many valuable results detailed above, results that carry significant scientific weight, as well as and a deeper understanding of the potential use of colour, not only in art and other recreation activities, but also in the application of colour in the design and decoration of dementia-specific environments.

Countering past negative experiences with novel and varied lived experiences

Experienced facilitators have noted that it is not uncommon for some participants to be psychologically held back by past negative experiences, or life-long inhibitions that they "can't draw a straight line" (Allen, 1995; Hubalek, 1997; Kramer, 2002; Malchiodi, 2002; Stott & Males 2004). Many participants say things like "I don't know how to", or "I never learned because my grade four teacher told me I had no talent". This overhang is

what Allen (1995) refers to as the “art trauma from grade school”. Many untrained artists claim they have no experience in the creative arts, but when gently questioned one usually learns that they have all applied themselves in the past to the many practical and traditional creative crafts, including cooking or dressmaking or using tools or a lathe in the garden shed.

Countering past negative experiences is to address the question of providing a novel and varied experience. This research project demonstrates that positive encouragement and skillful intervention by the facilitator, lessens the common inhibitions mentioned above. Rogers (1954) refers to “the emergence in action of a novel relational product growing out of the uniqueness of the individual on one hand and the materials, events, or circumstances of his life on the other” (Rogers, 1954, p. 139). Rogers believes that creativity lies dormant within the individual and can be activated under the right conditions, a creative experience that can be described as novel. Mendez (2006, p. 5) concurs and adds “novelty functions” such as “the ability to think unconventionally, use divergent thinking in open-ended situations and be open to new experiences” is fundamental to creativity. If nothing more, this art activity opened the participants to new and novel experiences.

The participants’ lived experience demonstrated that the capacity to enjoy the creative arts appears to be limitless when conducted under safe psychological conditions. The project once again reinforces the notion of the “critical partnership”, and that the skill of the facilitator is critical in building confidence in participants at the outset of the activity.

Given the nature of dementia, particularly the inherent difficulty of sequencing the stages and steps in an activity as complex as painting, this project highlights most of the individuals in the study are able to achieve independently, with and/or without the assistance of the facilitator during such an activity. The steps detailed in MATRIX ONE - the art activity,

established a uniform structure and were successfully implemented with every participant after due consideration of each person's needs.

The research project revealed a fuller understanding of the concept and role of the facilitator in a dementia-specific art activity, and how the relationship between facilitator and participant contributes to the individual's lived experience of the art activity and to their wellbeing. It has provided a unique opportunity for the facilitator to gain scientifically valuable knowledge and experience regarding the use of pre-drawn images and how individuals living with dementia use and enjoy colour and share their experiences. More significantly, it demonstrates that a person-centred approach, combined with one-on-one activities, alleviates boredom and yields quantifiable wellbeing outcomes and contributes to a positive lived experience for the majority of residents and, not least for those living with more advanced dementia.

Patterson and Perlstein (2011, p. 28) write that, "arts and crafts projects, often called 'busy work', may serve to keep people occupied whereas artistic activities go further and engage the mind, body, and emotions sparking curiosity, problem solving and artistic accomplishment". A person-centred, one-on-one approach also affords each individual an opportunity to express appreciation and gratitude in a reciprocal relationship. McFadden, Frank and Dysert (2008) quote Martin Buber's reflections on 'the between', an important state and aspect of life-world, that appears when people "stand in a living reciprocal relationship to one other". The opportunity to foster a trusting and reciprocal relationship between the participant and the facilitator is presented during a one-on-one art activity. Trust and reciprocation strengthens the bedrock of wellbeing - that is the individual's sense of identity and self-worth and personhood.

The use of technology

This project reinforced the notion that the key to person-centred care is skilled observation. The use of technology, in particular the videotape, has

proved to be an invaluable observational tool. The videotape enabled the art activity facilitator to consider subtle occurrences and body language that normally go unnoticed, or are unable to be observed by the facilitator during the busy moments overseeing the activity and meeting the participant's needs. Videotape records provide valuable, and often subtle information about the participant; it can pinpoint techniques and interventions that may need to be implemented and developed for that individual. Videotape hones observational skills, it shows what to look for and how to implement changes for the better. It also shows what not to do.

Care partnerships

This project demonstrated that much can be learned from both the art activity participants and the comments on the activity by family members. Snowdon (2001, p. 53) writes, "family members and friends and caregivers are all deeply affected as they witness and attempt to cope with the relentless deterioration... [and] many families face it in painful isolation". The comments made by LF's life partner in the case notes, provide an insight into the lived experience and levels of grief and loss experienced by family members. They highlight the equally important consideration of being mindful of the emotional health and wellbeing of care partners. The impact that a care partner's attitude has on the wellbeing of an individual living with dementia in their care is often over looked and goes under researched. The importance of maintaining positive relationships between family members and staff members in the development and sustainability of effective care partnerships cannot be overstressed. Family participation in art is an ideal medium.

Additions to the knowledge pool through the medium of art

It has been shown that each individual uses a variety of lifelong skills in decision-making, but artistic skills and capabilities are too often ignored or underestimated. Patterson and Perlstein (2011, p. 28) write that through art participation individuals "develop a strong sense of control and self

confidence because of their deep involvement in the creative arts”. This research project documents how those living with dementia engage in and enjoy both active and passive art participation. The identification of innate skills and the myriad ways of knowing are documented throughout the case notes of this project. These may be used in the future to adapt or develop art activities, or for general use by art and other activity facilitators. Such skills deserve to be added to the knowledge pool.

Similarly, the methodological decisions prompted by this research project have provided new knowledge and techniques as they relate to the lived experience of participants measured by dementia-specific assessment and evaluation tools.

The author of this thesis, in the process of developing the appropriate methodological mix to meet the challenges raised by this thesis developed MATRIX ONE - the art activity, that will now be known as the *Gross McAdam Dementia-Specific Art Activity Process*, and MATRIX TWO - the eight Kitwood tenets, that will now be known in its applied format, as the *Gross McAdam Dementia-Specific Art Activity Wellbeing Assessment Tool*. MATRIX THREE - the CEAA tool, proved to be easy to implement and each matrix offers, an effective structure to document the wellbeing outcomes of residents as they participate in art activities. This information may be used for individual lifestyle care plan recommendations, or to assist facilities in meeting their accreditation requirements.

Lived experience and wellbeing assessments and evaluations

Existing evidence (Alzheimer’s Society, 2010) demonstrates that individuals living with dementia are able to express wellbeing in various ways, but accumulated evidence of this healthcare sector clearly suggests that appropriate programs and activities are just not taken seriously. Dismissal of activities is primarily justified with the claim that the scientific assessment of their outcomes is weak. In light of this reality, providing facilitators with

the means and the capacity to make more accurate wellbeing assessments and evaluations through the medium of art is a priority. The identification and documenting of the stages and steps of a dementia-specific art activity outlined in MATRIX ONE - the art activity, is therefore of particular importance as it has not been attempted before. And, the technique of identifying each and every stage and step of an activity may be adapted and applied to any dementia-specific activity. The creation of new programs areas and art activity and other program development, may begin in this way. If measuring the wellbeing content of the activity becomes more straightforward, accessible and accurate the possibility of validating programs and activities using such techniques will presumably, significantly advance the steady acceptance of the value of such activities in dementia-specific care and contribute immensely to the lived experience of those living and working there.

A small dementia-specific art activity resource

The following pages of this chapter consist of a small dementia-specific art activity and wellbeing stock resource that has been compiled and formulated during this research project. The resource contains recommendations, most notably practical techniques for use by recreation and art activity facilitators that are designed to improve the facilitation of art activities and possibly lead to increases in participant wellbeing outcomes. The techniques have been linked with Kitwood's positive person work tenets in order to demonstrate how they might be used to contribute to and create increased wellbeing opportunities for the participants.

The resource begins with a brief description of Kitwood's twelve "positive person work tenets" and is followed by the techniques that the facilitator might contribute to the activity. This is followed by a brief explanation of the possible wellbeing opportunities that might be created and experienced by the participant.

RECOGNITION (REC)

Positive person work tenet number 1

Recognition is made up of two parts. Firstly, recognition acknowledges that each person living with dementia is unique. Secondly, recognition acknowledges that each person is still a person worthy of respect irrespective of his or her level of cognitive impairment.

Facilitator contribution and technique

Address and acknowledge each person by name. Maintain direct eye contact. Listen carefully and mirror conversation. Use a gentle touch. Combine a slow and careful explanation of the activity with a visual and practical demonstration of creative aids and painting techniques. Offer choice and a risk free opportunity to make decisions.

Wellbeing opportunities

The freedom to make decisions when choosing and selecting colours, brushes, stencils and creative aids not only celebrates the uniqueness of each person, but can lead to a feeling of personal control and self-worth.

NEGOTIATION (NEG)

Positive person work tenet number 2

Negotiation and consultation with each individual on his or her preferences, desires and needs creates a degree of personal control.

Facilitator contribution and technique

Understand and appreciate anxieties and insecurities such as “I can’t draw a straight line”. Take into account that the person processes information more slowly. Combine a slow and careful explanation of the activity with a visual and practical demonstration of creative aids and painting techniques. Offer choice whilst creating opportunities for risk-free decision-making. Reinforce actions initiated by the person through positive affirmation.

Wellbeing opportunities

Negotiation and consultation with each person, combined with a careful explanation of the art activity and a demonstration of the aids, creates a safe environment and a sense of relief free of misunderstanding. Such negotiation and the resulting relief can lead to a sense of personal control over an activity and the environment.

COLLABORATION (COL)

Positive person work tenet number 3

The facilitator and the participant are “aligned in a shared task with a definite aim in view” (Kitwood, 1997, p. 90).

Facilitator contribution and technique

Invite the person to make choices. Support decision-making through positive affirmation of individual choice. Invite tactile exploration of the canvas and materials. Match and improvise painting and the creative aids to the person’s level of ability. Through discussion, try to include images that have personal meaning to the participant.

Wellbeing opportunities

Positive encouragement and reinforcement of each person’s initiative and ability to make decisions promotes choice and creates a feeling of safety and inclusion. Trust built up through partnership is established and reinforced, particularly when images, that have personal meaning, are created for the participant by the facilitator.

PLAY (PL)

Positive person work tenet number 4

The primary aim of the activity is participation, allowing the activity to be spontaneous and self-expressive.

Facilitator contribution and technique

Create a safe emotional and physical environment with the introduction, use and demonstration of safe art materials. Listen carefully and mirror response. Maintain direct eye contact. Encourage experimentation and creativity by improvising and matching techniques and materials to the person's ability. Source photographic references and participant-specific props. Encourage reminiscence and conversation through humour.

Wellbeing opportunities

The introduction of new creative outlets during participation in a one-on-one unrushed activity promotes spontaneity, self-expression and exploration. The freedom to exercise unrestrained choice when choosing colour combinations, and reproduce personal images, provides an additional opportunity for reminiscence and exploration leading to enjoyment and personal achievement.

TIMALATION (TIM)

Positive person work tenet number 5

Usually a form of sensory and/or sensual contact such as aromatherapy or massage but, in the context of an art activity, it can be used to describe sitting close to each other combined with discussion and explanation, including physical contact with the art materials and props (including stencils and photographs) to provide the participant with "reassurance and pleasure, whilst making few demands" (Kitwood, 1997, p. 90).

Facilitator contribution and technique

Discuss drawn images on the canvas and their sensory associations - the smell of eucalyptus leaves or pine trees, the sea, or flowers etc. Encourage tactile exploration of the canvas and experimentation with the paint and brushes, props and aids. Discuss the colours, the brush and the “flow” of the paint across the painting surface.

Wellbeing opportunities

The physical sensation of sitting next to the facilitator and sweeping a brush filled with colour across a smooth surface makes few demands. Imagination and this smooth sensation creates an opportunity to “go with the flow” of creative experience. This enables the participant to engage in creativity on different and deeper levels.

CELEBRATION (CEL)

Positive person work tenet number 6

Kitwood (1997, p. 90) describes celebration as an “expansive and convivial ambience experienced by those living with dementia when engaged in a form of interaction where fear and responsibilities disappear”.

Facilitator contribution and technique

Encourage the participant to express his or her opinion on the theme of the work at hand, the colours and shapes and what it feels like to make a contribution and be part of a permanent artwork that will live on after them.

Wellbeing opportunities

Inclusion in a communal artwork where dozens of contributions make up a whole and where there is no pressure to perform or create a masterpiece

expands personhood and self-worth. Participation allows each individual to take pride in his or her personal contribution and achievement, and to celebrate his or her inclusion in the completed work. It also creates a sense of place in a group, and acceptance as an equal by others within the group.

RELAXATION (REL)

Positive person work tenet number 7

Many living with dementia have “particularly strong social needs [and] are only able to relax when others are near them or in actual bodily contact”(Kitwood, 1997, p. 91).

Facilitator contribution and technique

Sit in close proximity to the participant. Speak in clear tones in a measured and low tone. Listen carefully and mirror response. Maintain direct eye contact. Relieve “performance anxiety” and pressure by creating and/or explaining drawn outlines. Slowly demonstrate props and aids. Share reflections and feelings of relaxation. Praise, encourage and reinforce participation.

Wellbeing opportunities

A one-on-one art activity in a safe and warm environment, with an attentive facilitator who explains the process slowly, sitting close by, can relieve pressure. Lack of pressure can create an opportunity for the participant to express creativity and fully engage. Whilst enjoying and sharing stories in another’s company, a feeling of inclusion, social acceptance and self-worth is more likely to be experienced by the participant.

VALIDATION (VAL)

Positive person work tenet number 8

Validation acknowledges the reality of each individual's emotions and feelings and promotes better understanding and acceptance of the individual.

Facilitator contribution and technique

Engage in personal conversation and encourage participation before the activity. Empathize with the individual and carefully mirror responses to display an understanding of his or her emotions and feelings. Accommodate each individual's level of ability through improvisation. Present familiar images, photographs and encourage reminiscence. After the activity, acknowledge both each unique contribution, and/or the personal effort expended by the participant in his or her attempts to achieve a goal.

Wellbeing opportunities

Art presents the participant with an opportunity to connect in the "here and now" reality of the colour, vibrancy and imagery associated with the activity, and feel self-worth and acceptance, initially from the facilitator and later from the group.

HOLDING (HLD)

Positive person work tenet number 9

With this tenet Kitwood draws on a substantial body of work developed by the psychoanalyst D.W. Winnicott. Winnicott (1971) was convinced of the importance of a "safe" emotional environment, and he coined the term "safe container" to describe his concept. Knill, Levine and Levine (2005, p. 50) describe the role the therapist/facilitator plays in creating this environment and where "the patient feels free to be himself without

constraints”. Kitwood (1997, p. 91) emphasizes that providing a holding “container” in a “safe psychological space” is important and must be carefully developed.

Facilitator contribution and technique

Create a safe, warm and friendly environment by simple explanations and demonstration of the art materials, and by reinforcing that there is no pressure to perform to a set artistic standard. Invite participation in the activity when the individual is at ease and comfortable; then praise, encourage, and value each individual by positively validating each contribution, no matter how small.

Wellbeing opportunities

An art activity in a safe, warm, friendly and un-pressured environment may also include images and props of personal significance to the participant to encourage a feeling of comfort and support. This atmosphere promotes participation and creative engagement. Positive reinforcement and emotional support in such an environment enhances personhood and celebrates the uniqueness of each individual.

FACILITATION (FAC)

Positive person work tenet number 10

Some individuals living with dementia have difficulty organizing their thoughts and activities in sequence. Facilitation fills in the missing gaps and enables the participant to “get started” in the art activity and/or complete each stage in sequence.

Facilitator contribution and technique

Slowly demonstrate each step and technique. Keep each participant on track by reinforcing the steps of the task and by the recharging brushes etc.

Encourage exploration of new materials. Offer choice by reassuring the participant that the facilitator is there to help. Improvise and demonstrate creative aids. Praise and value every participant's contribution, no matter how small.

Wellbeing opportunities

Reinforcement that the facilitator is there to help and encourage the participant, to “get started” on an exploration of new activities and art materials is reassuring. An additional reassurance that the participant will be assisted at each stage, so as not to forget the steps involved, builds an added sense of security and confidence. Such security creates an opportunity to “go with the flow” and engage in the activity and exploration on a different and deeper level. A feeling of confidence and self-worth created by inclusion and acceptance will likely be experienced by the participant.

Kitwood added the final two tenets, “creation” and “giving”, explaining that in most situations the participant is nearly always “at the receiving end” of care. These tenets allow the participant to take the leading role and express gratitude, whilst the facilitator is offered the role of empathetic respondent.

CREATION (CRT)

Positive person work tenet number 11

The participant brings a spontaneous offering of skill and ability to the activity.

Facilitator contribution and technique

The facilitator's role is to encourage spontaneity, creativity and originality within the art activity by assuring each individual that every contribution,

no matter how small, is valuable and worthy, and that every contribution creates a visual “life story” that will “live on” and be admired and appreciated by other participants and a wider audience.

Wellbeing opportunities

The promotion of a feeling of involvement, contribution, freedom of expression and creativity creates a sense of self-worth. Being a valued member and part of a community that has created an artwork that will be a lasting legacy, and a reminder of each person’s life and time and contribution, presents the person with an opportunity to fulfil the desire for what Lifton (1971) describes as “symbolic immortality”.

GIVING (GIV)

Positive person work tenet number 12

Giving is described as the expression of warmth and sincerity - combined with concern, affection and gratitude - demonstrated by the participant.

Facilitator contribution and technique

Acknowledge each individual’s contribution, no matter how small, and express appreciation and gratitude during and immediately after the art activity and acknowledge any response from the participant. On completion of everyone’s contribution to the finished work, reinforce the importance of each individual’s contribution by acknowledging each unique contribution.

Wellbeing opportunities

Each individual’s contribution of time, and the sharing of thoughts and ideas goes into creating “the story” of the work and gives life to a communal work. Acknowledgement of this contribution creates a feeling of self-worth,

personal achievement and pride in his or her contribution and that of others.

The author of this research project submits the practical recommendations above to the beginning of dementia-specific knowledge resource base to promote and advance the concept of wellbeing. It is a small contribution aimed at the betterment of the lived experience of all peoples living with dementia and their care partners.

Conclusion

This chapter began with an overview of the term wellbeing, as society perceives it. The chapter then defined how experts in the field, as well as peak body organizations, relate the concept of wellbeing to those living with dementia. The research study outcomes were documented and a distillation of the “universal essence” of the lived experiences of the research participants was presented. Finally, the chapter ended with a small stock resource of new knowledge in the form of a practical list of facilitation techniques and recommendations for use by recreation and art activity facilitators that have emerged from the research project.

This chapter documented the lived experiences of the art activity research participants and the next chapter will explore the lived experiences of the facilitator in the form of a small heuristic study of the phenomenon.

CHAPTER TEN

The heuristic study: A personal observation and exploration of the author's professional practice.

Introduction

The preceding chapter documented the lived experiences of the art activity research participants, and this chapter will begin to explore the lived experiences of the facilitator. It will take the form of a small heuristic study of the phenomenon. The author's lived experience will be documented through her personal observations and reactions to the creative engagement of her research participants during the art activity. The aim is to point the way for the possible expansion of new ideas and to improve the author's professional practice so that her practical work and experiences may be of use to others.

The purpose of an heuristic research activity is to discover "what is possible" and much depends on the "personal perspective of the interpreter" (McNiff, 1998, p. 53). McNiff (1998) writes, "the Greek word 'heuriskein' means to discover and find" and he makes the observation that heuristic research cooperates with empirical ways of knowing the artistic process and culminates in an "affirmation of the personal perspective" of the researcher. He believes that art-based research expands heuristic research and this is achieved by introducing "creative expression to the experimental process" (McNiff, 1998, p. 53). Schmidt (2006, p. 31) describes heuristic thinking, as problem solving "using cause and effect instead of relying on known and invaring formulae to reach a conclusion". McNiff (2007, p. 34) agrees and says that science and its reliance on invaring formulae, as it strives for replication, "tends to reduce experiences to core principles while art amplifies and expands" any thesis.

Some background

I have held an interest in dementia since my late mother-in-law developed early onset Alzheimer's disease in the mid-1970s. My mother-in-law lived in England where National Health Service institutions owed too much to a former and now thankfully bygone era. My memory of bewildered patients wandering scantily clad and barefoot on cold shiny linoleum, along green and cream corridors, and rows of narrow beds in curtained communal wards where the air was thick with the smell of stale urine and disinfectant, has stayed with me. The vagaries of what was thought to be best practice care at that time is still deeply troubling and equally unforgettable.

This experience with my mother-in-law was my second glimpse into this zone of confusion, as well as mystery and illusion, that is dementia. My first spellbinding entree into this world took place on one cold winter's day in 1956.

On that day, our family travels took us on what to a small child seemed to be an interminable distance, into the mountains to visit my maternal relatives. My sister and I sat in the back seat of the family's blue Studebaker progressively overcome by nausea as the car wound round and round the narrow bends of the steep slopes ascending Warburton. The sunlight flashes through the forest canopy reflecting the giant gum trees into patterns on the leather seats. My grandmother's cousins' garden was carved into the hillside and their house is perched at the top of a steep cliff.

I feel like Alice in Wonderland avoiding the cracks as I skip along the crazy-paving pathway as it zig-zags through the dense pattern of rhododendrons and camellias leaves. When I finally reach the top, to my utter surprise, we are greeted by some of the most unusual people I have ever met. There are three women who live together in the house and they are all, as my mother refers to them, "deaf and dumb".

Two of the women excitedly chatter using sign language as they exchange family news between themselves. The third woman is, however, the most interesting. Her name is Eva. She stares blankly out across the top of the blue gums in the valley as if listening for the sound of kookaburras in the still afternoon air. She fascinates me. Even though my own mother was born with a profound hearing impairment, this is my first window into the strange world of complete silence. Eva is then over eighty years old. It is the only time I meet her. As I sit opposite her I begin to notice a tremor that overtakes her fingers as they roll and tap over her thumb. As she attempts to sip her tea, the drops splash onto the arm of the chair and her embarrassed sisters quietly smile in my direction as they mop up the spills.

The experience is memorable; it is more than fifty years ago, but I remember sitting spellbound in the parlour that afternoon. I began to make what I now realize was my first focused observation of another human being. I was so quiet that my mother thought I must be sick, but later as we began our long descent down the mountain in the mist and fog, and I fire endless questions at her, my mother turned to me and says simply: "Parkinson's disease and senile dementia, it is very sad".

During the research project at Nixon Hostel one participant momentarily transported me back half a century. His name is Fred. Fred's hand shakes in a familiar way as he talks about Upper Beaconsfield and his love of native birds and the smell of wood fire smoke and eucalyptus as it lingers on the chill winter air. And, when Fred finally comes to the project, his conversation rings out like short staccato machine gun fire, as brush strokes driven by his tremor burst across the canvas. I hope that painting might be his escape and I am more than a little disappointed when he says the experience is not for him.

My own introduction to the creative wonders of colour began when I was old enough to pick up a pencil. Even as a small child I found it possible to at least glimpse the wonderment of colours, with each new layer presenting

me with a real sense of freedom to explore and immerse myself deeper in the experience. Since that time, art has been an escape and a fulfilment for me, and the joy of colour has become something central to my wellbeing.

Much has been written about creativity and how it allows a person to make a positive connection to the world. Art to me is something that is tangible and fulfilling, and my love affair with colour and art was sealed, all those years ago in 1960.

Janice Borham arrived at the start of Grade 4 with a brand new box of seventy-two Derwent coloured pencils. As if offering a sacrament, Janice slowly and proudly eased the pencil box from its exquisitely decorated cardboard slipcase that depicted the cool waters of the Derwent River and the beautiful Cumberland Lakes. The waters looked particularly inviting on that long hot summer afternoon in our classroom. I watched as Janice carefully opened the triptych sleeves of the box to reveal each pencil standing neatly in cardboard pocket rows, like choral singers in tight formation. It seemed that each pencil held a special position in the pencil box and each formed part of a magical rainbow hue. I often gazed with longing at the pencil box perched on top of our shared wooden desk and I imagined the masterpiece I would create by blending the subtle variations of Spectrum Blue and Cedar and Sap and Olive Green. Sometimes Janice let me read the back of the box. Tiny print recorded the name and number of each coloured pencil, No 19-66 Chocolate and No 19-20 Crimson Lake.

During the long Friday afternoons set aside for creative expression, Janice, occasionally let me use one or two of her pencils. I remember savoring the moment as I read each pencil's embossed name and number printed in fine gold lettering. Every afternoon I watched Janice count her pencils and lovingly run her fingers over them, as she inspected and replaced each colour, always gold lettering to the front in its correct number order. My dream was to own my own.

Derwent pencils came in boxes of 12s, 24s, 36s, and 72s in those days, but they could also be bought individually for a shilling each. My week's pocket money was only one shilling, and it took me more than a year to save twelve shillings to buy my first box of twelve. I bought my own escape into this magical world of colour, and my heart was lifted each time I pulled my pencils from the slipcase to embark on the next adventure. The distinctive smell of the pencil shavings, as I whittled and sharpened the points with my pocket knife, still lingers.

As a special treat, when I was sick or during long cold winter afternoons, my mother let me colour the illustrations in her childhood *Girl's Own* annuals. I would open her books on the tartan travel rug in front of the open fire and spend hours studying the detailed pen and ink drawings, deciding which one to colour in first.

Colouring and shading Arthur Rackman's hidden butterflies and delicate line drawings of fairies and flowers I experimented with dark and light shading and watched as each successive colour deepened the foliage. I soon learned perspective and the subtle craft of creating three-dimensional forms with shadows. Often my inner thoughts merged with the patterns and for a while I had the freedom to enter faraway places and dream of different worlds. I soon graduated to pen and ink drawings of my own on scraps of brown wrapping paper. That led to even bigger sheets of off-white butcher's paper my mother saved every week and ironed smooth for me so that I could draw on them.

I was born with dyslexia and didn't learn to read when I was a child. Bent over illustrations in books, and with sheets of paper spread out on the lounge room carpet, I taught myself how to draw instead. Dyslexia is a disability that affects the way an individual processes, learns and remembers information. As a result, I did not learn to read and write fluently until I was in my mid-twenties. Cathy Malchiodi (2002) eloquently describes the role drawing played in my early life when she writes:

As children we use line as a form of language to communicate events and experiences for which we do not yet know the words. We draw to express what we see and what we imagine. Drawing uses line as their basic element. Lines define shapes, create boundaries, lead the eye, express rhythm, and take us from one place to another... Although you can certainly express your feelings through lines, forms and colours, drawing's special mission as a form of self-expression is narration. It is a way to tell stories, to talk and communicate through visual means. If hand-drawn lines were the only symbols you could use to communicate with, you would still have an endless source of symbols to say whatever you wanted to (Malchiodi, 2002, p. 53).

Because memory, learning and reading have always been problematic for me, and in my mind memory and creativity are inextricably linked, the progressive loss of memory of those living with dementia has over the past decade become increasingly more interesting to observe and study. I am convinced that it was my early emphasis on drawing and art, because I could not remember symbols and learn to read, that has enabled me to develop a set of visual, observational and artistic skills that have helped to build a fulfilling professional career over the past forty plus years in the creative and visual arts.

In particular, the drawing and shading exercises taught me to observe and “see” rather than just look, and the colour exercises and experiments had the effect of slowly turning my emotionally painful dyslexic world into an emotionally gratifying one. Colour filled me with joy and the flow of drawn lines evolved into the creation of a means of communication. For me, dyslexia has ensured that I visualize my world, above all, in pictures. Dyslexia has given me the ability to observe and “see” creative design solutions, a skill that has been the key to any success I have had as a graphic designer and illustrator.

Livingstone (2002, p. 201) has a theory that artistic ability in dyslexics “may arise from the same differences that cause their reading problems”. She believes that “slightly diminished spatial processing, which could be a result of [the] Where system slowness, may contribute to artistic abilities by

making it easier to render a three-dimensional world into two dimensions”. This explanation makes perfect sense to me. When I was a small child, I was often confused by my surroundings and I learned to understand the simplicity of transferring drawn images onto a flat two-dimensional surface and to use it as a means of communication. And, it has occurred to me during the course of my research that the primary reason why I draw lines on the flat surface of the communal artworks is because it performs exactly the same function for those living with dementia. It is because they too experience slightly diminished spatial processing and become confused by their surroundings. Livingstone also thinks that, “artists who excel at conveying depth may have poor depth perception”. She believes “seeing the world as flat just might be easier” for these artists (Livingstone, 2002, p. 103).

Livingstone writes that the concept of the “line” is so “fundamental in art, [because] in nature there are no lines” and it draws a person’s surrounding together (Livingstone, 2002, p. 10). Lines that are processed slowly can be understood perfectly by those with dementia; lines help them interpret a world that is sometimes confusing. This might explain why working at a slow pace without pressure there is something immensely gratifying about working within the safety and predictability of lines on a flat surface. To me colouring the gap between the lines brings with it a real sense of achievement. To my mind this simple accomplishment is the wellspring that art contributes to wellbeing.

John Ruskin (1819-1900) believed the “two twin purposes of art are to make sense of pain and fathom the source of beauty”. He also wrote: “The really precious things [in life] are thought and sight, not pace” (Grayling, 2001, p. 39). Interestingly enough, the traits of thought and sight (including pace) have helped me develop visual awareness, as well as a unique set of practical skills that I have discovered are the keys to life-story interpretation and art program facilitation. Practicing art in its many expressive forms for nearly fifty years has enabled me to develop as a

facilitator, and it has also given me the confidence to use creativity and colour and art for the betterment of others. I have used sight extensively in observation as well as pace to modulate an activity in dementia-specific care during my career as an art activity facilitator. As a result, my art practice has developed into something more fulfilling to me than just a personal observation and interpretation, or even a means to create a “source of beauty” in the world. Not only has art enabled me to explore an interest in understanding the psychology of my own wellbeing, to “make sense” of my own emotional “pain”, a near universal desire, but my professional path has led me, with my eyes open, into the fascinating if sometimes painful world of dementia.

Making things and engagement is an art activity requires time and psychological space, and much of my time is spent beside participants who are grappling with differing levels of memory loss. The communal artworks I have been involved with are real, they do exist; they are tangible evidence that those living in care genuinely want an opportunity to participate in art, to relive boredom and idleness, and feel a connection with the world. Art brings with it an outlet and a means of expression that sparks enjoyment in life, and irrespective of impairment, the eagerness and the ability to participate in art would seem to be universal. Art fulfils a very special need within those living with dementia, even if only for that moment, but might well be recalled time and again.

On countless occasions, I have observed the thrill that creative expression brings and I have experienced the rich insight that art can give those who live with dementia in residential aged care. The participants can and do want to reflect on life and have their experiences and contributions to the world acknowledged, as a consequence and because of active participation the communal artworks speak to the unique story of a group of individuals in time and through those images the participants can find a voice that speaks for them.

Until now, a busy life facilitating numerous communal art projects has never afforded me either sufficient time or any real opportunity to take stock of my art practice, to reflect, or to evaluate and study at length the people I work with. But, that work, facilitating art in activities with individuals living with dementia, has made me very curious to test Maslow's theory that "the creative person, in the inspirational phase of the creative furor, loses his past and his future and lives only in the moment".

I embark down this path in the knowledge that some of my participants may appear to only "live in the moment" to begin with, and I am ever mindful of Edith Kramer's reminder that no one can predict with certainty, or quantify what another will experience whilst absorbed in the creative process. That said, to me it is nonetheless obvious that the concept of filling the often depressing and empty hours of boredom and isolation in an aged care facility with creativity and beauty is indisputably worthwhile, and that art has a unique capacity to engage individuals in many different and remarkable ways. Ruskin said "it is not what we get but what we become by our endeavours that makes them worthwhile" (Grayling, 2001, p.39). And, if I can make practical improvements to my practice from my observations and reflections then all parties will be well served.

The project

It is always difficult to start any new project. I have waited almost a decade before launching into this research project. It is, to say the least, a daunting endeavour.

A tremendous amount of preparation goes into any project of this size. I spent the first two years of my research time exploring Kitwood's theory and developing a dementia-specific holon to assess an art activity, whilst at the same time trying to analyse my working methods by simplifying the process into stages and steps to create a workable and replicable structure. Every morning during the two weeks preceding the start of a particular

project is spent looking at, and working through, the long list of things left to complete.

The design

Designing images for any communal project is exciting and often time is a challenge, but the most difficult design aspect for any graphic designer or art facilitator is to create an unmistakable focal point; the visual anchor of the painting or design. In mid-July 2010, my assistant and I prepared the canvas by sewing up the sides. I applied two coats of acrylic paint to ensure that the surface of the canvas was very smooth and would not drag on the brushes or absorb too much paint. Meanwhile, my mind worked overtime on the design, the challenge to do justice to the themes the residents' put forward in their earlier life-story interviews. During the rest of July 2010, I worked diligently to simplify the elements of the design concept to create the visual images that would appear initially in black outlines on the canvas surface.

My initial design idea saw the placement of two individuals lounging in deck chairs. This design was to represent the migrant experience and sea travel, (all of the participants who had migrated to Australia had come by sea) and the relaxation of retirement, but this image did not quite render enough focal or graphic impetus to the overall design. And, besides, it did not adequately capture the musical theme, stimulated by the conversations with the residents, or the idea of participation in communal singing or the songs, mentioned by the residents. I wanted to create a dynamic and central focal point to the design and so capture the essence of a live performance during the war years, a memory still very familiar and real to many of the Nixon Hostel participants.

The final image of a male and a female singer performing into a 1940s microphone evolved naturally during my research into graphic images of the period (see below). The larger than life cameo figures appear as though

looming through a ship's porthole. The figures were drawn from reference sources and deliberately pieced and joined together to create this visual effect with due consideration of the artwork's final placement on the wall in a busy corridor.

The artwork's function was intended to be much more than decorative. It was designed as an additional and useful reminiscence and singing prop for care staff. The finished artwork now hangs in such a way that, on approach down the corridor, the images provide even the most impaired individual with clues and cues to the artwork's unmistakable musical theme and, one hopes, this particular selection of images may well jog the memories of past songs and experiences, and joyous if clouded intimations of long forgotten moments.



This may be too ambitious but it is hoped that passersby will retain the

images long enough to perhaps link them together and so recall them as popular tunes, melodies and songs. Staff will be able to use the artwork and the images successfully in other ways, not least to encourage residents to take short walks from different parts of the facility, to engage in a word search to find his or her name imbedded in the work, and the illustrations of more than a dozen Broadway hits could be used by staff to lead into a sing-a-long.

The creative and unusual use of artworks was first demonstrated to me when I toured one of the Hearthstone Foundation's aged care facilities on New York's Upper West Side in 2007. I sat with the care manager, and discussed the residents' reaction to a reproduction of Wyeth's *Christina's World* (see Appendix G). This artwork is strategically placed at eye level on the wall of a busy corridor opposite a comfortable couch. The care manager told me that when people pass the artwork they often stop to sit and rest and that Christina's image almost invariably generates a conversation between residents.

Singing

Most of those living with dementia can join in and sing when led in a familiar song. Even when individuals cannot remember all the words to a song the chorus is almost always predictable and they swing around quickly at regular intervals. Whilst many residents' often cannot remember the words initially, "automatic memory pilot" almost always kicks in and more often than not the words somehow "magic up" over the three or four minutes that the tune lasts. Even more interesting, once in the forefront of a person's mind, some musical phrases can sometimes get "stuck on the brain". It is not uncommon for participants to unconsciously sing or hum or repeat musical phrases whilst deeply absorbed in the painting process.

The life-story interviews reveal most residents living at Nixon Hostel enjoy dancing and singing. Community singing was an important morale booster

during the Second World War years (1939-1945). In Melbourne community singing continued as a regular and popular favourite at Brunswick Town Hall, where Dick Cranbourne's sing-a-longs lasted well into the late 1950s and early 1960s. It is probably true to say that *Morning Melodies* and the recent resurgence of local choirs, are a continuation of a forgotten legacy of community participation through singing dating from that time. Even those who have lost the ability to speak may sometimes sing. I have witnessed this phenomenon on many occasions whilst observing skilled music therapists at work, in particular Sally Banks at Broughton Hall in 2003. This experience strengthens Ellen Dissanayake's (1998) theory and belief that music and art constitute a primal heritage in humans. These experiences have taught me to never underestimate what an individual *might* be capable of.

Writing a journal of the project

The decision to write notes at the end of each day of the art activity in a project journal was made because it is a very hard task to separate individual experiences and to try and recall who did what, and when and how they did it. It was basically to record my impressions and thoughts to follow up and to reflect on later.

I suppose it is with a mixture of excitement and trepidation that I entered Nixon Hostel on 6th August 2010 to commence the project. Although I begin the project in early 2010 it is delayed by many months because of my unexpected breast cancer diagnosis in February 2010. The treatment is exhausting and effectively dominated my life from February to August 2010.

Staff members at Nixon Hostel were very supportive during this period, but my major concern centred on whether or not I would have enough stamina and energy to complete the project on time. Bringing art to individuals living with dementia is a very life affirming experience, and my past community involvement has always given me a positive and rejuvenating boost of energy. The project planning stages kept me going through the long

hard months of cancer treatment and secretly I hoped the project would continue to play a major role in my recovery.

The project begins

I decided to commence the project with a person who worked with me on the *Memories* artwork commissioned by Alzheimer's Australia Victoria for World Alzheimer's Day in 2007. To re-assure myself, on arrival I proceeded straight to her room only to find her unwell and unable to work with me. This sends me a bit "wobbly" for a few minutes, but I soon regrouped and quickly had the activity set up on a table in an alcove off one of the communal lounge rooms behind the activity manager's office.

I sat for a few minutes pondering the selection of my first participant and try to settle my first day nerves. I decided to "bite the bullet" by choosing another resident who helped create the *Memories* artwork three years before, hoping she will be a fairly predictable starting artist, someone I can reasonably expect to be a "well-known quantity". The initial stage and the first steps of the art activity are carefully implemented and soon she is happily immersed in the process, and even though the activity is quickly over it runs like clockwork.

After about ten minutes, outside in the courtyard, two workmen begin putting up the summer shade cloth and soon the noise of drilling and hammering gathers in volume. At times the noise and interruption almost sends me crazy and those residents idly sitting doing nothing in the lounge room seem to be physically distracted and greatly affected by the noise. Interestingly, the next participant heralds the first real surprise of the project. Once seated and engaged in the process, she sits working, completely absorbed on a very deep level in the painting for more than forty-five minutes under conditions that arguable must be described as extreme and difficult. Not only does she appear to block out the noise completely, but she starts to sing songs and engages in conversation on a

wide range of topics. This experience indicates that some individuals can work for up to forty-five minutes with minimal assistance from the facilitator even under extreme conditions. When engaged in art activity some individuals can concentrate, and seemingly move into different levels of consciousness, all the while painting and singing or holding a conversation in an effortless and natural manner.

It is always gratifying when an unknown resident's contribution is astonishingly long and productive, and all the more so for being unexpected. This is also the case again with the first participant on day two. Another participant works for more than forty-five minutes and her contribution gives the project much needed momentum. Communal artworks invariably develop a life of their own under such conditions and they soon begin to evolve; but this project ushers in a new, interesting and unprecedented trend when, on the third day, the contribution of another participant lasts for almost an hour. This sort of commitment in time and concentration is most unusual particularly for someone living with dementia.

Dementia-specific accounts of extended periods of engagement such as this have occasionally been documented since the 1980s (Wald 1983), but they usually go unrecorded and unpublished. It follows, if an art activity is successfully introduced by the facilitator, and if that activity is engaging, then it is possible that some individuals may remain focused for extended periods, even though extraneous noise and distractions might normally be expected to intrude and impede the activity.

Although I have never seriously considered it before, watching the participants sweep their brush over the artwork's surface it occurred to me that perhaps the paint combined with the smoothness of the surface of the canvas might also be an important factor in the successful longevity of some participant's contribution to the activity. Once again, Malchiodi (2002) gives a plausible and reasonable explanation when she writes:

Like drawing, painting can communicate a story, but its true mission is to tap and express feelings. Paint is sensuous, fluid and sometimes difficult to control. Each time you pick up a brush to paint, there is the potential to express something gentle or bold or spectacular. Paint has a unique personality: it can be stimulating because of the colour and brushstrokes, and at the same time hypnotic and almost sedating because of its fluidity (Malchiodi, 2002, p. 59)

Malchiodi states that because paint it is “so fluid and uncontrollable” it helps her to “surrender the need for control”. She says the fluid texture of paint has taught her to “literally ‘go with the flow’”. It appears to have the same all consuming effect on some of my participants.

By day two, the project is up and running and all of my first day jitters have subsided. The topic of conversation between residents in the lounge room touches on profound life issues. A news item on television sparks off a discussion on the ethics of living a good, decent and moral life. Consensus is soon reached and it becomes clear that overall the residents think being brought up properly and behaving properly and obeying the law are issues that are fundamental to living life in harmony with one another.

The idea that people with dementia lose the ability to recognize moral sensibility raises serious ethical questions. This conversation is evidence that quite profoundly affected individuals still “know” the difference between right and wrong or when something does not ring true or seems unfair. What is also made clear from the conversation is that individuals living with dementia can usually detect insincerity.

The way the first participant of the day is chosen is never hard and fast; in fact, most are chosen by working down a list of residents or by chance, by serendipity. The starting days of any new art project always seem to proceed very slowly and one is tempted to jump in and help the painting along, but the project must be let to evolve on its own, on its own terms. This is when unexpected surprises occur and insight is gained. Any facilitator’s hope is that every single person will participate but of course this is not always the case. On some days, seizing the moment becomes all-

important and one cannot afford to let disappointment set the tone for the day when a participant declines the opportunity to participate.

Putting together an art activity can be physically exhausting for the facilitator, and some participants require a lot of assistance. Even participants who appear to require little assistance can still consume a great deal of the facilitator's energy. Very vocal participants can be particularly taxing, tiredness overtakes them in mid sentence, talking and painting can stop abruptly, and exhaustion suddenly becomes obvious. The activity can usually be re-ignited after a short rest interval and knowing when to step in to assist, and when not to step in, is a learned skill and can only be gained by experience. To know when to intervene and finally end an activity is also a skill; some participants, regardless of fatigue, appear unable to self-regulate the impulse to push on with the activity and their motivation remains unclear. Most individuals want to achieve goals, we are conditioned to please and most of us thrive on accomplishment. Irrespective of dementia, most individuals want to experience a feeling of completion and are generally pleased when thanked at the conclusion of our contribution. In this way art creates a further opportunity to engender wellbeing.

Each person deserves to be given the same commitment with an equal access to the skills and energy that a facilitator can bring to the project. Each person is an individual and each requires a uniquely individual contribution with special attention being paid to the value of that person, and the importance of validating his or her experience. Particular attention to detail is required to follow the various stages and steps at the commencement of an art activity and then maintaining the conditions that are conducive to a positive outcome. Whether filling paint pots or recharging brushes, or anticipating when to step in or make suggestions, or recommend the cessation of the activity, the facilitator owes a duty of care responsibility to the individual to monitor the situation accurately.

Midway through the project, the Aged Care Standards and Accreditation

Agency (ACSA) visit the facility for a spot accreditation and this provides an opportunity to explain the mechanics of the research project in detail to the accreditors. The rest of the day is spent lunching with a resident and going over preparations for the next day. This gives me a much-needed break and the participants something different to watch.

The calmness of the residents at Nixon Hostel during the week is the facility's most noticeable quality, and the atmospherics engendered by "wrong" agency staff employed on the weekend are obvious. A well-established equilibrium is disrupted and this creates a ripple effect, understandable when residents, who are usually calm and relaxed, react to a new regime and new people. Two participants come to the activity under these conditions and are soon pacified. One participant however is so relaxed he takes a catnap when I am picking out an assortment of new colours to show him.

This is a tangible example of the ability of art to divert and reassure. With any diversion, reassurance that values the integrity of an individual is pivotal to a person-centred approach. It helps reinforce the value of even a passive engagement in any activity and it also demonstrates how significant passive participation can be and should not be underestimated.

Each individual has a very different attitude toward the art activity. What each individual is able to achieve is dependent on his or her self-perception and level of impairment. Linking sections of any artwork with footy team colours for example almost always guarantees participation and engagement. Planning an activity so that it doesn't clash with luncheon preparations also maximizes participation.

After the first two or three weeks the project has a momentum of its own, it attracts the attention of more and more participants. The images begin to look more finished, with the addition of splashes of red and purple paint that lift the work. The bright colours and images draw an increasing number

of admirers. It's a pity Nixon Hostel is divided into three different and separate wings, as C Wing residents now display proud ownership of the artwork and it is becoming a focal talking point.

Every morning many residents indicate their appreciation of my presence with wide smiles and greetings. Even though residents on C Wing live with quite advanced dementia, they demonstrate the ability to engage wholeheartedly in the painting and appear to recognize something positive and affirming in the activity. Alas, demonstrations of Kitwood's "giving" tenet are rarely documented in care-plan files or case notes and are almost never noticed.

It becomes clear that it is important to keep the artwork on open display. The concept of "giving" is manifested in quite touching and reciprocal relationships between individual residents. It may be that the "giving" tenet or sentiment is not always demonstrated at the time of the activity, and may occur naturally when a participant returns to the status of an observer, or is drawn back by the colours. The artwork on open display promotes feelings of inclusion in the activity (TMc), sharing in the process by doing (JO) and helping out and offering to clean up and being useful in assisting to pack things away (GW).

The unfinished artwork's first public display

At the resident's meeting, the nearly completed artwork is paraded before the residents and their family members. The project is greeted with audible gasps of surprise. Some family members express shock and astonishment at the result. As usual, those who held reservations at the beginning of each project, including staff members, ask the usual (unanswerable) questions about the process. They ask, "how is it possible to engage everyone in the process?" Working through the stages and steps in the art activity with thousands of participants over the last ten years, the intangible parts of the

process still hold their mystery and remain something of an enigma. There is an unknown factor in this kind of activity that cannot be quantified because every experience is unique and as varied and idiosyncratic as each individual participant.

The project draws to its conclusion

The end of the project draws near. Time is spent tidying up and “editing” the artwork by going over and strengthening the black lines, and applying the finishing touches and highlights to the faces. Each day sees the project coming to a natural conclusion, and pressures dissipate and fade. There is a growing air of expectation among the participants as they wait to see and admire their finished handiwork. It is good to work to a target that is paced, not too rushed, but not too slow. And, it is very gratifying when the last brush strokes are complete and everyone’s name is recorded on the work, a step that is universally acknowledged as a tangible sign of recognition and permanence. (Shaw & Wilkinson, 1996).

After the project is completed, reviewing the films of the art activity is a revelation. Not only are they absorbing, not least observing the subtle non-verbal responses that are often missed during the activity itself, but it is also the first time in my career that I have viewed myself in action and facilitating. The camera is set up in a corner and is partly obscured by the “Rubbermaid” art cart and it captures everything. Most of the time I am unaware of its presence and the participants are not at all bothered by it. When working with one more able-bodied participant, it is myself not the participant with dementia, who displays signs of restlessness. I fidget with the brushes and paint pots whilst the participant works on regardless. During another particularly long engagement, the participant politely tells me to stop interrupting her, as she is busy trying to concentrate on the job at hand and I am a distraction. The uploading of the video footage is a very “steep learning curve”, and I am repeatedly up half the night trying to master this skill.

The heuristic study final observations

For some years my practice has been to draw the image outlines on the canvas in thin black biro. Frequently I have observed participants can become annoyed with themselves for “going over the lines”. I understand that this disrupts the “flow” and I began to realize that this is probably linked to a preoccupation with staying between neat and clean lines in “art” learned during technical drawing classes, or penmanship exercises and imbedded during their formal schooling. Allen (1995, p. 23) writes when she was at school “colouring outside the lines was considered a mistake and meant forfeiting the chance to draw”, and she writes she has observed that her clients find, “sometimes having a structure to fill can be soothing [because] knowing where the boundaries are is reassuring”. After assisting clients during art activities, Klammer (2010) coined the term “spontaneity within structure” to describe drawn images on canvas. She found the outlines gave her clients the confidence to complete the activity. The task of testing and evaluating the suitability and use of thicker black line outlines to reassure participants, when creating images for transfer onto the artwork’s surface, is set out below in the simple what, why and observation criteria.

During the art activity I asked each participant, at the beginning of the activity, if he or she could see the black lines, and in due course, noted the individual reactions of participants who “went over the lines”.

The what: Thicker black lines to enhance the image so that participants can see the images better.

The why: To eliminate performance anxiety and assist a more “risk free” participation.

The observation: The thicker lines proved to be much more successful than the thin black biro lines used in the past. The majority of participants (thirty-three) were able to see the black lines clearly at the start of the art activity, and overall the thicker lines proved to be wide enough so that the

participants were able to stay between the lines. “Going over the lines” was still an issue for those who did go over the lines, but overwhelmingly there was little anxiety because going over the lines was not common and when it did occur a damp mop-up cloth quickly alleviated any concerns.

The outcome: Livingstone’s (2002) simple explanation of spatial processing in the preamble to this study, along with Klammer’s (2010) observations, and this exercise, have helped me to better understand the value of using drawn lines on an artwork surface. All of these factors have further convinced me of the particular worth of this sort of structure within an art activity when working with individuals with slightly diminished spatial processing. Thick black lines have always worked well for me and this exercise has demonstrated that they work well for those living with dementia.

Colour and its value in dementia-specific care

The what: Colour sense and colour memory, and an appreciation of colour and design, remain constant throughout the dementia progression (Whalley, 2001) and the ability to creatively use colour is inherent in all humans irrespective of age or, remarkably cognitive impairment such as seen with dementia (Dissanayake, 1998).

The why: In the past, knowledge of colour and its use in art was central to human survival (Dissanayake, 1998). The enjoyment of art and the manufacture of crafts evolved to counter the harshness of subsistence labor (Grayling, 2001).

The observation: The capacity to enjoy and appreciate colour seems limitless in those living with dementia as observed in this research. Each participant was extended a wide choice in the colour decision-making process and almost every individual exercised that choice. Videotape captures participants carefully studying the colour choices surrounding his or her designated painting area before making a decision. On other occasions, participants are recorded seeking advice and reassurance from the facilitator on his and her ultimate colour choices. As the project neared

its conclusion, the artwork attracted a constant stream of onlookers drawn primarily to its colour mix.

The outcome: The desire to flourish creatively, as a means of escape and to alleviate boredom has been demonstrated countless times during this project. The extent to which individuals living with dementia retain colour sense and a colour memory, is under appreciated and under utilized. The use of colour in future creative dementia-specific program design is an area that deserves greater attention and imaginative thought.

Organizational structures

Three participants in the first three days made contributions that exceeded forty-five minutes. All three lived with dementia and two of them indicated later that they had no recollection of their contribution to the artwork. This occurrence poses the question of why participation of this kind, given its potentially profound insight, is not being documented in Australia or elsewhere. Perhaps it is due to the vexed but ever present question of time allocation and organizational structures. Perhaps our apparent lack of curiosity about the key questions is determined by such mundane considerations as staff shortages and the low status of the aged care sector.

It is reasonable to argue that being in a position to limit the number of participants to as few as two per day is a luxury only an independent facilitator or researcher could fulfil or justify. Unlimited time spent on one activity, considering the cost of allocating staff to that activity, would probably be seen as an extravagant waste of money in the busy day to day running of a facility with limited resources. An independent facilitator or researcher, on the other hand, has the freedom to organize his or her time and is usually not bound by bureaucratic structures and time limitations.

Perhaps the most common complaint I hear, when presenting and teaching, is on the lines: "I just haven't the time to spend working with individual residents on a one-on-one activity". Australian aged care funding and

accreditation is not structured to encourage one-on-one participation in most activities. Given the numbers who live in care and the staff to resident ratios there is a pressing need for the aged care sector to take time to think laterally in order to address creative challenges. It can only be hoped that in the future individual freelance facilitators will be independently funded to fill this glaring gap in service provision.

It is not always a question of either/or. By the time an activity facilitator brings eight people to the table for an activity he or she could have worked with four of them individually in the same time. If a project moves from person to person around a facility it still fulfils the legislative requirements to provide meaningful activity and one-on-one interaction and it also meets care planning requirements and assessment criteria.

The facilitator must be both the key and the solution to any challenge. His and her skill base is wholly dependent on experience and outlook and personal motivation, and the curiosity to explore and improve. The success of this art activity is most likely due to one or more of the following factors:

- An independent facilitator is not rushed and can work through a long list of activities and participants.
- The participants pick up on the fact that the facilitator is not rushed and therefore can relax into the activity and do not feel pressured to finish.
- The participants like structure in their activities and are more confident to paint within the black outlines.
- The participants are familiar seeing the facilitator at work and relax in response.

Grief and loss is always present in an aged care facility and it is not always addressed given the time limitations that restrict care staff. The importance of the physical closeness of the participant to the facilitator should not be underestimated; something Kitwood was very well aware of and stressed in

his development of the “timalation” concept. Closeness creates a sense of comfort and support, and trust and security and it also re-affirms the equality of the relationship between the participant and the facilitator. On most occasions closeness gives the activity the particular edge that is important when working with individuals living with dementia; it also allows the participant the time to ease into the activity without feeling rushed or pressured to perform. As Reed (2005, p. 3) observed, “more creative works [are] accomplished by participants who [are] given an unspecified measure of time” and it is an observation borne out by this art activity research.

Learning to work with those living with dementia, to develop trust and the sense of emotional security in a “safe psychological space”, is a valuable life skill. As Kitwood astutely observed, time allows an opportunity to share stories and experiences and the art activity provides a rare opportunity for male participants in particular, who can sometimes be reserved and guarded, to share their emotions. Even though it may not be articulated or externalised by the participant at the time, and the facilitator may not even know it, ultimately, if the participant is the focus of person-centred care the integrity of that position and that individual will not be taken for granted. In my experience the ability to become an intuitively sensitive art facilitator has to be learned and practiced. There is no other way.

Unfortunately, there is still a common misconception that individuals living with dementia will respond to an art activity in a negative way; that is, as the saying goes, they will “eat the paint”. The reality is often, as elusive as the concepts of wellbeing or creativity or “going with the flow”, it varies from day to day and from individual to individual. The personality at the emotional core of the individual invariably determines the way the person approaches the activity, and how that individual relates to his or her participation and responds to the facilitator. For example, participant KW, a former ballroom dancing instructor, says “you are such a dear and I love you” when he hears that he is to reproduce something from his past life as he paints the dancer’s feet.

KW, and IT both come to the activity without hesitation and stay and join in with enthusiasm. LG is happy to paint, take a breath and then rejoin the activity. This kind of participation reinforces the notion that unrushed one-on-one activities, in which there is no actual or subliminal performance expectation or time limit, works best. This project demonstrates that quite remarkable experiences can be documented within a “safe psychological space” and the right ambience, and given that adequate time is allocated to the activity.

Conclusion

Early in the course of this project I soon became aware of the remarkable similarities between my childhood quest to understand the world through colour and art and creativity and the obvious engagement and immersion and absorption in colour and the creative experience of the art activity participants.

Although my professional practice over the past decade has shown me that the capabilities of those living with dementia should never be underestimated, I was nonetheless still genuinely surprised to observe participants living in the and “present” in the “real” world, and fully committed to an intense and single-minded engagement in an art activity. Most would agree that activities that increase wellbeing, and assist those living with dementia to come to terms with aspects of a bewildering inner and outer world, are beneficial. This research project demonstrates that when individuals living with differing levels of dementia fully embrace and participate in structured art activities their positive responses are palpable and their engagement with life demonstrable.

The question I frequently ask myself is an obvious one: Why would the creation of communal works of art that have given purpose and meaning to my own life fail to lend meaning and a creative outlet to individuals with

supposedly less connection to the world? My experience provides the answer: They are no less capable of benefiting from and enjoying the unique elixir that art can supremely inspire.

SUMMARY OF THE THREE CHAPTERS OF PART THREE

Few if any researchers conducting art research itemize or fully explain the facilitation process, and no one has explored dementia-specific neuropsychology and art creation beyond a few basic steps. As a result, PART THREE detailed not only the theoretical framework underpinning this research, but the chapters also explained why it was necessary to create an original dementia-specific “holon” in the quest to design and develop a dementia-specific research methodology to best reach the research objectives and outcomes.

To understand the mechanics of a dementia-specific art activity as a whole, a matrix detailing the four stages and the thirty-nine steps that make up an art activity was constructed. Wellbeing is elusive, but Kitwood (1997) identified seventeen elements that he believed are essential to wellbeing in a person-centred approach to dementia care and these were applied to each of the four stages and thirty-nine steps of the art activity. This created a workable and informative dementia-specific holon that separated and identified eight tenets for special investigation. Finally, another tool, the CEAA research tool, designed to quantitatively assess six wellbeing domains completed the data collection methodology.

Most would agree that activities that increase wellbeing, and assist those living with dementia to come to terms with aspects of a bewildering inner and outer world, are beneficial, but the author has proffered some observations on one-on-one activities, and the pivotal and important role the facilitator has to play in the success of any art activity.

The research has revealed a new understanding of the world of colour and art and creativity experienced by the participants and why it is almost always coupled with an obvious engagement and immersion and absorption in the creative experience. These chapters demonstrate that when individuals living with differing levels of dementia fully embrace and participate in structured art activities their positive responses are palpable

and their engagement with life demonstrable. This reinforces many of the findings of experts in the field and is arguably very relevant to the wider application of art in aged care.

PART FOUR

CHAPTER ELEVEN

The Research Project Conclusion

Luis Fornazzri (2011), addressing delegates at the 6th International Conference on Health, Aging and the Creative Arts, made the following observation: “the artist’s studio, regardless of its location, is a natural laboratory for the investigation of neuroscience and neurology and creativity”. Allen (2006) believes that those who create the artist’s studio have the potential to contribute much to social action and social justice and the lived experience of those for whom they advocate. Allen outlines the responsible role that an art facilitator plays in community arts projects and writes that those who facilitate community arts projects must have a commitment to those who come to the studio. Allen believes that often those who come to the studio “need to be held and seen, to be affirmed and welcomed by the studio and the art-making process”. Allen believes that the facilitator’s primary role is “to listen to herself to notice what calls for her witness”... and whilst her contribution might be “to the community soul”, or to activate “new pathways”, or “take account of all stakeholders”, by listening to the “silence between sentences”, typically her role is to “offer art as a respite, a momentary pause in an awful reality” (Allen, 2006, p. 81).

Few would disagree with the notion that the progressive loss of one’s memory represents a loss of selfhood and personhood for those who experience it, and the reality and stigma that surrounds dementia is one of life’s awful realities. Allen entreats us to “chart the grief-filled places” and affirms that it’s not good enough to stand back and “refrain from working in the world because it is too big for us to finish” (Allen, 2006, pp, 86-87).

A voyage of discovery

For me this voyage of discovery was fascinating and immensely confronting. Personal challenges, not least major thoracic surgery and then surgery and

treatment for cancer, and many professional obstacles had to be faced and overcome. The challenge of charting and mapping the often-unfathomable depths and un-navigated waters that contribute to the nature of the relationship between dementia and art and wellbeing was daunting. That said, it has given me a deeper appreciation of my place and role as a facilitator in the lived experience of the individuals I encounter. And, it has reinforced my belief that art, like no other medium, has a unique contribution to make to aged care. Realistically, the scope of this research project is the work of two lifetimes. It is just too big for one person to finish and, if one is true to the phenomenological approach to enquiry, the process is never really finished.

The project limitations and significance

Although many hands created the “*Getting to Know You*” communal artwork, the twelve research participants ensured that the study was very small but personally very significant. My dyslexia when combined with my formal art school training, has taught me to observe slowly and ‘see’ detail and difference. The phenomenological approach reinforces, and is consistent with, the personal observations I have made over the past decade whilst facilitating the MAC.ART program. This research project has also led me to a deeper understanding of *my* lived experience, shared with more than three thousand participants over my career in aged care. This experience has been enriched by this research and is consequently rendered more significant and meaningful than I could have imagined prior to embarking on this doctoral study.

An extension of Kitwood’s theories

Although the research participants in this project were few, nonetheless the scope of the research has ensured that Kitwood’s wellbeing and positive person work theory has been extended and new information has been documented about the lived experience of those with dementia. In

particular, how individuals at the end of their lives participate in creative expression whilst living in residential aged care is personally significant. This research project must therefore be seen for what it is; it is the end of one person's personal beginning. It is hoped that the outcomes will be of use to art facilitators and will encourage them with renewed confidence in different approaches and ways of thinking about the facilitation of art activity programs.

Current research

Much needs to be done in the future to promote art as an activity among managers and facilitators working in dementia-specific care, and to educate the wider public of its value. This is particularly so, given the outcomes of the most current research conducted in British Columbia, Canada.

Gottlieb-Tanaka and Graf (2011) paint a bleak picture of the confused and apparently directionless state of research into the creative arts in dementia-specific care, in particular the lack of acceptance of art as an activity in the aged care industry. The meta-analysis review of the literature (Gottlieb-Tanaka and Graf, 2011) on creative expressive programs for people living with dementia, combined with a survey of creative activity programming in some of the leading aged care facilities in the English-speaking world (Graf & Gottlieb-Tanaka, 2011) has revealed a state of affairs that reinforces the call for the urgent consideration of new thinking in dementia care, a call consistent with the findings of this research.

In the first of the studies noted above, Gottlieb-Tanaka and Graf's (2011) set out to identify and analyze peer reviewed journal articles that claim to improve the quality of life and wellbeing of those living with dementia. There is a general expectation that the individual psychosocial needs of aged care residents may be met, and quality of life increased, through creative expressive arts programming. The review began by identifying three hundred and seventy-six peer reviewed articles on creative expression

programs delivered in aged care facilities. For the final selection, the content of each article had to report original research of the efficacy of different types of creative expression programs in dementia-specific care. Only ninety-seven articles survived this selection and of these only fourteen were exclusively concerned with art activities.

On deeper investigation, Gottlieb-Tanaka and Graf found that few of the ninety-seven articles established or referred to the researcher's primary philosophical approach to care, as a result many did not fully grasp the meaning and purpose of creative expressive activities, and not surprisingly most did not fully describe the program or activities under investigation in any detail. A large number failed to report the frequency of the activities or specify the size of group or the level of dementia of the participants. Although it was claimed that the people who wrote the journal articles had 'certified' qualifications, the journal articles themselves rarely addressed the question of the qualifications and skills of the activity facilitators conducting the study. What became apparent across the literature was that trained volunteers are much in demand and that most art activities would not exist in facilities without them. It also appears that less than half the writers demonstrated an understanding of what creativity means in terms of a dementia-specific, creative expression activity and the rest seemed to be unclear about the creative process in general. Most studies included both men and women and the facilitators commonly used a mixture of activities in each session. Many writers reported only positive outcomes and some writers did not report any changes or improvement in quality of life. In all, Gottlieb-Tanaka and Graf identified over seventy reasons why the designs of the studies they reviewed, and the reporting of the creative expressive activities under investigation, would not meet the common expectation of a standard, biomedical research performance criteria.

In the second of the studies conducted by Graf and Gottlieb-Tanaka (2011), surveying "the state of creative activities in British Columbia care centres", the results once again confirm why art activities remain mostly untried, are

grossly undervalued and rarely researched. Graf and Gottlieb-Tanaka distributed one thousand survey forms to aged care centres across British Columbia, but only 34% - seventy-nine facilities - returned the survey. Activity directors completed most of the surveys, and the results confirmed that the average annual activity program budget for the majority of facilities is a mere \$1,000 per annum.

The current state of art activities

This study revealed that the majority of activity program directors work fulltime and are formally trained in the delivery of recreation and lifestyle programming to certificate, diploma or university degree level. This training ensures that a wide variety of activities are made available to residents, but only 0.02% of activity directors believed that they or their staff were qualified to deliver an art program. This may be indicative of three things: firstly, the notion that only art therapists are qualified to deliver ‘proper’ art activities, other than traditional “arts and crafts” activities to residents in care. Secondly, that most students receive inadequate training in different forms of art, other than the standard “art and craft” activities, during their training in recreation and lifestyle program facilitation. Thirdly, that it is not uncommon for activity directors to lack confidence in their own artistic skills and are therefore often reluctant to personally implement art activities themselves. Whatever the reason, only twenty of the seventy-nine facilities deliver a regular weekly art program and in most facilities it is much less frequent. At some facilities art activities are only delivered once a year. In 90% of cases, it appears that volunteers are the individuals who regularly facilitate the “art” activities. It is hardly surprising then, then given these realities, that there still appears to little understanding of the overall purpose of the role of the arts in the aged care sector. And, it can be reasonably argued, that what applies in Canada, a prosperous first world country with a much admired ‘socialized’ healthcare system, is probably ahead of most other first world countries in this area.

An original contribution to knowledge

This research project has enabled me to develop and offer an original contribution to knowledge in the form of a new dementia/disability model. In addition, I offer an original and tested dementia-specific art activity matrix suitable for use by volunteers and program directors alike. To reiterate, this research project is the first time that the steps of a dementia-specific art activity have been separated, identified, analyzed and documented in any detail. It is also, to my knowledge, the first time that the steps of a dementia-specific art activity have been comprehensively integrated with Kitwood's theories. This action has, through the experience of the phenomenon, created an empirical testing method that can replicate an art activity. A method of replication is critical if future researchers are to attempt to counter the seventy or more most common criticisms leveled by reviewers against creative expression research data identified by Gottlieb-Tanaka and Graf (2011).

Two important components of a dementia-specific art activity

The analysis and separation of the steps of the art activity has clearly identified two important components of a dementia-specific art activity. These components are, firstly, the "critical partnership", the relationship that must be established at the start of any art activity between the facilitator and the participant during the activity. And, secondly, the pinpointing of the art facilitator's other duties and techniques that can lead to a successful art activity and wellbeing outcome.

An understanding of the importance of establishing structured steps also enables more accurate comparisons to be made between the various art activities and programs being implemented around the world. Structured steps provide a means to identify which parts of an art activity that are most likely to contribute to participant wellbeing outcomes. In the case of this research project, structure enabled a safe container to be established

by the facilitator of the art activity, thus allowing the participant to become absorbed in the “flow” of the painting experience. Expressions of joy, experienced both in the ‘now’ of the creative moment, and also in a living reciprocal relationship with the facilitator, soon followed. Both the participant and facilitator were then presented with the rare opportunity to express gratitude.

Art is one of the few activities that naturally leads to the expression of a wide range of emotions and where the psychosocial wellbeing of the individual can be so readily observed and measured.

In this research project, a practical example of how an appropriate tool may be used during expressive arts research was demonstrated by the application of MATRIX TWO - the eight Kitwood tenets. MATRIX TWO proved to be a practical art activity wellbeing assessment tool mainly because it simply observed ‘how’ the participant experienced the art activity. MATRIX TWO gives a simple and uncomplicated structure by which to document observations and to make evaluations of both the activity and the participants lived experience.

The creative capability of individuals living with dementia

This research project has demonstrated that individuals living with dementia are much more capable of creative endeavour than most people, even those who work in care, give them credit for. In fact, they can participate in, and remain concentrating on, activities that are engaging and interesting for considerable lengths of time. But, due to busy lifestyle activity schedules, budgeting restrictions and poor staff training and understanding, they are rarely afforded this opportunity and when they are their skills are rarely observed, least of all documented. Most failures to implement appropriate art activity in aged care appear to be based on the quasi-medicalization of art that sees it purely as a “treatment modality” (Allen, 1995). This is a situation where ‘art’, as opposed to “arts and

crafts”, which can be facilitated by volunteers, is seen by management as only worthwhile and worthy of funding if it can be seen to have a measurable therapeutic outcome. Art in this circumstance is often linked to the notion that only certified practitioners are qualified to administer and interpret it.

A small stock resource

Graf and Gottlieb-Tanaka (2011) have identified what would seem to be considerable confusion as to the value and purpose of some forms of ‘art’ in dementia-specific care. To counter this, during this research project, I have created a small stock resource for use by recreation and art activity facilitators. This small stock resource has several aspects. Firstly, it documents some techniques that may be of use to facilitators and then explains the anticipated wellbeing outcomes that give purpose to the kind of art activity that has been the focus of this research project. Secondly, the stock resource has been compiled so that ‘art’ that culminates in a permanent community mural, for example, can be differentiated from art therapy or the product associated with the ‘busy work’ of the “arts and crafts”, variety and so often dismissed as little more than a time filling activity.

All forms of art have a natural place in dementia-specific care, and that is why this stock resource was developed, to give dementia-specific art, other than activity formally classified as “art therapy”, and not “arts and crafts”, both a new place and credibility in dementia-specific care. To sum up, art is a human tradition and part of our primal heritage and those living with dementia need art and other interesting and creative activities to help them achieve a sense of purpose and to live out a life as close to a fulfilling human existence as is humanly possible.

Drawn lines - assisting the brain to get started

Baines (2011, p. 124) writes that there is “a basic understanding that the person with dementia finds it hard to start from nothing”. Baines uses an assortment of small objects to “assist the brain to get started” because she says “we need to begin with something”. The drawn images on the surface of a canvas perform this function during the course of this research project and are an integral part of both the art activity and the project in general.

This research project has shown that clear black line images on a flat surface create space for creativity. They allow a person living with dementia to slowly process the emotional content of the image and to compensate for any loss of spatial processing skill. This important discovery lends itself to further research and to the development, production and application of pre-drawn creations that are dementia-specific and designed especially for aged care. An added bonus is that such pre-fabricated designs would also relieve many facilitators from performance anxiety. This is particularly important among those facilitators and volunteers who have had no formal art training and, as such, believe that they cannot produce drawings and images that are of a so-called “professional standard”.

What the research revealed

The combination of the above contributions of this phenomenological research project has finally made it possible to reveal the often hidden artistic ability of residents living in dementia-specific care more fully. In addition, it has allowed the principle researcher to, firstly, identify which parts of an art activity are most likely to contribute to a sense of wellbeing and accomplishment for the participant. And, secondly, to develop practical art activity facilitation techniques, that may be implemented by facilitators and volunteers alike to promote the wellbeing and self-worth of participants.

As mentioned above, drawn lines on the surface of dementia-specific art exercises provide space for creativity and enables participants to make a start. It also appears that some activity facilitators lack personal confidence in their artistic ability and this restricts and limits the scope of creative opportunities for participants. A research project into staff attitudes and their perceptions about dementia-specific art and creativity would greatly assist art activity designers in new program and product development.

Future research

To provide more humane and better person-centred care, further research into the concept of wellbeing, utilizing creative expressive art forms may be conducted in the following way:

Phenomenological research: Research involving the participation and the publication of art facilitator's personal lived experiences and findings, to create deeper understanding and acceptance of dementia-specific creativity and the lived phenomenon of art.

Evaluation research: Research involving the detailed structure of art activities and their replication. This type of research would provide not only better documentary evidence of the efficacy of dementia-specific art activities, but also more credible art activity project evaluation and validation.

Action research: Research involving the facilitation of all facility, multi-disciplinary hands-on workshops aimed at empowering activity facilitators, to implement art and change biomedical cultural attitudes and widespread existing antipathy or misunderstanding about the place of art in the aged care sector.

Ethnographic research: Research involving the compilation of the lived experiences of elderly individual living with dementia in culturally and

ethnically diverse communities.

Theoretical research: Research involving the application of Kitwood's wellbeing theory to other program designs, in order to structure the steps of different dementia-specific activities, with the result of more effective replication and comparison.

Further dementia-specific research and development in the form of:

The development and introduction of new dementia/disability language and terminology.

Plain language approaches to grant submission writing.

Art education research and training package development.

Informed publications formulated to influence policy makers.

Peak bodies partnerships and mentoring programs.

Communal artworks and community arts projects.

Audio-visual training aids.

Innovative program and art product development.

Recommendations

The beginning of this conclusion began with an observation by Luis Fornazzari, one of the world's leading experts on the role of the arts in neurological research. Fornazzari (2011) highlighted the unique opportunity that the art studio has to contribute to the scientific quest to discover and begin to understand the wonder and range of the brain's plasticity. The many scholars whose work has contributed to the depth and breadth of this research project have revealed many discoveries that are roughly joined together to form the following concept.

The ability to pick up a paintbrush and to paint is a primal heritage, as is the ability to enjoy colour. In addition, many living with dementia, when assisted to get the brain started, can remain engaged in painting for

extended periods of time. Researchers have established that healthy brain tissue can work in conjunction with diseased brain tissue and, that the amygdala, the storehouse of emotional memory, remains intact until late in the dementia progression. When combined with simple black line illustrations, that have significant personal life-story meaning, these factors enable those living with dementia to overcome spatial processing difficulties by slowly scanning the images for meaning. They are then able to find meaning and purpose in the activity and they are usually more than happy to make their creative contributions to communal and individual works of art.

In this way, the art studio has the potential to contribute much to future research into brain plasticity and dementia-specific art. But, in the meantime an effective way must be found to communicate the value of art in aged care, in particular its power to contribute to wellbeing. Modern technology is probably the most efficient vehicle. More than a decade ago, McNiff (2000, p. 98) wrote that “civilization does advance through new technologies and art [as] therapy needs to move with it... We simply need the imagination and creative resources to seize the opportunities”. What is envisaged is the establishment of an international dementia-specific art activity resource pool, on a website along the lines of the original and highly successful ‘ideas website’, *Arts and Letters Daily* (www.aldaily.com). The website would be a repository of information on the creative expressive arts and dementia and also an aggregator of information with links to other relevant sites. Once established, the dissemination of information must begin, firstly, within the aged care industry, starting with education and training packages and materials directed toward the art activity education of management and staff currently working in aged care and policy makers.

Secondly, the curriculum and training materials of recreation and lifestyle activity facilitation training courses must be improved and/or developed in order to reduce and dispel the confusion that currently surrounds art and its application in dementia-specific care. An international resource pool would

contribute ideas to curriculum and training development.

This research project demonstrates that a whole range of art activity possibilities and opportunities can be designed to overcome the current void that exists between the polar opposites of ‘art therapy’ and ‘arts and crafts’, like two ships passing each other unseen in the night. In the sea of muddle, which characterizes this aspect of aged care, what is needed are new vessels properly funded and researched and exposed to the clear light of day.

The ‘clinification’ of art in aged care shrouds art in unnecessary mystery and, as a result, rarely adequately serves the best interest of the recipients of aged care. Whilst clinicians continue to create a ‘pecking order’ that influences management perceptions about who is best ‘qualified’ to facilitate art activities, innovative art program designs and ideas are derailed and halted. The international resource pool would publish and promote the designers of innovative art programs and facilitate cross cultural exchanges and links between designers.

In addition, the continuing perception that art is messy, is often combined with the assumption that art is too expensive to introduce, and therefore not worth the resources, time or effort. The international resource pool would counter these perceptions in the following ways, beginning, firstly, with the art re-education of staff and facilitators through the publication of plain, readable, staff and/or volunteer educational training material. And, secondly, by the circulation of research materials and information that contains both practical techniques for facilitators, and includes sound budgeting models and/or grant submission writing advice for managers.

And, thirdly, it is essential that there be an increase in simple, less complicated dementia-specific art activities that can be successfully and easily replicated. The resources would include art activities that are based on theoretical frameworks and more clearly defined and structured. And,

where designers are willing to share and document their facilitation process and materials list, adding them to the international resource pool to be published and a distribution network of these resources established. Such an international resource would equip future researchers to use the most current and appropriate methodology so as to confidently compare different dementia-specific art activities in a more scientific reputable manner.

Finally, sharing knowledge through an international resource pool will ensure that less confusion exists regarding the role of art in dementia-specific care, and the value of art activities and their important benefits and outcomes are communicated to educate both the industry, policy makers and the wider community.

PART FIVE

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Appendix A

The individual case studies

Including data from MATRIX TWO - the eight Kitwood tenets, and MATRIX THREE - the CEAA tool, for individuals in the CEAA wellbeing research study.

The following information is the research data gathered for eleven individuals living with various and non-specific dementias in the CEAA study of wellbeing. The twelfth case study appears in the discussion chapter.

Each case study begins with an individual CASE STUDY INTERVIEW. This is followed by the information gathered from MARIX TWO - the eight Kitwood tenets, and MATRIX THREE - the CEAA tool.

Note: MATRIX ONE comprises the stages and steps of the art activity.

Dorothy D. (DD)

Born in Toolamba, Victoria, on 25.03.1923

THE CASE STUDY INTERVIEW

Dorothy was born on a dairy farm near Shepparton and grew up there with her brother and five sisters. In those days the cows were milked by hand and “all hands were on deck” to help with the day-to-day running of the farm. Dorothy learned sewing and preserving and all of the traditional country crafts from her mother.

After leaving school, Dorothy got a job in a milk bar, where she met Roy, her future husband. Dorothy had to return home to nurse her mother when she fell ill but the couple was able to marry in 1947. The couple moved to Brighton, in Melbourne, where Roy had a job in the motor industry and Dorothy settled into her life as a homemaker caring for her four young daughters.

After two or three more moves, in 1962, Dorothy and Roy built a new house in Dingley and Roy pursued his interest in the restoration of Austin 7 cars. The business flourished and in 1978 they moved to bigger premises in Mentone giving Roy the space to expand the business into the sale of veteran car spare parts. The couple enjoyed travelling together to various swap meets around the country.

THE ART ACTIVITY

Dorothy worked on the palm tree fronds that Ollie began on the afternoon of 11.08.10. The building was reasonably quiet this afternoon and this gave Dorothy few distractions as she painted the fronds and part of the sun and a patch of blue sky during her forty-five minute contribution. Dorothy did not talk much as she was working and was not at all distracted by one of the volunteer visitors, who became quite vocal and talked loudly in the background with two other residents.

The research question:

- And, what skills did this individual living with dementia exhibit during the art activity?

Dorothy was able to see the lines and her brush strokes were short but sure and confident, she followed the lines without difficulty. In the quiet surroundings Dorothy showed steady concentration, only working on one area at a time with meticulous detail, and she didn't like being interrupted. At one stage, when I offered refreshment, Dorothy even said "can't you see I am busy doing this at the moment". It was as much as to say, politely of course, to "stop interrupting me". Dorothy was quite particular about getting straight back onto the task at hand.

Dorothy commented that the process "takes a lot of concentration" and that I was "not to interrupt" her as "I can only do one thing at a time". Dorothy seemed to like the colour changes and the new challenges of each stage and colour, but gave no indication that she would initiate the colour changes herself. That said, Dorothy appeared to enjoy each change of colour every now and then, and seemed to become very involved in the process of adding to and building up the layers of colour. Although she did not say much she worked with great concentration for about forty minutes, until the bus returned and the building became too noisy. Eventually, Dorothy placed the brush down and was happy to have afternoon tea when asked.

Post art activity observations of the lived experience

Dorothy was unsure that I was sincere when I thanked her for her contribution, and it took a few minutes to reassure her that I was genuine in my appreciation of her contribution and that I was not going to "say something different when [her] back [was] turned". Dorothy's uncertainty demonstrates the vital importance of the final stage of any activity, and

that it needs to end on a genuine and sincere note.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents 'how' DD experienced the art activity phenomenon.

Participant's name: DD	Art activity = 47 minutes
Attachment	A rapport between DD and the facilitator was established immediately
Holding	A trusting and safe environment was established because of the above factors
Timalation	DD worked independently without assistance or any need for the facilitator to sit near her
Relaxation	DD totally relaxed into the art activity and showed affection to the facilitator
Celebration	DD relaxed into the activity quickly and worked consistently and displayed no indication that the activity presented any problems
Play	Throughout the activity DD concentrated and painted independently displaying meticulous attention to detail. Although she did not independently initiate colour changes she nonetheless appeared to enjoy the colours when they were introduced and used them to build up layers of colour and detail
Creation	DD could see to follow the lines. She dipped her brush independently and her brush strokes were short but sure and confident
Giving	Although DD was not very vocal during the activity, except to comment on how much concentration it took, she did express her opinions quite forcefully at its conclusion

MATRIX TWO wellbeing outcomes:

A holding container and safe psychological space were quickly established. DD both understood what was required of her and she soon relaxed into the activity and was able to work independently with minimum facilitator intervention. DD used a full range of fine and gross motor skills, she dipped her brush independently and displayed an appreciation of colour, taking advantage of the colour changes to blend them into her design. At the activity's conclusion, DD articulated astute comments about the work and the facilitator

When optimum and safe conditions were presented to her, DD relaxed into the activity and was free to make choices. Under these conditions, DD was able to use all of her motor skills and she smiled and displayed affection. The intervention lasted a considerable length of time, in fact over forty-five minutes. The activity presented DD with a rare opportunity to be creative and so regain her self-esteem.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents 'what' DD experienced during the art activity phenomenon.

Participant name: DD	Length: 47 mins		
Assessors and assessment method -tick scores	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	2	2	2
M2. Recites			
M3. Invents memories			
Attention			
A4. Levels of attention	4	4	4
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	2	5	4
L7. Uses key words/simple sentences/body language	2	4	3
L8. Uses humour when writing			
L9. Uses humour when speaking	3	3	3
L10. Uses elaborate/informative descriptions			
L11. Uses facial expressions to communicate understanding	6	6	6
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			

P16. Responds to comments - shows compassion and/or reflections	4	4	4
P17. Shows self-esteem/confidence	2	2	2
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems	8	6	7
R20. Makes clear decisions and choices	6	4	3
Emotions			
E21. Uses facial expressions to express moods and emotions	4	3	5
E22. Expresses mood in visual display	4	5	5
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	47	50	50

MATRIX THREE wellbeing outcomes:

The CEAA tool indicates that DD uses humor, complete grammatical sentences and a wide range of facial expressions and body language to communicate her enjoyment and satisfaction with her participation in the art activity. The video shows that on one occasion DD extends her hand to the facilitator and on another she gently and affectionately taps the facilitator’s face with the end of her brush.

The CEAA tool indicates that DD’s area of real strength in the art activity lies in her ability to reason and make clear choices and solve problems. Linked to this, the video shows that on another occasion DD is observed to “sit back and take in the bigger picture”. The video documents that DD appears to show a keen interest in the facilitator as new colours are introduced, and DD is seen to watch her closely as she patches up an area of thin paint in the sky. The video documents that although visibly tired by the end of the activity, DD nonetheless appears both very relaxed and at the same time totally engaged in concentration in the activity, not noticing background noises. The film captures what appears to be DD almost

“locked” into the “flow” and the rhythm of the brush strokes as she completes painting the sun and the sky using a full range of gross and fine motor skills throughout.

DD’s questioning of the facilitator’s sincerity at the activity’s conclusion is surprising given her level of cognitive impairment and the fact that she could not remember her participation in the art activity later on the same day.

The tick score totals between the three observers indicate each observer made similar observations across each of the designated wellbeing domains. The tick score records are almost even, JGM = 47, LS = 50 and CB = 50. This indicates there are no major discrepancies between the observations across all of the CEAA wellbeing domains.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

DD was born in rural Victoria and has been living with non-specific dementia for more than a decade. DD has a shy and reserved personality and thoroughly enjoyed her quiet life as a mother and homemaker before entering care. DD’s life partner and her daughters are instrumental in regularly meeting her immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO - the eight Kitwood tenets, and MATRIX THREE - the CEAA tool, indicate the following: the facilitator was able to implement the activity and the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

DD was quite reserved and shy when she came to the activity, and although she did not say much throughout she freely entered into the activity and sustained a long and productive engagement. DD is often observed in deep

concentration and she seems to have engaged fully in the creative “flow” of the activity. DD is seen to use her well-established skills to the best of her ability and takes every opportunity to explore each creative possibility as it is presented. DD’s contribution to the activity is typified by a visible personal engagement with the facilitator and an appearance of quiet enjoyment in the activity.

The wellbeing assessment

DD’s overall participation demonstrates that the lived experience of the art activity, in terms of Kitwood’s identity and personhood wellbeing indicators, contributed to her wellbeing at the time. And, as a result, she reached and maintained a relatively high state of wellbeing during her long and productive engagement in the phenomenon.

Jack O'B (JO)

Born in Melbourne, Victoria, on 10.04.1922

THE CASE STUDY INTERVIEW

I met with Jack on 12.03.10 to record his life story. Jack was sitting with Lorna, a Nixon resident who is also his former partner, and both were being visited at the time by Lorna's sister Gwen. Together we sat and talked about Lorna's and Jack's enduring friendship and the close relationship that formed between their two families after they became Highett neighbours in the 1940s.

Jack's early life was not easy, he and his twin brother Frank were brought up in a South Melbourne orphanage and, as a result, a very strong bond existed between them. Frank lived in a nursing home in the Northern Suburbs of Melbourne until his death in August 2010. Both boys were adopted out and Jack spent a year or two living with his new family in Warrandyte. He was sent out to do manual work on farms in the Western District of Victoria when he was thirteen. As Jack did not have much schooling, in 1940, to better himself, on turning 18, he joined the Army. After basic training he was sent by the Army to "the tropics" and was stationed on Bougainville in New Guinea. Jack saw out the war there and says he was lucky because he did not "see much action". Jack says his most frightening job was sentry duty because he was by himself in the dark, which reminded him of the darkness of the orphanage, and he remembers the heat was oppressive.

When Jack was de-mobbed in 1945 he bought himself a house on the Nepean Highway in Highett. He says he was never a drinker and it was easy for him to save the deposit from his Army pay. Jack says he tried several jobs, but eventually he settled into work as a plumber fitting hot water services. He says he enjoyed meeting people and "crawling about in people's roofs".

Ten years after the war, Jack married his first wife, Mavis, and in the 1956,

the following year, Raymond, the first of his two sons, was born. His second son David was born seven years later in 1963. Mavis was a mother-craft nurse and together the couple shared a common interest in family camping holidays when the boys were small, and later they travelled around Australia together. Mavis died in 1981 and two years later Jack married Elsie. After 1984, in his retirement, Jack spent his time restoring cars and was a member of the Chevrolet and Morris vintage car clubs. Elsie died in 1998.

Jack loves music and classic wartime movies. Jack said he did not, or perhaps can't remember, doing art at school, as those were tough times, but he did say he would give it a go.

THE ART ACTIVITY

On 27.08.10, Colette, the activities manager, brought Jack to the activity when Lorna was at her hairdressing appointment. It soon became apparent that Jack's language processing ability has deteriorated markedly over the months since I first interviewed him in March, and even though he was happy to run his hands across the surface of the artwork and to chat with me, he could not be persuaded to paint, and I did not press the issue. Jack's reluctance to actively participate may be due to a number of reasons that are not part of this research project.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Jack was happy to sit as a very active passive observer whilst I talked about the singer's red "fire truck red" jacket (an image on the artwork) and the glass of coca-cola on the rum and coca cola panel. He sat totally engaged in the process as I proceeded to paint the singer's dark brown hair. To introduce the glass of coca-cola I sang a few bars of the Andrew's Sisters hit

song. When I asked Jack who might have sung the song “drinking rum and coca-cola”, he replied “was it perhaps Bing Crosby?” and he was all smiles when I mentioned the Andrew Sisters. He then tried to fill in the chorus lines of the song as I sang it over. After some discussion about the colour of the cocktail drink “umba-rella” and the drought breaking rains, Jack indicated he was tired and wanted to return to his room.

The activity had already lasted forty minutes when I accompanied him to his room. When we got there Jack very gracefully showed me his “treasures” neatly lined up on his chest of drawers. They consisted of a model Morris Minor car, and his “fire engine red” tin fire truck. By sharing his treasures with me, in a show of reciprocation and appreciation, Jack was happy for me to leave.

Post art activity observations of the lived experience

Jack appeared to enjoy the activity and also seemed to be aware of his diminishing skills. Jack has always been someone who has been prepared to “give it a go”, but perhaps now his participation in such an activity will manifest itself in a more passive engagement with gentle encouragement and praise on his contribution.

In sharing his “treasures” Jack amply demonstrated reciprocation and appreciation as outlined in Kitwood’s “giving” tenet.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents ‘how’ JO experienced the art activity phenomenon.

Participant’s name: JO	Art activity = 15 minutes
Attachment	JO was brought to the activity by Colette and he was soon settled into the chair in front of the artwork
Holding	A safe and secure environment was quickly established, but JO exercised choice and self-determination by deciding not to actively participate in the painting part of the project

Timulation	Because of JO's advanced Alzheimer's like dementia, it was necessary for the facilitator to sit next to him and involve him in all aspects of passive participation
Relaxation	JO appeared to enjoy a very "active" passive participation, "helping" the facilitator to make colour choices whilst smiling and engaging in simple conversation and reciting the verses of familiar songs with the facilitator
Celebration	JO appeared happy to sit and enjoy his passive participation
Play	Although JO did not work independently but did actively appear to enjoy his passive participation
Creation	JO exercised choice and self-determination by not participating in the painting
Giving	After the activity JO shared his "treasures" with the facilitator in a show of reciprocation

MATRIX TWO wellbeing outcomes:

Although a "safe psychological space" was quickly established, JO's advanced Alzheimer's like dementia determined his level of participation, and it was necessary for the facilitator to sit next to him and actively facilitate all aspects of his passive participation. JO was consulted and made colour choice decisions and appeared to enjoy chatting and singing. JO's helping role in the work was simplified and the facilitator deliberately did not introduce complex sequences. As a result, JO was not placed under emotional pressure to get anything right and was not overwhelmed making decisions. This rendered the activity virtually "risk free" and JO was also afforded an opportunity to show his appreciation through reciprocation.

For JO "active" passive participation can be seen to be of as much benefit to him as the participation of any other participant in the activity. Whilst the reasons for JO's choice not to paint are unknown, honouring his decision not to participate in this way gave JO an opportunity to exercise choice and self-determination and created a semblance of control over his environment. JO's engagement with the facilitator in the activity was nonetheless as inclusive and full, joyful and productive as that of any other participant.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents 'what' JO experienced during the art activity phenomenon.

Participant name: JO	Length: 15 mins		
Assessors and assessment method -tick scores	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	2		2
M2. Recites			
M3. Invents memories			
Attention			
A4. Levels of attention	3	3	3
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	3	5	4
L7. Uses key words/simple sentences/body language	7	5	6
L8. Uses humour when writing			
L9. Uses humour when speaking	2	3	2
L10. Uses elaborate/informative descriptions			
L11. Uses facial expressions to communicate understanding			
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections		4	
P17. Shows self-esteem/confidence		1	
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems	1	1	1
R20. Makes clear decisions and choices	5	3	4
Emotions			
E21. Uses facial expressions to express			

moods and emotions			
E22. Expresses mood in visual display	4		3
E23. Expresses mood in music	1	1	1
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	33	32	31

MATRIX THREE wellbeing outcomes:

The CEEA tool and the video indicate that JO is only able to respond to conversations with difficulty. There are considerable word processing delays, and he is now limited to the use of simple one or two word sentences in response to questions. Even though Alzheimer’s like dementia affects his language, JO uses facial expressions to indicate both his mood and his understanding of the activity. For instance, JO shows his appreciation of the artwork when he is seen to pat and stroke the canvas and to run his hands over it to feel the surface texture.

JO also makes quite definite decisions, the most notable being his decision to decline the opportunity to paint, which was quickly followed by his decision not to leave the activity immediately. Instead, JO sits beside the facilitator and the video documents him smiling and records his efforts to join in with songs and respond to the facilitator to the best of his ability. The video documents his absorption and his enjoyment in his passive and “risk free” contribution to the art activity, particularly when the facilitator introduces the rum and coca-cola segment.

The tick score totals between the three observers indicate each observer made similar observations across each of the designated wellbeing domains. The tick score records are almost even, JGM = 33, LS = 32 and CB = 31. This indicates there are no major discrepancies between the observations across all of the CEEA wellbeing domains.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

JO was born in Melbourne and his early life was spent in an orphanage with his twin brother. JO's early years were hard and he has had to be self-reliant and resourceful all of his life. JO was admitted to care about three years ago, but has been living with Alzheimer's like dementia for some time. JO has a kind and loving personality and he states that he was fulfilled in his long employment as a plumber and that he also thoroughly enjoyed his hobbies before entering care. JO's supportive family and his partner, who also lives at Nixon Hostel, are instrumental in regularly meeting his immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: the facilitator was able to implement the activity and although JO's engagement was "passive", the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

JO was mildly anxious when he was brought to the activity but this soon dissipated and he freely made the decision to stay and take the opportunity to explore and enjoy its possibilities through passive engagement. Given JO's level of cognitive impairment and language difficulties, his contribution to the activity is typified by positive emotional responses and a respectful demeanour. JO appeared to find enjoyment in both the facilitator's company and his engagement in the activity.

The wellbeing assessment

JO's passive participation and quiet interest in the art activity demonstrates that his lived experience, in terms of Kitwood's identity and personhood

wellbeing indicators, contributed something to his wellbeing at the time
And, as a result, he reached a moderate state of wellbeing during the
phenomenon.

Joyce B. (JB)

Born in Melbourne, Victoria, on 13.07.1927

THE CASE STUDY INTERVIEW

I met with Joyce on the morning of 23.03.10 when she was sitting with Gwen. Joyce says she is from Yarraville and she grew up in a house on a double block that her parents bought after they emigrated from the UK in the 1920's. The family came to Australia because Joyce's brother Tom was unwell and Australia's climate was thought to be better for him. Joyce said her father grew vegetables and ran "chooks" on the spare block that "fed the whole street".

Joyce went to Francis Street Primary School until Form 2. After Form 2 she was enrolled in a dressmaking course at the local Technical College and then helped at home until she was fifteen, and of working age, when she got a job at Wood's Drapery Shop in Yarraville. Joyce worked at Wood's until she married Norman, who she met at a party in Footscray when she was 21. When Joyce left Woods to get married in 1948 the manager gave her some lengths of lace and taffeta for her wedding frock and trousseau as a wedding present.

Joyce said Norman was a wonderful dancer and husband and the couple lived in Footscray briefly after they married until they saved enough money to buy a block of land on Parkers Road, Parkdale. The couple built and moved into their first home there in 1955 with their two children, Lynette, who was two, and Noel who was a newborn. The couple's extended family also moved from the Western suburbs to live close by. Norman was at that time employed by Younghusbands Limited, the Melbourne stock and station agent, but in 1961 the couple bought a newsagency which they ran jointly for the next seven years. The couple owned a flat and holidayed at Coloundra in Queensland every year until Norman died of cancer in 1988. After Norman's death Joyce worked part time for Myers department store and this enabled her to travel throughout Australia and to America and

Europe.

Joyce says she has never painted and was “no good at it” at school, although says she loves all kinds of music, particularly background music and singing because her father was a talented singer and she has fond memories of him performing.

THE ART ACTIVITY

Another resident had carefully prepared the background colour of the female singers dress ahead of time so that Joyce, the haberdasher and former dressmaker, could apply the lace pattern designs on the afternoon of 26.08.10.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Joyce used the stencils to great effect to create the lace collar of the singer and enjoyed the creative challenge of placing the shapes in regular designs. She was soon totally engaged in the process and worked hard and consistently and extremely productively for the next fourteen minutes, until she declared she was tired and announced her intention to return to the A wing. Joyce declined the opportunity to decorate the edge of the ballroom dancer’s frock and ended the activity by saying she did “not have enough time” because was expecting “the family to visit”.

Post art activity observations of the lived experience

Calling on her life skills, Joyce made clear and decisive decisions about the placement of the lace stencils and she filled and coloured the edges of the collar quickly as if laying out and positioning lace motifs on a dress pattern.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents 'how' JB experienced the art activity phenomenon.

Participant's name: JB	Art activity = 14 minutes
Attachment	JB was brought to the activity by Colette and because she is still very articulate and a "talker" she was soon engaged in conversation with the facilitator
Holding	Easy conversation established a safe and secure environment quickly
Timalation	It was not necessary for the facilitator to sit next to JB, but it was necessary for the facilitator to explain and demonstrate the creative props and stencils to her
Relaxation	JB showed signs of comfort and relaxation and enjoyment in the activity whilst she deliberated on the layout and the position and placement of the props as she created the lacework pattern
Celebration	JB was so absorbed in the process that during the activity she did not display any reservations
Play	During the activity JB made very definite decisions and she used the stencil to great effect to create the lace collar. JB reminisced about her former employment and her life before she was married
Creation	JB displayed her old dressmaking and pattern design and creation skills whilst she worked
Giving	Throughout the activity JB conversed and passed positive comments on the process and appeared grateful for the opportunity to participate

MATRIX TWO wellbeing outcomes:

Once the safe space was established and the props and stencils had been demonstrated, JB worked at a cracking pace overlaying the stencils and creating the designs. JB used all of her pattern creation and dressmaking expertise to create the designs and she articulated the steps as she went until fatigue from such a burst of creative energy finally stopped her.

Linking an activity with a participant's former life greatly enhanced the possibility of a positive wellbeing outcome for that person and this was perfectly demonstrated in this case. JB displayed a palpable sense of

accomplishment in her demeanour indicating wellbeing and renewed self-esteem.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents 'what' JB experienced during the art activity phenomenon.

Participant name: JB	Length: 14 mins		
Assessors and assessment method - tick scores	JGM Video	LS Live	CB Video
Memory	2	3	3
M1. Reminisces			
M2. Recites	1		
M3. Invents memories	3	3	4
Attention			
A4. Levels of attention			
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	10	6	8
L7. Uses key words/simple sentences/body language	3	2	23
L8. Uses humour when writing			
L9. Uses humour when speaking	2	1	6
L10. Uses elaborate/informative descriptions	1		1
L11. Uses facial expressions to communicate understanding	1	3	
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections	2	1	
P17. Shows self-esteem/confidence	2	2	1
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			

R19. Shows insight/solves problems	10	4	13
R20. Makes clear decisions and choices	7	6	20
Emotions			
E21. Uses facial expressions to express moods and emotions	1	3	3
E22. Expresses mood in visual display	1	2	1
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	46	36	85

MATRIX THREE wellbeing outcomes:

The CEAA tool and the video records indicate that JB uses complete grammatical sentences and responds promptly to comments and humor and uses a wide range of facial expressions and body language to communicate her enjoyment and satisfaction with her participation in the art activity.

The CEAA tool indicates that JB’s real strength during the art activity is her ability to reason and make clear choices and solve problems. JB mirrors and repeats the facilitator’s instructions, skillfully uses her fine and gross motor skills and her visual and spatial skills to hold and manipulate the stencils and maneuvering them to fit into the designated shape and her design ideas. JB makes astute comments such as “this will fit this space” and we can “get another one in there”, and “we will try it and see”. JB adds comments that painting is “messy isn’t it”, and “I need more paint” when she notices that her brush is dry.

The video documents that after a flurry of quite intense activity JB suddenly appears visibly tired near the end of the activity and says, “I’ve had enough”. JB then ends the activity by announcing “I helped a little bit” and says she must return to her room because she is “expecting a call from the family”.

The scoring between the three observers is uneven JGM = 46, LS = 36 and CB = 85. This has created a discrepancy between the observational scores, particularly on question seven. This question relates to language skills and the tool asks if the participant uses key words and simple sentences and body language. For question seven, JGM scored 3 and LS scored 2, but CB scored 23 observations. JB is very articulate and CB appears to have scored single word responses within complete sentences and this alone appears to have influenced CB's overall score and accounts for the discrepancy.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

JB was born in England and immigrated to Australia as a child. JB has been living with non-specific dementia for some time. JB's dementia has not affected her language ability and she continues to display an outgoing and sociable personality. JB says she thoroughly enjoyed her life in retail sales and was fulfilled in her active role as a mother and grandmother before entering care. JB's life partner has been dead for more than two decades, but her children are instrumental in regularly meeting her immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: the facilitator was able to implement the activity and the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

JB is very bright and chatty when she comes to the activity and she freely enters into the activity and then sustains a very productive participatory engagement. JB is often observed in deep concentration, pondering her design options and she makes vocal design and colour decisions. JB is seen to engage fully with the facilitator and in the creative "flow" of the activity and she uses her well-established sewing and design skills to the best of her

ability, as well as taking advantage of every opportunity to explore each creative possibility when it is presented. JB's contribution to the activity is typified by a very vocal engagement with the facilitator and an appearance of active enjoyment in the activity.

The wellbeing assessment

JB's overall participation demonstrates that the lived experience of the art activity, in terms of Kitwood's identity and personhood wellbeing indicators, contributed to her wellbeing at the time. And, as a result, she reached and maintained a relatively high state of wellbeing during her intense, but very productive engagement in the phenomenon.

JB's early background in music and singing might be used to great advantage and armchair travel is another outlet to be explored to its full extent with her.

Geoff W. (GW)

Born in Melbourne, Victoria, on 06.06.1924

THE CASE STUDY INTERVIEW

I spoke with Geoff in the garden in the morning. Although he has a severe hearing impairment as a result of a “war wound”, with a “silver plate” inserted into his skull, he was about to answer questions I wrote on his communication board. Geoff said he went to primary school and went to Trinity College before he studied architecture at Melbourne University. Geoff said he enjoyed drawing at school, which gave him his entry into his future architectural studies. Although he loved to paint, Geoff said he could not find time to complete paintings when he was a young man because he was too busy, instead he said he took up leather and silver work. Geoff says even now he still enjoys fixing leather and using his tools and usually wears his leather “work apron” during the day.

Geoff says that his father was a professional soldier and was a Brigadier during WWII. Geoff “joined up” as a private when he was 17 in 1941, eventually working his way up to the rank of Sergeant Major. He says his Army training taught him to be a “jack of all trades” who could “turn his hand to anything”, and it came in handy when he was stationed behind enemy lines in British North Borneo during the war.

For many years, Geoff owned and ran a property on what was the old Yanakie Station at the top of Wilson’s Promontory in Gippsland. Geoff said although he never married, he did briefly share his life with a partner on that property. He said he sold the property later for \$100,000 cash to a well known “underworld figure” but would not say who the person was.

THE ART ACTIVITY

Before lunch on 29.08.10, Geoff came to the activity between smokes. It was another good opportunity to use the communication board to good

effect. Geoff sat and worked on the artwork and then chatted and reminisced for about forty minutes. Much time was spent initially looking for his glasses, but they could not be found and all the searching did not deter Geoff from painting.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Through the communication board the activity finally started and Geoff applied a few brush strokes to the saucer of the Tea for Two panel. After the painting activity, a long and emotional episode unfolded in which Geoff reminisced about some of his experiences behind enemy lines in Borneo during WWII. In particular, Geoff spoke of his acceptance into Indonesian village society and the appreciation of a village chief after he had tracked and finally rescued two little girls lost in a cave in the jungle. Geoff said he was more than happy to share stories about his life and he also said that life on the farm and his love of dolphins had given him great fulfillment.

Post art activity observations of the lived experience

Geoff sat in the courtyard after the art activity and was quite overcome with emotion. An opportunity for a soldier or sailor or flyer to articulate and express grief and loss is an important process in making sense of the loss of comrades and coming to terms with the trauma of war. The time to spend with residents who are returned service personnel, to reminisce about the war, is often not possible in the busy day to day running of a facility and staff may be too frightened to broach that subject, or may not always be aware that the validation of each person's war service can be very cathartic for such individuals, who sometimes feel that their service is under appreciated and unrecognized.

Since the activity Geoff has hovered around the artwork, even peering

through the outside window on his “smoko” on two or more occasions, probably drawn by the colours and the feeling of inclusion. On another occasion he even wanted to help clean up, and be useful in assisting me tidy up and pack things away, which was another way that he could share and more fully participate in the activity.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents ‘how’ GW experienced the art activity phenomenon.

Participant’s name: GW	Art activity = 37 minutes
Attachment	The communication board was used to good effect in establishing a fruitful and productive rapport with the facilitator
Holding	A productive, trusting and safe environment was quickly established using the communication board
Timalation	It was necessary for the facilitator to utilize the communication board extensively, but it was not necessary to sit either next to him or even near him
Relaxation	GW appeared to be very comfortable and was relaxed enough to share his stories during and after the art activity
Celebration	A lifetime spent in the creative arts meant that GW was able to fully engage in the art activity without any sign of reservation or timidity
Play	GW was able to work independently of the facilitator and as such fully engage in the art activity
Creation	GW displayed a comprehensive range of skills and dexterity whilst painting
Giving	GW expressed gratitude for his participation by the trust he showed in the facilitator when he shared his wartime stories experiences at length at the art activities completion. In addition, on following days GW hovered near the activity and helped the facilitator to pack up and tidy up around the activity

MATRIX TWO wellbeing outcomes:

The communication board ensured that a productive and safe environment was quickly established and GW was then free to demonstrate his creative skills. A trusting bond between GW and the facilitator meant that he was able to share his experiences through reminiscence and was presented with an opportunity to express gratitude.

The art activity afforded GW an opportunity to actively display his considerable artistic talent and, through reminiscence, share his life story. Being heard under such rare conditions enabled GW to regain a modicum of self-esteem.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores

MATRIX THREE documents 'what' GW experienced during the art activity phenomenon.

Participant name: GW	Length: 37 mins		
Assessors and assessment method	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	13	8	9
M2. Recites			
M3. Invents memories	9		6
Attention			
A4. Levels of attention	3	4	4
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	13	6	12
L7. Uses key words/simple sentences/body language			
L8. Uses humour when writing			
L9. Uses humour when speaking	6	7	4
L10. Uses elaborate/informative descriptions	4	5	6
L11. Uses facial expressions to communicate understanding	2	8	4
L12. Makes vocal responses to music			
Psychosocial			

P13. Attracts/holds attention telling a story	2	4	3
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections	1	4	4
P17. Shows self-esteem/confidence	3	3	2
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems	8	5	6
R20. Makes clear decisions and choices	5	5	5
Emotions			
E21. Uses facial expressions to express moods and emotions	7	4	6
E22. Expresses mood in visual display	7	4	6
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories	2	6	3
E25. Shares thoughts and speaks from the heart	5	9	7
E26. Shares wisdom/life experiences	2	9	5
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	94	95	99

MATRIX THREE wellbeing outcomes:

The CEAA tool indicates that when GW is asked a question using the communication board he responds in complete grammatical sentences, and expresses humor such as “I can’t hear a bloody thing”, using a full range of facial expressions, eye contact and body language to communicate. GW indicates his enjoyment and satisfaction with his participation in the activity by sharing reminiscences about his life experiences and by engaging fully and freely in conversation with the facilitator.

In this instance, the CEAA tool is not sophisticated enough to capture the overlap between questions twenty-five and twenty-six or indeed the wisdom and truth of GW’s life lessons. GW’s real strength lies in his ability to articulate his thoughts and to use reason and make clear choices to solve

problems. Fortunately, the video perfectly records and documents GW as he shares deep thoughts and feelings and compassion and as he candidly recalls and retells his adventures and disappointments. The video also indicates that GW uses a full range of fine and gross motor skills.

The tick score totals between the three observers indicate each observer made similar observations across each of the designated wellbeing domains. The tick score records are almost even, JGM = 94, LS = 95 and CB = 99. This indicates there are no major discrepancies between the observations across all of the CEAA wellbeing domains.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

GW was born in Melbourne and has been living with a non-specific dementia as a result of an acquired brain injury. GW enjoyment of life is limited by a profound hearing impairment sustained during World War Two; but nonetheless, his bright and quick-witted personality shines through when a communication board is used to good effect. GW enjoyed an outdoor and somewhat adventurous life before entering care. GW does not have a life partner or immediate family and does not appear to have anyone aside from care partners to regularly meeting his immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: the facilitator was able to implement the activity and the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

GW was attentive and interested when he came to the activity and although he appears not to have heard much throughout, he freely enters into the activity and then sustains a very productive engagement. GW is seen to use his well-established creative skills and although he is a “dab hand” at

painting, he nonetheless takes the opportunity to explore each creative possibility. After the painting activity is completed, GW launches into deep conversation and he seems to engage fully in the creative “flow” of his storytelling. GW’s contribution to the activity is typified by a trusting personal engagement with the facilitator and an appearance of quiet enjoyment when sharing his story.

The wellbeing assessment

GW’s overall participation demonstrates that the lived experience of the art activity and the follow on conversation, in terms of Kitwood’s identity and personhood wellbeing indicators, contributed to his wellbeing at the time. And, as a result, he reached and maintained a relatively high state of wellbeing during his engagement in the phenomenon.

Molly H. (MH)

Born in Birmingham, England, on 21.01.1918

THE CASE STUDY INTERVIEW

After lunch on the afternoon of 22.03.10, Molly and I talked about Vera Lynn and life in Birmingham during the war. Molly said she didn't go out much during the war but preferred to stay at home because Birmingham took "a pounding" during the Luftwaffe air raids.

Molly and I talked about her school days and she told me that she reached high school level and her memory of her time at school was that it was very strict. Molly didn't remember doing any or much drawing except during geometry, but she remembered learning to read and write at school and the technical skills she had to master in the penmanship exercises set by her teacher.

Molly married Bill Hall who had been a soldier in a Scottish regiment during WW1 and the couple had no children together. The couple immigrated to Australia during the 1950s. Molly is a very private person who has a great love of words, both written and spoken. She relishes the crossword in the daily paper and reading magazines and spends most of her time listening to talk back radio each day.

THE ART ACTIVITY

Molly concentrated and worked for an astonishing seventy-two minutes on the afternoon of the 27.08.10. I use the word 'astonishing' reservedly as Molly was one of the artists' who participated, in a very brief engagement of less than five minutes, on the World Alzheimer's Day artwork in 2007. Colette very skillfully brought Molly to the activity by saying that Dr. Zhu, her doctor, thought "it might be good for her" and, as a result, Molly was very eager to please him.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Molly was delighted to paint the female singer's hair red in a colour that was quickly and playfully dubbed "the Julia Gillard red". Molly then continued on to paint with great dexterity and flair, in what can only be described as a marathon, the circle background behind the singers, then the tea cup, and the tea, and finally the piano keys. On more than one occasion, I presented Molly with the opportunity to end the exercise voluntarily, but she did not pick up on the cues and eventually I had to call a halt to the activity myself because Molly started to look physically tired and lunchtime was pending.

Post art activity observations of the lived experience

Molly's painting skills are well established and throughout the activity she displayed a keenness to attempt and complete the next section or new step. Molly has an ability to concentrate and become totally involved in the work at hand. Molly may be ninety-two years old but she displayed very definite choice and decision-making processes, and she handled the brush with great dexterity in and around tight corners and into difficult spots. She was also really quite definite about her choice and selection of colours.

At one stage Molly requested a tissue and, in my absence looking for tissues, she announced that "[I] should be somewhere else" but she was not sure where. Molly's determination to carry on in my absence indicates that she may be unable to regulate or initiate the end of activity by herself even though she was feeling very tired.

Molly's contribution far exceeded my expectations. The last time we met in 2007, for the World Alzheimer's Day artwork, she worked for an extremely short period of time. The difference this time we attributed mainly to

Collette’s influence and good offices and the idea that Molly’s doctor made the recommendation. Dr Zhu only made the recommendation in passing and although “therapeutic lies” (encouraging participation to please Dr Zhu) are not always recommended or encouraged, in this case it was very beneficial. Molly attained a sense of accomplishment, a mastery over her surroundings and a feeling of completion. It was a job well done and Molly gave every indication she was pleased.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents ‘how’ MH experienced the art activity phenomenon.

Participant’s name: MH	Art activity = 72 minutes
Attachment	Colette brought MH to the activity and she was soon settled because she believed she was there on Dr. Zhu’s orders
Holding	A safe and secure environment was quickly established because of the above factors
Timalation	It was not necessary for the facilitator to sit beside MH as it was soon apparent that she was very capable of participating without assistance
Relaxation	MH seemed comfortable and relaxed and at times even eagerly asked the facilitator what was the next section to do
Celebration	MH appeared free of any constraints or worries as she participated
Play	MH worked independently even when the facilitator briefly left the activity to find her a tissue
Creation	MH used her well established painting skills and techniques to the best of her ability
Giving	MH appeared to have attained a palpable sense of accomplishment and mastery over her environment and cheerfully expressed her gratitude

MATRIX TWO wellbeing outcomes:

Colette expedited the creation of the safe working space that began MH’s participation. The driving force behind MH’s seventy-two minute participation in the activity was very clearly her desire to please her doctor. Dr Zhu told MH that participation in the activity might be good for her and,

as a result, the ninety-two year old was motivated to use all of her skills, motor and inter-personal, to the best of her ability.

The attainment of mastery over her environment, combined with MH's desire to please Dr Zhu by demonstrating her artistic accomplishments, indicates a strong sense of self-worth and wellbeing.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents 'what' MH experienced during the art activity phenomenon.

Participant name: MH	Length: 72 mins		
Assessors and assessment method - tick scores	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	2	1	2
M2. Recites			
M3. Invents memories			
Attention			
A4. Levels of attention	4	4	4
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	6	8	7
L7. Uses key words/simple sentences/body language	5	6	6
L8. Uses humour when writing			
L9. Uses humour when speaking	4	4	4
L10. Uses elaborate/informative descriptions			
L11. Uses facial expressions to communicate understanding	7	6	8
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			

P16. Responds to comments - shows compassion and/or reflections	1	6	5
P17. Shows self-esteem/confidence	3	3	2
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems	5	9	6
R20. Makes clear decisions and choices	12	6	7
Emotions			
E21. Uses facial expressions to express moods and emotions	3	2	3
E22. Expresses mood in visual display	1	1	1
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	53	56	55

MATRIX THREE wellbeing outcomes:

The CEAA tool indicates that MH responds to questions with complete grammatical sentences, she also responds to humour and uses a wide range of facial expressions and body language to communicate her enjoyment and satisfaction with her participation in the art activity.

Both the CEAA tool and the video record document that MH understood all parts of the activity and freely and fully participated using fine and gross motor skills. During the activity MH is observed requesting further information to help her complete tasks by asking the facilitator “what is next?” and “what colours have you got?”, and just “tell me where to put it”. MH enquired of the facilitator “do you mean here?”, and then “we can always give it a try”. MH is seen to be very particular about staying between the lines and takes great care to mop up any spills with a tissue. MH totally focuses on painting and her rhythm is not unlike an action that might be used when icing a cake. Her brush strokes are punctuated occasionally with a mid-air flourish of the brush. All of these actions indicate that MH retains a strong ability to reason and make clear choices and solve problems. When

the facilitator asked MH if she enjoys painting she confided that, “painting is something to do”.

The tick score totals between the three observers indicate each observer made similar observations across each of the designated wellbeing domains. The tick score records are almost even, JGM = 53, LS = 56 and CB = 55. This indicates there are no major discrepancies between the observations across all of the CEEA wellbeing domains.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

MH was born in Birmingham, England, and immigrated to Australia with her partner in the 1950s. MH has been living with non-specific dementia and in care for over five years. MH has a shy and reserved personality. MH’s life partner is deceased, but one of her nieces appears to be instrumental in regularly meeting her immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: the facilitator was able to implement the activity and the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

MH, although very shy and quite reserved, came to the activity and although she did not say much throughout she eagerly entered into the activity primarily to please her doctor and, as a consequence, sustained a very long and very productive engagement. MH seemed to engage fully in the creative “flow” of the activity and used her well-established skills to the best of her ability. MH asked appropriate design questions and took every opportunity to explore each creative possibility as it is presented. MH’s contribution to the activity is typified by what appears to be a commitment to the process to please her doctor and an appearance of quiet enjoyment and satisfaction

in her personal achievements.

The wellbeing assessment

MH's overall participation demonstrates that the prospect of pleasing Dr Zhu during the lived experience of the art activity, in terms of Kitwood's identity and personhood wellbeing indicators, was one factor that contributed to her wellbeing at the time. Overall, MH reached and maintained a relatively high state of wellbeing during her very long and productive engagement in the phenomenon.

Terence McC. (TMc)

Born in Middlesbrough, England, on 02.11.1922

THE CASE STUDY INTERVIEW

I attempted to interview Terry, to hear his life story on the afternoon of 23.03.10, but unfortunately his hearing impairment made my efforts most difficult to sustain. Colette was able to fill in some biographical details.

Terry was born in Middlesbrough in the UK in 1922 and joined the Royal Navy in 1940 as soon as he turned eighteen. After basic training, Terry served as a submariner in the Pacific theatre of war tracking Japanese fleet and troop movements. Terry's active service in the Royal Navy has given him a lifelong interest in military strategy and naval history, particularly the fine art of submarine warfare. Terry is also very knowledgeable about the political leaders and the political climate of the times.

After the war Terry served his apprenticeship in boilermaking and became a "fitter and turner" in the Royal Navy. It was this trade, in the services, that eventually brought him to Australia in the mid-1950s. Terry had married Ethel, who was born in Wales, and the couple emigrated to Australia soon after aboard the "Iberia" on 24th July 1955. The couple settled in the Highett/Cheltenham area and soon bought their first car, a Ford Prefect. The following year, 1956, their first son Robert was born. In quick succession, their daughter Frances was born in 1957. The couple's family was complete after the birth of John in 1963.

Terry had various jobs as a boilermaker and kept up his interest in English football and horse racing. The couple led a simple family life together whilst Terry cultivated, and became very knowledgeable about, growing roses.

THE ART ACTIVITY

Terry worked for a total of eight minutes on the morning of 29.03.10. Terry was happy to paint on the blue sea panel of the artwork in recognition of his service in the Royal Navy. I initially introduced the activity using the gold and red submariner's badge worn by former and returned naval personnel. Terry immediately recognized the red crown and badge and then continued by saying that it was his service in the Royal Navy that had brought him and his wife to Australia in the 1950s.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Terry worked for about four two and a half minute stints. He picked up the brush and painted skillfully with short dabbing strokes. At the end of about eight minutes he said "I am getting tired now" and laid down the brush.

Post art activity observations of the lived experience

Later, Terry was drawn back to the activity in the afternoon and sat for quite a while, about fifteen minutes in total, quietly enjoying a rest and listening to Bing Crosby. Terry was very relaxed as he watched and carefully observed me whilst I did some work preparing an area for some new participants.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents 'how' TMc experienced the art activity phenomenon.

Participant's name: TMc	Art activity = 8 minutes
Attachment	TMc was brought to the art activity by care staff and although his advanced Alzheimer's like dementia and his profound hearing impairment hampered communication he was happy to chat with the facilitator
Holding	A safe and secure environment was quickly established
Timalation	TMc's hearing impairment and advanced Alzheimer's like dementia made it necessary for the facilitator to sit next to him and assist him to get started in the process
Relaxation	Until he grew too tired and quit, TMc appeared relaxed and comfortable
Celebration	TMc was pleased that his service in the Royal Navy was recognized and he gave the impression of being free of cares
Play	Advanced Alzheimer's like dementia prevented TMc from working completely independently
Creation	TMc was able to hold the brush and paint in short dabbing strokes for short periods of time, but was unable to dip his brush independently
Giving	At the end of the activity TMc said, "I am getting tired now" and then "thank you"

MATRIX TWO wellbeing outcomes:

Although TMc had to be assisted at each stage of the process by the facilitator, he nonetheless smiled and appeared happy and safe in his surroundings. TMc seemed to enjoy dabbing the brush across the canvas to create the ocean waves that are reminiscent of his life at sea. TMc is a very quiet, polite and gentle person and these qualities of his personality have not been lost during the progression of his dementia experience.

Assessing the wellbeing outcomes of any individual with a profound hearing impairment and advanced Alzheimer's like dementia can never be easy, but TMc's occasional comments about his time in the Royal Navy and his non-

verbal clues and signs act as reasonably accurate indicators of his enjoyment of the activity. The fact that TMc was drawn back to the activity later in the day and sat for another fifteen minutes beside the facilitator is also an indicator that the activity generated a “safe psychological space”. The importance of the “holding container” and its role in the creation of a positive response in participants cannot be overstated.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents ‘what’ TMc experienced during the art activity phenomenon.

Participant name: TMc	Length: 8 mins		
Assessors and assessment method - tick scores	JGM Video	LS Live	CB Video
Memory	1	1	1
M1. Reminisces			
M2. Recites			
M3. Invents memories			
Attention			
A4. Levels of attention	2	1	2
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	4	2	1
L7. Uses key words/simple sentences/body language	4	4	3
L8. Uses humour when writing			
L9. Uses humour when speaking			
L10. Uses elaborate/informative descriptions			
L11. Uses facial expressions to communicate understanding	3	2	
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			

P16. Responds to comments - shows compassion and/or reflections			
P17. Shows self-esteem/confidence			
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems			2
R20. Makes clear decisions and choices		1	
Emotions			
E21. Uses facial expressions to express moods and emotions		1	4
E22. Expresses mood in visual display			1
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	14	12	14

MATRIX THREE wellbeing outcomes:

The CEAA tool and the video capture the reality that TMc is only able to respond to conversations with difficulty because of a profound hearing impairment and advanced Alzheimer’s like dementia. Considerable delay in word processing means he is limited to the use of simple one or two word sentences in response to questions. Nonetheless, TMc effectively uses facial expressions to indicate both his mood and his understanding of the activity. The video images capture his enjoyment in the activity and his ability to make very simple comments about his life in the Navy. TMc was able to complete the activity but had to be assisted by the facilitator at each stage.

The tick score totals between the three observers indicate each observer made similar observations across each of the designated wellbeing domains. The tick score records are almost even, JGM = 14, LS = 12 and CB = 14. This indicates there are no major discrepancies between the observations across all of the CEAA wellbeing domains.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

TMc was born in Middlesbrough, England, and has been living with Alzheimer's like dementia for over five years. TMc enjoyed a fulfilling life in the Royal Navy, and then, after he immigrated to Australia, he worked in heavy industry before entering care. TMc's life partner and supportive family are instrumental in regularly meeting his immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: even though the facilitator had to fully assist TMc to implement the activity, the independent evaluators successfully documented some signs and wellbeing outcomes. The assessment tools proved sensitive enough to capture some useful information.

TMc came to the activity and the facilitator had to aid and assist him at all stages of the activity, but once started TMc demonstrated he could hold the brush and paint independently. Irrespective of his hearing and cognitive impairment, TMc's contribution to the activity is perhaps best judged by his occasional comments, his non-verbal communication and his facial expressions that manifest what appears to be a visible enjoyment in the activity.

The wellbeing assessment

TMc's overall wellbeing outcomes are difficult to access due to the factors above. But, the lived experience of the art activity, in terms of Kitwood's identity and personhood wellbeing indicators, appeared to contribute something to TMc's wellbeing at the time. In addition, TMc returned to sit with the facilitator later. From this it may be deduced that he probably reached a moderate state of wellbeing from the overall phenomenon.

Mimma P. (MP)

Born in Calabria, Italy, on 02.04.1934

THE CASE STUDY INTERVIEW

I had a conversation with Mimma on the afternoon of 22.03.10. She told me something about her life speaking very softly in both Italian and English as she proudly showed me photographs of her family. Mimma immigrated to Australia in 1958, during the post WW11 mass migration of Italians.

Mimma was able to tell me more about her life history when Dawn, an Australian friend and translator was visiting on the afternoon of 23.03.10. Dawn was able to translate as Mimma told me her story. Mimma was born in the village of Vibo Valentia, in Calabria, and because the family were very poor farmers she only had about five years of formal schooling. After Mimma learned to read and write she joined her five sisters and her brother as they worked together in the fields growing a variety of different kinds of vegetables.

Mimma's father came to Australia first in 1957 and then he sent for the rest of the family who migrated the following year. Mimma says the decision to leave everything behind was very hard, but they came as a family to support one another and she felt special because she had Santoro, her "brand new husband". Mimma said she was already 24 years old, considered old to get married in Calabria, and although it was an arranged marriage Santoro was a very good husband and provider for their three sons and one daughter, who were all born in Australia, after they settled in the bayside suburb of Mentone.

Mimma says she was happy to spend her life as a homemaker, cooking pasta and traditional Italian meals and caring for her growing family, whilst Santoro worked hard building a successful commercial and domestic tiling business.

THE ART ACTIVITY

On the afternoon of 06.08.10, Colette brought Mimma to B wing and then the art activity. Mimma sat with me for about five minutes until she was up to having a try at the artwork. Mimma has quite a pronounced tremor in both hands and today they seemed to be quite pronounced, but she picked up the brush and applied a few brush strokes on the “yellow brick road”.

After a few dabs, Mimma, indicating her dissatisfaction with her output, put down the brush. Later, when her arm was fully supported, Mimma was able to demonstrate that she is able to participate. Interestingly, the rigors seem to noticeably decrease during the activity. After another five minutes of painting some yellow paint on the “yellow brick road” panel, she put down the brush and indicated she had had enough.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Although I have planned a special intervention, to assist Mimma to use her tremor in a positive way by dabbing patterns on an area of the artwork, when she was once again presented to contribute, for the second time, the artwork was not at a sufficiently finished enough stage. Instead, the second time I assisted Mimma by holding her elbow again and gently pushing her hand forward until the brush made contact with the surface. Mimma, then in full control, placed three perfectly formed circles on the surface completed with a single stroking movement - although slightly blurry at the edge due to her tremor. Mimma seemed delighted with the outcome, took a slight break, but once again became quite distressed when, on returning to the activity to complete some more circles, she was overtaken by a quite pronounced tremor. After quite some reassurance from the facilitator, about five minutes later a much calmer Mimma indicated with her thumb that she wanted to leave and quit the activity.

Post art activity observation of the lived experience

During the activity, as the tremor became progressively worse, Mimma put down the brush and then spoke at length and great in detail about her disability and the experiences that both her mother and father had living with the same disability. The activity provided Mimma with an opportunity to share her grief and this seemed to pacify her.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents 'how' MP experienced the art activity phenomenon.

Participant's name: MP	Art activity = 8 minutes
Attachment	A rapport was established quickly because MP was introduced to the activity by Colette and the facilitator had spent some time over the previous weeks gaining MP's confidence
Holding	A friendly and "safe" environment was quickly established because of the factors above
Timalation	Because of MP's disability, it was necessary for the facilitator to sit very closely by her, and physically assist her, by supporting her elbow
Relaxation	MP appeared not able to fully relax into the activity because of her acute awareness of her disability which she discussed at some length with the facilitator
Celebration	MP's disability appeared to greatly influence both her participation and her self-perception of her ability to engage in the activity
Play	On completion of the three yellow concentric circles MP appeared to be pleased with the outcome
Creation	MP appeared disappointed that she was not able to participate more fully because of her disability
Giving	MP expressed gratitude for her participation and apologised for what she perceived as her shortcomings

MATRIX TWO wellbeing outcomes:

MP speaks Italian and a language barrier exists, so the facilitator worked hard to build a friendly relationship with her before the activity. As a result, MP was happy to come to the activity and allow the facilitator to assist her

at every stage of the activity. MP apologised for her disability but expressed gratitude and thanks for the opportunity to participate.

Wellbeing is very difficult to assess in an individual where a language barrier exists. MP appears to be acutely aware of her disability, is ashamed of its shortcomings and is sad that she can no longer participate at a level that she once might have. Although all of these factors have an impact, MP was nonetheless happy to be part of the activity when others were not. This shows MP's ability and capacity to rise above obstacles and embrace life and be part of it which all indicate her wellbeing.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents 'what' MP experienced during the art activity phenomenon.

Participant name: MP	Length: 8 mins		
Assessors and assessment method - tick scores	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	4	3	2
M2. Recites			
M3. Invents memories			
Attention			
A4. Levels of attention	1	1	3
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	2	3	9
L7. Uses key words/simple sentences/body language	2	3	10
L8. Uses humour when writing			
L9. Uses humour when speaking			
L10. Uses elaborate/informative descriptions	2	2	
L11. Uses facial expressions to communicate understanding	3	3	3
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a	1	1	

story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections	2	2	
P17. Shows self-esteem/confidence			
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems	1	1	5
R20. Makes clear decisions and choices	3	2	4
Emotions			
E21. Uses facial expressions to express moods and emotions	1	3	8
E22. Expresses mood in visual display	3	3	5
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			2
E26. Shares wisdom/life experiences			1
E27. Discusses religion and tradition and cultural/spiritual/customs			1
TOTAL SCORE	27	28	53

MATRIX THREE wellbeing outcomes:

The CEEA tool indicates, and the video records, that MP uses grammatical sentences in her mother tongue, and uses a wide range of facial expressions and body language to communicate her emotions. Even though MP appears pleased with her contribution, the enjoyment and satisfaction that MP might have experienced during her participation in the art activity is marred by her disability and her self-perception of that disability.

The scoring between the three observers is uneven. It is uneven across more than one question and this creates a discrepancy in the final observational scores (JGM = 27, LS = 28 and CB = 53). JGM and LS do not speak Italian and the discrepancy is probably due to a language barrier because JGM and LS scored almost the same on each question across the whole tool. By

comparison, CB, who understands Italian, and is familiar with this participant's personality, and was able to understand MP's spoken comments whilst she observed the video of the activity. CB was therefore able to gain more information, particularly on questions that relate to language and culture, than the other observers. Personal knowledge of this participant and spoken Italian appears to have influenced CB's overall score, which is almost double that of the other two scorers.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

MP was born in rural Calabria and immigrated to Australia in the late 1950s. MP has been living with non-specific dementia and a neurological condition that causes a tremor for some time. MP has a very likeable personality and she enjoyed her role as a mother and cook and homemaker before entering care. MP's life partner is deceased and her daughter and grandchildren are instrumental in regularly meeting her immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: the facilitator was able to implement the activity and the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

MP came to the activity with an accepting attitude and her comments throughout indicate she freely participated in the activity she took the opportunity to participate and use her remaining skills to the best of her ability until her tremor halted the activity. MP's contribution to the activity is typified by her positive willingness to engage and enjoy the activity until her tremor forced her to stop.

The wellbeing assessment

MP's overall participation demonstrates that the lived experience of the art activity, in terms of Kitwood's identity and personhood wellbeing indicators, contributed to her wellbeing at the time. And, as a result, she reached a moderate state of wellbeing during the phenomenon.

Lorna G. (LG)

Born in Mirboo North, Victoria, on 17.09.1920

THE CASE STUDY INTERVIEW

I spoke with Lorna on the morning of 23.03.10 after morning tea. She told me she was born in Mirboo North in Gippsland and grew up as one of nine children in a small house on the top of a hill with beautiful views. The family lived well, not least because her mother was a wonderful cook and there “was always plenty to do to help Mum”. Lorna loved going to Mirboo North Primary School, even though it was a two-mile walk either way each day. Her Dad only had a horse and “jinka” to get about in. Lorna told me she remembered drawing and painting at school, but hasn’t painted since because she had too much to do caring for her family. Lorna says she has always loved dancing, ever since she and her sister used to dance on the table top as little girls.

Lorna married Bob, who was a carpenter, and they lived in rural Victoria and ran a dairy farm near Rochester. The couple had a son, Rob, and twin daughters, Rosemary and June.

When Bob became ill, the couple moved to Melbourne to be near their children and Lorna’s sisters. It was while living in Highett, after Bob died that she met JO (her partner and another Nixon Hostel resident). Lorna’s sister, Gladys, was here this morning and they sat chatting with JO about their friendship together living in Highett.

THE ART ACTIVITY

Lorna painted for about seven minutes on the afternoon of 06.08.10 in a “trial run” on the first day of the art activity. She explained she had been quite a painter and decorator in the past, she also said she could not see the images clearly enough to stay within the lines. This did not matter as she was painting the sea panel at the bottom of the work.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

Lorna painted in continuous dabbing strokes working from left to right across the work. Although Lorna was sure she could see the black outlines, she did seem to follow the lines quite instinctively. Lorna stopped and although she showed obvious signs of tiredness, such as blinking her eyes and taking deep breathes, she continued on until I suggested she stop. The noise of the workmen at the facility was very disrupting, and after a few minutes Lorna put down the brush and seemed happy, if not a bit relieved, when another participant came to the table to start her contribution.

At the end of the activity, when I complimented Lorna on her contribution, she retorted, in her usual and humorous and straight forward manner, “Oh!” she said, “they just look like scribbles to me!” On departing the activity area Lorna, in an obvious display of exuberance, launched into the most incredible “soft shoe” shuffle, in time with the music and the song “hey good looking, what ya got cooking”, which was playing on the CD player in the lounge. Lorna stood opposite Pam in the middle of the lounge room floor and they began dancing and singing and laughing together.

Lorna’s daughter Rose appeared just as I was starting the activity with Lorna a second time on the morning of 03.09.10. I decided to work with Lorna again because the first time she didn’t have her glasses on and I wanted to see if wearing her glasses made a difference to her enjoyment of the activity.

Lorna and Rose together painted and decorated the “Tea for Two” teacups and talked and reminisced throughout the whole activity. The activity was punctuated with songs and jokes, and the swapping of recipes and comments about life on the farm in Gippsland. The activity lasted for a good thirty-five minutes until it was time for Lorna to go to lunch. It was a very

special activity that Rose can remember with some warmth and pride if she wishes.

Post art activity observations of the lived experience

Lorna was extremely dexterous with a small brush and traced the inside of the cups and the handle with a skill she did not display on the first occasion, much to do with seeing properly with her glasses on, and probably being more relaxed and less nervous with Rose sitting beside her. Lorna who turned ninety on September 17, 2010, continues to sing and yodel and dance the “Charleston” when taking part in structured activities and goes about her life with good humour and natural wit, with quick quips such as “I am so hungry I could eat the plate”.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents ‘how’ LG experienced the art activity phenomenon.

Participant’s name: LG	Art activity = 35 minutes
Attachment	The activity had been underway for a couple of minutes when LG’s daughter Rose arrived and so the activity immediately got off to a good start
Holding	Rose ensured that a safe and secure environment was established immediately
Timalation	LG sat between Rose and the facilitator
Relaxation	The activity was punctuated with jokes and songs and reminiscences
Celebration	LG smiled and laughed and yodelled giving every indication that the activity was enjoyable
Play	LG painted and decorated the tea cups and saucers independently
Creation	LG made colour choices and used the brush with dexterity and skill
Giving	Both LG and Rose expressed gratitude for the activity and their joint participation together

MATRIX TWO wellbeing outcomes:

The arrival of Rose ensured that a safe and secure environment was established immediately and this combination of circumstances meant that

the activity developed into much more than was expected. The activity became an opportunity for both women to express affection and gratitude, and because it was punctuated with laughter and reminiscences it brought pleasure and joy to all participants and many on-lookers.

It is unusual in an aged care facility for a mother and daughter to engage in creative activity together, and the opportunity to reminisce and sing and paint together is very rare and very special. These activities reinforce many old bonds between two individuals as well as cementing the cornerstones of wellbeing, not least respect and love and affection, but also emotional security and acceptance.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents 'what' LG experienced during the art activity phenomenon.

Participant name: LG	Length: 35 mins		
Assessors and assessment method - tick scores	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	7	3	4
M2. Recites			
M3. Invents memories		2	
Attention			
A4. Levels of attention	4	4	3
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	9	7	2
L7. Uses key words/simple sentences/body language	9	7	28
L8. Uses humour when writing			
L9. Uses humour when speaking	2		3
L10. Uses elaborate/informative descriptions			
L11. Uses facial expressions to communicate understanding	3	5	
L12. Makes vocal responses to music	3	3	
Psychosocial			

P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections	4	4	
P17. Shows self-esteem/confidence	3	1	
P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems	3		2
R20. Makes clear decisions and choices	10	3	7
Emotions			
E21. Uses facial expressions to express moods and emotions	3	2	3
E22. Expresses mood in visual display	3	2	2
E23. Expresses mood in music	3		2
E24. Expresses mood in anecdotes and stories			3
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	66	43	62

MATRIX THREE wellbeing outcomes:

The CEAA tool indicates that LG uses complete grammatical sentences and a wide range of facial expressions and body language to communicate with others. LG's outgoing personality and her love of singing and dancing and joking shine through and it shows in her enjoyment and satisfaction with the art activity. The arrival of LG's daughter Rose at the start of the activity was a bonus as it eased LG into the activity, and then ensured that it became something much more meaningful and memorable for both individuals. The activity was punctuated with LG joining in with the singing of *My Blue Heaven* and *Tea for Two*, and discussions of cooking and food preparation. In the periods when LG was resting and observing, she was alert and followed the conversations with interest, even adding the

occasional comment, such as the tang of Worcestershire Sauce is “very tasty”. LG displayed a full range of fine and gross motor skills and was happy to make choices and decisions throughout.

The scoring between the three observers is uneven on two questions. They are question seven, concerned with language skills, and question twenty to do with decision-making ability. The final observational scores are JGM = 66, LS = 43 and CB = 62. JGM and LS scored very similar observations for question seven, JGM = 9, LS = 7, but CB scored 28. As LG is reasonably articulate, it would appear that CB scored single word responses within sentences for question seven, whereas JGM and LS did not. This explanation, over other possible explanations, appears to have influenced CB’s overall score. On question twenty, LS comments that LG’s daughter exercised an undue influence on her mother’s decision-making process and this accounts for her low score on that question.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

LG was born in rural Gippsland and has been living with non-specific dementia for almost a decade. LG has a happy and fun loving personality and enjoyed country life in rural Victoria before moving to the City and then entering care. LG’s partner and her daughters and her large supportive family are instrumental in regularly meeting her immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: the facilitator was able to implement the activity and the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

LG came to the activity with her usual optimistic outlook, but the

serendipitous arrival of her daughter soon after meant that she freely entered into the activity, and with her daughter's encouragement, took the opportunity to use her remaining skills to the best of her ability. LG's contribution to the activity is typified by her engagement and obvious enjoyment in the activity and conversation.

The wellbeing assessment

LG's overall participation demonstrates that the lived experience of the art activity with Rose at her side, in terms of Kitwood's identity and personhood wellbeing indicators, contributed to her wellbeing at the time. And, as a result, she reached and maintained a relatively high state of wellbeing during the phenomenon.

Noel A. (NA)

Born in Calgoa, North Western Victoria, on 08.01.1931

THE CASE STUDY INTERVIEW

I was chatting with Noel on the afternoon of 23.03.10 when his wife Pam arrived for a crochet lesson with Bridie, another Nixon Hostel resident. Noel tells me he was born in Calgoa near Swan Hill where his family ran the local telephone exchange, post office and general store. Noel's boyhood was spent riding horses, fishing and playing football and cricket. He went to high school at St Patrick's, a Christian Brothers college in Ballarat.

When Noel was about eighteen he came to Melbourne to live with an aunt in Middle Park and was soon playing football and cricket for South Melbourne. Sport and membership at these clubs played a very important role in the first three decades of Noel's life and work. Noel is a very sociable and was a successful travelling sales representative for the Spalding sports company, selling golfing equipment. He visited many professional golf courses around Australia and overseas. He also enjoyed hosting an open house "happy hour" once a week for neighbours. He liked the house and garden kept in an immaculate condition.

Noel's photo album is full of photos of the family taking caravan and camping holidays. Noel says he has had two wives and has two children by his first wife, their names are Jan and Liza. Noel is particularly proud of Jan, who has a PhD in Marine Biology, and does not see Liza often. Pam is his second wife who he married in 1985.

Noel says he has only painted houses before and only with a four-inch brush. He is not sure if he can paint on a canvas but is prepared to give it a go.

THE ART ACTIVITY

Noel came to the activity on the afternoon of 23.08.10 as he was visiting C wing to see Colette. Noel often sits in Colette's office and they chat about life.

The research question:

- What skills did this individual living with dementia exhibit during the art activity?

After a lengthy preamble Noel was quite definite that he did not want to “bugger it up”, as he put it, but was delighted to sit and chat as I went about the process of editing and patching up thin, non-opaque parts of the artwork. Noel soon settled into his director's role, applying keen observation, and was quick to pick up drips and mistakes. This involvement in the activity was so relaxing that on one occasion, when I went to the “rubber maid” to get more colours, Noel took a “cat nap” for a minute or so.

Post art activity observations of the lived experience

Since this activity Noel has been very interested in the work and asks me every time he sees me “is the job complete yet?” Assuming his mantle as the project manager, Noel is quite insistent that his wife Pam should be informed and kept up to date on the progress of the work. Pam saw the work at the residents' meeting a few weeks prior and was surprised at the level of professionalism. When the process was explained to her in more detail she appreciated the reasons and the structure of the process and made some positive comments.

MATRIX TWO - the eight Kitwood tenets

MATRIX TWO documents 'how' NA experienced the art activity phenomenon.

Participant's name: NA	Art activity = 36 minutes
Attachment	NA was sitting in Colette's office when she brought him to the activity and a rapport with the facilitator was quickly established
Holding	A safe and secure environment was also quickly established, but NA exercised choice and self-determination by deciding not to actively participate in the painting part of the project
Timalation	NA sat beside the facilitator observing and directing proceedings
Relaxation	During his "active" passive participation NA was so relaxed that he took a short cat nap
Celebration	NA was concerned that he would "bugger it up" and that probably explains his choice and/or reluctance to paint
Play	Although NA chose not to paint he did however actively direct the editing and fix-ups
Creation	NA displayed his former business and managerial skill when directing the editing process
Giving	Since NA's participation he has followed the progress of the work with great interest

MATRIX TWO wellbeing outcomes:

With Colette's help a safe place was quickly established. NA was fully consulted but still declined the opportunity to paint. Instead, NA soon assumed the role of supervisor of works. In this position he was not placed under any pressure, or put in position to "bugger it up", or get anything wrong. NA seemed to enjoy his role surveying the work, picking up and pointing out mistakes. The activity under these conditions was virtually "risk free". NA was afforded an opportunity to follow the progress after his participation.

NA's "active" passive participation can be seen to be of as much benefit to him as the participation of any other participant in the activity. Whilst the full reasons for NA's choice not to paint were not articulated, his perfectionism may have played a part. Respecting NA's decision not to participate afforded him an opportunity to exercise choice and self-

determination and thus regain a semblance of control over his environment. This probably made a contribution to his overall wellbeing. NA's supervisory role in the activity was arguably as full and productive as any other participant and it brought him enjoyment and satisfaction.

MATRIX THREE - the CEAA tool, incorporating three assessors tick scores
 MATRIX THREE documents 'what' NA experienced during the art activity phenomenon.

Participant name: NA	Length: 36 mins		
Assessors and assessment method - tick scores	JGM Video	LS Live	CB Video
Memory			
M1. Reminisces	1	3	1
M2. Recites			
M3. Invents memories		1	
Attention	4	4	4
A4. Levels of attention			
Language			
L5. Produces complete written sentences			
L6. Produces complete spoken sentences	8	9	2
L7. Uses key words/simple sentences/body language	10	4	45
L8. Uses humour when writing			
L9. Uses humour when speaking	6	7	9
L10. Uses elaborate/informative descriptions			
L11. Uses facial expressions to communicate understanding		3	
L12. Makes vocal responses to music			
Psychosocial			
P13. Attracts/holds attention telling a story			
P14. Attracts/holds attention singing a song			
P15. Attracts/holds attention dancing/performing/playing an instrument			
P16. Responds to comments - shows compassion and/or reflections	2	4	
P17. Shows self-esteem/confidence	1	2	

P18. Shows interest in grooming/clothing			
Reasoning/Problem solving			
R19. Shows insight/solves problems	8	8	3
R20. Makes clear decisions and choices	3	3	5
Emotions			
E21. Uses facial expressions to express moods and emotions	2	1	2
E22. Expresses mood in visual display	2	3	
E23. Expresses mood in music			
E24. Expresses mood in anecdotes and stories			
E25. Shares thoughts and speaks from the heart			
E26. Shares wisdom/life experiences			
E27. Discusses religion and tradition and cultural/spiritual/customs			
TOTAL SCORE	48	52	71

MATRIX THREE wellbeing outcomes:

The CEAA tool and the video record document that NA uses complete grammatical sentences and a wide range of facial expressions and body language to communicate his satisfaction with his role in the art activity. NA's sense of humour is evident when he tells the facilitator that everybody needs a "warm bum to heat the seat" and other asides.

NA makes a definite decision to decline the opportunity to paint very quickly. He says his decision is because he does not want to "bugger it up". NA quickly assumes and seems to relish a supervisory role, as he remains seated beside the facilitator. He is interested in "where the artwork is going when it's finished" and who has "done the work" and has his wife Pam, seen it. The video documents NA as he carefully runs his hands across the surface and as he surveys the artwork and points out odd drips and spots and mistakes to the facilitator. NA's absorption and enjoyment in his passive but "risk free" contribution to the art activity is so relaxing that at one point he cat naps when the facilitator's back is turned while mixing paint.

The scoring between the three observers is uneven JGM = 48, LS = 52 and CB = 71. This has created a discrepancy between the observational scores

particularly on question seven. This question relates to language skills and the tool asks if the participant uses key words and simple sentences and body language. For question seven, JGM scored 10 and LS scored 4, but CB scored 45 observations. NA is quite articulate and CB appears to have scored single word responses within complete sentences and this alone appears to have influenced CB's overall score and accounts for the discrepancy.

The research question:

- What signs of wellbeing, if any, including engagement, concentration and emotional response, were observed during the one-on-one art activity?

NA was born in rural Victoria and spent an idyllic early life riding horses in the bush. NA was admitted to care about two years ago, but he has been living with non-specific dementia for some time. NA states that he was fulfilled during his long employment in sporting goods sales and management positions before entering care. NA's very supportive partner and her daily visits are instrumental in meeting his immediate wellbeing needs.

The wellbeing evidence collected over both MATRIX TWO and MATRIX THREE indicate the following: the facilitator was able to implement the activity and although NA's engagement was "passive", the independent evaluators successfully documented multiple signs of wellbeing outcomes that the assessment tools are designed to capture.

NA was brought to the activity and he freely made the decision to stay and take the opportunity to explore and enjoy its possibilities through passive engagement. NA appears to quickly relax in the facilitator's company and he finds unexpected enjoyment in the activity, particularly in his directorial and supervisory role.

The wellbeing assessment

NA's passive participation but keen interest in the art activity demonstrates that his lived experience, in terms of Kitwood's identity and personhood wellbeing indicators, contributed to his wellbeing at the time. And, as a result, he reached a high state of wellbeing during the phenomenon.

Appendix B.

The Getting to Know You artwork.
1.5 metres deep by 2.5 metres wide.



The “*Getting to Know You*” artwork description

The musicals of the 1940s and 50s are usually popular with most residents living in care. Most enjoy a sing-a-long whilst others are happy just to listen or beat time to the music with their feet. The theme of this particular artwork was decided in the very early days of the project, just as I was beginning to get to know the participants. The project’s name emerged when I arrived at the facility one morning and the overture medley of tunes from *The King and I* was blaring out from the CD player in the resident’s lounge room.

Led by an activity worker, the residents are in their chairs, and as the last notes fade, they sit in quiet anticipation of the next offering. Very soon the opening notes of a new song are audible, and after the first few bars when a familiar tune become recognizable, one or two residents launch into full song. Buoyed by enthusiasm, the other listeners are soon mouthing the words to the chorus and their hands sway in time to the music. *The King and*

I is a favourite from my childhood and I soon find myself singing along to. In the process I realise that I am getting to know each of the singers better.

The *Getting to Know You* artwork celebrates the life and times of the participants through popular songs from their heyday. It is not a complex work, but the colours harmonize and could be said to sing in time to their own beat. The two central figures loom through a ship's porthole. This man and woman represent the migrant experience, on the sea journey of a lifetime to Australia, on the other side of the world. They sing with anticipation of a new life beyond the European battlefields. They sing to set the scene.



The Nixon residents come from all corners of the globe. The swaying coconut palms represent idyllic childhoods spent in the Seychelles and Mauritius and Ceylon, or the war service memories of returned soldiers, who served in Bougainville and behind enemy lines in Borneo during World War 2. “Anchors Away” acknowledges the Royal Navy Submarine Corp and the sacrifice of the fighting men and women of the Royal Australian Navy.



The blue birds symbolise leaving Great Britain and sadness in bidding farewell to its white cliffs for the last time. They also acknowledge the Nixon Hostel, ex-service personnel who served with the Royal Australian Air Force and the Royal Air Force and others within the resident community who journeyed from England, Scotland, Wales and Ireland to make Australia their new home.





The Home Sweet Home panel is symbolic of a human desire to live in peace and harmony, and to forge new friendships in the hope that sharing life's triumphs and tragedies over a cup of tea will somehow ease the burden. We try and stay in tune and dance in step with our partners along the road through life. As we age, we look forward to time spent sipping drinks and relaxing in the sun, and we all hope for a peaceful experience at sunset when our boat's red sails guide us safely into port at the end of our journey.



Appendix C

Art material list.

Canvas: Fredrix artist's canvas - "Dallas", Cotton Duck with uniform medium texture.

Velcro and sewing cotton.

Artwork installation materials: Pine batten, wood screws and staple gun.

One Rubbermaid "art cart".

Paint brushes: Ten, acrylic soft-tipped brushes in assorted sizes.

Paint: Thirty tins of acrylic, non-toxic paint in assorted colours.

Paint tin opener and stirrer.

Four, one litre water jars and a four litre plastic bucket.

Assorted mop-up clothes and/or paper towels.

One box of facial tissues.

Stencils: Assorted handmade and store bought in various themes.

Creative aids: Assorted doilies and sink strainers and stamping blocks.

Tracing paper, adhesive and masking tape, scissors, tape measure, ruler, two C-clamps, lead pencils, eraser and biro.

Ring binder, plastic pockets and spare paper.

Video camera, tripod, extension leads and a powerboard.

Computer, computer cables and video software.



Appendix D (1)

NEXT OF KIN CONSENT FORM FOR PARTICIPANTS INVOLVED IN RESEARCH AT NIXON HOSTEL

We would like to invite the individual described as the participant below to be a part of a study into the relationship between art and wellbeing. The study will specifically investigate how individuals living with dementia engage in a one-on-one art activity, during the production of a large-scale collaborative artwork (2.5 metre by 1.5 metre). During the art activity the study will measure how participation in the activity contributes to each individual's wellbeing. And, secondly, the study will observe how individuals living with dementia use their art and other skills during the activity.

CERTIFICATION BY NEXT OF KIN

I, (Click here to add participant, or next of kin and/or the individual(s) appointed by law) of (Next of Kin's suburb) certify that I am at least 18 years old* and that I am authorized to give my consent for (add name of the participant) to participate in the study:

The relationship between art and wellbeing in individuals living with dementia being conducted by Julie Gross McAdam at Victoria University under the supervision of Professor Maureen Ryan.

I certify that the objectives of the study, together with any risks and safeguards associated with the procedures listed hereunder to be carried out in the research, have been fully explained to me by Julie Gross McAdam and that I freely give my consent for (name of participant) to participate in the below mentioned procedures:

- Paint a section of a communal artwork
- Work at the activity for as long the participant wishes
- Be observed and photographed whilst painting

I certify that I have had the opportunity to have any questions answered and I understand the art activity is free and that (name of participant) will retain the copyright of the artwork image in "joint authorship" at no cost. I understand (name of Participant) can withdraw from the research study at any time and that I can withdraw my support at any time. I understand such withdrawal will not jeopardise (name of Participant) or me in any way.

I have been informed that the information (name of Participant) provides will be kept confidential and used for no other purpose than this research project.

Signed by :

on behalf of:

Date:

Any queries about your participation in this project may be directed to the Principle Supervisor: Professor Maureen Ryan 9919 4179. If you have any queries or complaints about the way you have been treated, you may contact the Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4781

Appendix D. (2)

INFORMATION TO PARTICIPANTS INVOLVED IN RESEARCH AT NIXON HOSTEL AND THEIR NEXT OF KIN

Nixon Hostel residents are invited to participate in a research project

Residents living at Nixon Hostel are invited to participate in a research project entitled : **The relationship between art and wellbeing in individuals living with dementia.** This project is being conducted by a student researcher, Julie Gross McAdam, as part of a PhD study at Victoria University, under the supervision of Professor Maureen Ryan of Victoria University. Many will remember Julie from 2007 when she facilitated the “Memories”, World Alzheimer’s Day artwork at Nixon Hostel.

Project explanation

The study will investigate the relationship between art and wellbeing. The study will specifically observe how residents living at Nixon Hostel engage in a one-on-one art activity, during the production of a large-scale collaborative artwork (2.5 metre by 1.5 metre). During the art activity the study will measure how participation in the activity contributes to each resident’s wellbeing. And, the study will observe how each resident living at Nixon Hostel uses his or her art and other skills during the activity. The project is free and the artwork will remain permanently at Nixon Hostel on completion.

What will the participant be asked to do?

Each participant will be asked to paint a small section of a communal artwork and spend as much time as he or she likes enjoying the activity. Each artist will be assisted by Julie if and when or as required during the activity. During the activity each person will be photographed with Julie while they work together.

What will the participant gain from participating?

Potential benefits include:

- Introduction to new and possibly fulfilling activities that reduce boredom and have the potential to lead to increased wellbeing and renewed interest in life
- The possible discovery of unrecognized creative ability
- Leaving a legacy by contributing to a permanent artwork
- Having fun

How will the information the participant gives be used?

The information will be used to develop new recreation programs and art activities suitable for those living with dementia.

What are the potential risks of participating in this project?

The Victoria University identifies potential risk associated with research. These risks fall under the following categories: physical, psychological, legal and others. To accommodate each potential risk factor:

- The research project will be conducted, at all time, in a safe emotional and physical environment in accordance with Nixon Hostel and each individual's personal responsibility under aged care, privacy and OH&S and discrimination legislation.
- This research project is not a clinical trial and uses no invasive medical procedures or chemical substances.
- The project does use non-toxic art materials and each participant will be fully supervised at all time to decrease any risk of accidental ingestion of art materials.
- The research will be conducted with due consideration of "best practice" principles set out in the diversional therapy national definition of practice guidelines.
- All documentation will be securely stored for the duration of the research project and there after in accordance with the prescribed statute of limitations.
- All documentation and photographs will be used only for the purposes of this research project
- Each participant and researcher will be accorded respect and dignity.
- Each individual is thus free to: decline the opportunity to participate, withdraw from the research project and/or discontinue participation at any time.
- Each individual will retain intellectual copyright to the finished artwork image in "joint authorship".
- A copy of the research report will be available at Nixon Hostel on completion of the research

In the "best practice" conditions that have been considered and planned for this research project there are few, if any, foreseeable OH&S, physical or psychological or legal risks to any participant .

How will this project be conducted?

The project will be conducted at Nixon Hostel. The theme of the artwork is created by the residents during the course of a standard MAC.ART program www.macart.com.au Each participant is then offered an opportunity to paint his or her section of the collaborative work.

Who is conducting the study?

The research will be conducted at Nixon Hostel, Chute Street, Mordialloc.

Principle Investigator: Professor Maureen Ryan, School of Education, Victoria University. Phone: 9919 4179

Student Researcher; Julie Gross McAdam MA, author and facilitator of the award-winning MAC.ART program www.macart.com.au Phone: 9772 0260

Any queries about your participation in this project may be directed to the Principal Researcher listed above.

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4781.

Appendix D. (3)

INFORMATION FOR THE INDEPENDENT ASSESSOR SCORING THE CEAA TOOL

You are invited to participate

You are invited to participate as an independent assessor in a research project entitled: **The relationship between art and wellbeing in individuals living with dementia**. This project is being conducted by a student researcher Julie Gross McAdam as part of a PhD study at Victoria University under the supervision of Professor Maureen Ryan of Victoria University.

Project explanation

The study will investigate the relationship between art and wellbeing. The study will specifically observe how individuals living with dementia engage in a one-on-one art activity, during the production of a large-scale collaborative artwork (2.5 metre by 1.5 metre). During the art activity the study you will be asked to measure how participation in the activity, contributes to each individual's wellbeing using the dementia-specific Creative Expressive Abilities Assessment (CEAA) research tool. The study will also observe how each individual living with dementia uses his or her art and other skills during the activity.

What will I be asked to do?

- You will be asked to attend a full briefing of the research project and undergo one-day training in the administration and use of the CEAA tool. On completion of training, you may be asked to score the tool on one or more occasions for every participant.
- During the research art activity, participants will be asked to paint a small section of a communal artwork. There is no set time limit and you will carefully observe the art activity, for as long as it lasts, whilst you score the tool sitting unobtrusively in a corner
- You may be asked to score the tool for as many as thirty participants. The overall project may last for four to six weeks depending on research project numbers and you will be expected to attend on three days a week for six hours a day for the duration
- You will be asked to give your time freely as part of a "placement" hours allocation for your aged care qualification
- You will be asked to observe and work within Nixon Hostel's ethical guidelines and the parameters of aged care legislation and regulations

What will I gain from participating?

Potential benefits include:

- New and/or increased skills acquisition through knowledge and training and application
- New understanding of individuals living with dementia, including the identification of possible creative capability
- Increased understanding of the role and value of the creative arts therapies in residential aged care

How will the information I give be used?

The information will be used to develop new staff training and recreation programs and art activities suitable for those living with dementia.

What are the potential risks of participating in this project?

The Victoria University identifies potential risk associated with research. These risks fall under the following categories: physical, psychological, legal and others. To accommodate each potential risk factor:

- The research project will be conducted, at all time, in a safe emotional and physical environment in accordance with both the facilities and each individual's personal responsibility under aged care, privacy and OH&S and discrimination legislation.
- This research project is not a clinical trial and uses no invasive medical procedures or chemical substances.
- The project does use non-toxic art materials and each participant will be fully supervised at all time to decrease any risk of accidental ingestion of art materials.
- The research will be conducted with due consideration of "best practice" principles set out in the diversional therapy national definition of practice guidelines.
- All documentation will be securely stored for the duration of the research project and there after in accordance with the prescribed statute of limitations.
- All documentation and video footage will be used only for the purposes of this research project.
- Each participant and researcher will be accorded respect and dignity.
- Each individual is thus free to: decline the opportunity to participate, withdraw from the research project and/or discontinue participation at any time.
- Each individual will retain intellectual copyright to the finished artwork image in "joint authorship".
- A copy of the research report will be available at Nixon Hostel on completion of the research

In the "best practice" conditions that have been considered and planned for this research project there are few, if any, foreseeable OH&S, physical or psychological or legal risks to any participant .

How will this project be conducted?

The project will be conducted at Nixon Hostel. The theme of the artwork is created by the residents during the course of a standard MAC.ART program www.macart.com.au Each participant is then offered an opportunity to paint his or her section of the collaborative work.

Who is conducting the study?

The research will be conducted at Nixon Hostel, Chute Street, Mordialloc.

Principle Investigator: Professor Maureen Ryan, School of Education, Victoria University. Phone: 9919 4179

Student Researcher; Julie Gross McAdam MA, author and facilitator of the award-winning MAC.ART program www.macart.com.au Phone: 9772 0260

CERTIFICATION FOR INDEPENDENT ASSESSOR

I certify that the objectives of the study, together with any risks and safeguards associated with the research, have been fully explained to me by Julie Gross McAdam and that I have had the opportunity to have any questions answered. I understand that I can withdraw from the research study at any time such withdrawal will not jeopardise me in any way.

I (name of participant) freely give my consent to participate.

Signed by :

Date:

Any queries about your participation in this project may be directed to the Principal Researcher listed above.

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4781.



Appendix D. (4)

INFORMATION FOR THE NIXON HOSTEL STAFF MEMBER SCORING THE CEAA TOOL

You are invited to participate

You are invited to participate as a staff member in a research project entitled: **The relationship between art and wellbeing in individuals living with dementia**. This project is being conducted by a student researcher Julie Gross McAdam as part of a PhD study at Victoria University under the supervision of Professor Maureen Ryan of Victoria University.

Project explanation

The study will investigate the relationship between art and wellbeing. The study will specifically observe how individuals living with dementia engage in a one-on-one art activity, during the production of a large-scale collaborative artwork (2.5 metre by 1.5 metre). Watching a video of the art activity you will be asked to measure how participation in the activity contributes to each individual's wellbeing using the dementia-specific Creative Expressive Abilities Assessment (CEAA) research tool. The study will also observe how each individual living with dementia uses his or her art and other skills during the activity.

What will I be asked to do?

- You will be asked to attend a full briefing of the research project and undergo one-day training in the administration and use of the CEAA tool. On completion of training, you may be asked to score the tool on one or more occasions for every participant.
- You will carefully observe the video of the art activity whilst you score the tool
- You may be asked to score the tool for as many as thirty participants. The part of the project may last for several hours at a time
- The tool will be scored during work hours
- You will be asked to observe and work within Nixon Hostel's ethical guidelines and the parameters of aged care legislation and regulations

What will I gain from participating?

Potential benefits include:

- New and/or increased skills acquisition through knowledge and training and application
- New understanding of individuals living with dementia, including the identification of possible creative capability
- Increased understanding of the role and value of the creative arts therapies in residential aged care

How will the information I give be used?

The information will be used to develop new staff training and recreation programs and art activities suitable for those living with dementia.

What are the potential risks of participating in this project?

The Victoria University identifies potential risk associated with research. These risks fall under the following categories: physical, psychological, legal and others. To accommodate each potential risk factor:

- The research project will be conducted, at all time, in a safe emotional and physical environment in accordance with both the facilities and each individual's personal responsibility under aged care, privacy and OH&S and discrimination legislation.
- This research project is not a clinical trial and uses no invasive medical procedures or chemical substances.
- The project does use non-toxic art materials and each participant will be fully supervised at all time to decrease any risk of accidental ingestion of art materials.
- The research will be conducted with due consideration of "best practice" principles set out in the diversional therapy national definition of practice guidelines.
- All documentation will be securely stored for the duration of the research project and there after in accordance with the prescribed statute of limitations.
- All documentation and video footage will be used only for the purposes of this research project.
- Each participant and researcher will be accorded respect and dignity.
- Each individual is thus free to: decline the opportunity to participate, withdraw from the research project and/or discontinue participation at any time.
- Each individual will retain intellectual copyright to the finished artwork image in "joint authorship".
- A copy of the research report will be available at Nixon Hostel on completion of the research

In the "best practice" conditions that have been considered and planned for this research project there are few, if any, foreseeable OH&S, physical or psychological or legal risks to any participant .

How will this project be conducted?

The project will be conducted at Nixon Hostel. The theme of the artwork is created by the residents during the course of a standard MAC.ART program www.macart.com.au Each participant is then offered an opportunity to paint his or her section of the collaborative work.

Who is conducting the study?

The research will be conducted at Nixon Hostel, Chute Street, Mordialloc.

Principle Investigator: Professor Maureen Ryan, School of Education, Victoria University. Phone: 9919 4179

Student Researcher; Julie Gross McAdam MA, author and facilitator of the award-winning MAC.ART program www.macart.com.au Phone: 9772 0260

Any queries about your participation in this project may be directed to the Principal Researcher listed above.

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4781.

CERTIFICATION FOR NIXON HOSTEL STAFF MEMBER

I certify that the objectives of the study, together with any risks and safeguards associated with the research, have been fully explained to me by Julie Gross McAdam and that I have had the opportunity to have any questions answered. I understand that I can withdraw from the research study at any time such withdrawal will not jeopardise me in any way.

I (name of participant) freely give my consent to participate.

Signed by :

Date:

Any queries about your participation in this project may be directed to the Principal Researcher listed above.

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4781.

Appendix E. William Hogarth's axil perspective drawing.

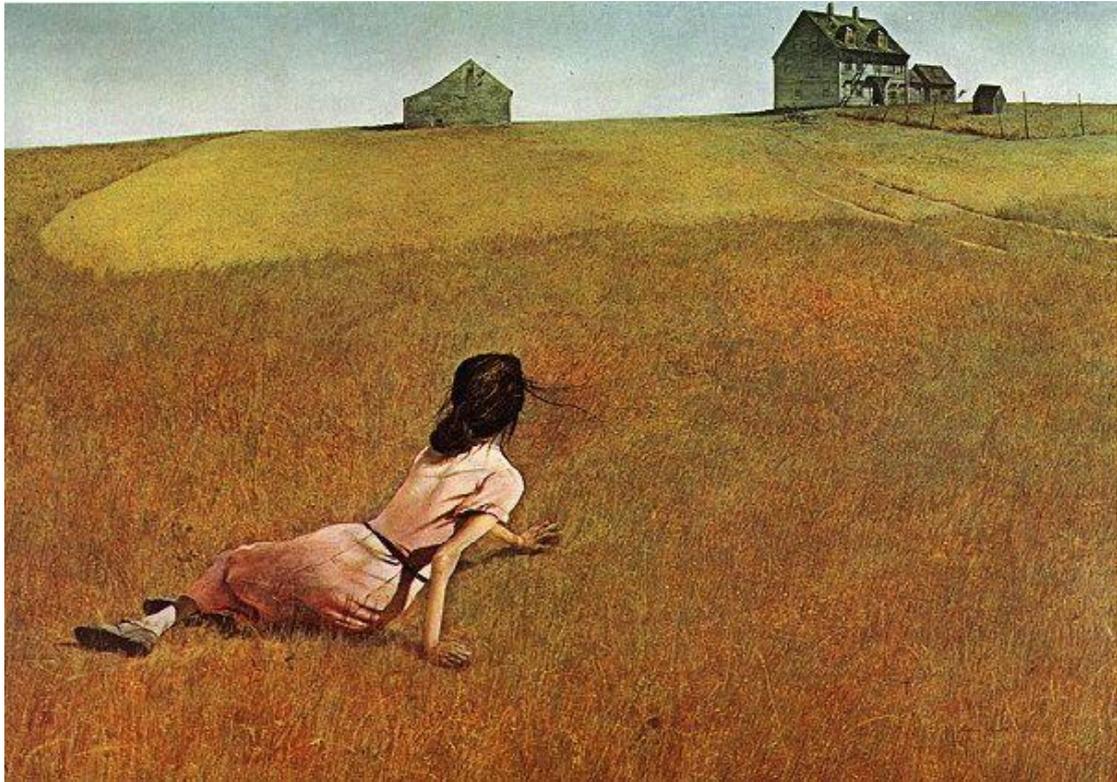


William Hogarth's illustration from Dr Brook-Taylor's 1754 self-help book explaining perspective. The slightly visually disconcerting appearance of axil perspective is clearly demonstrated.

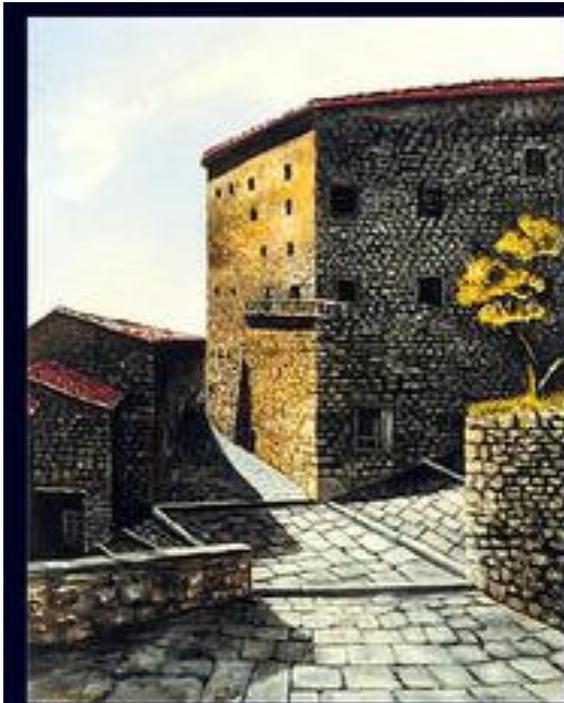
Appendix F - William Utemohlen's self-portraits.



Appendix G - *Christina's World*, by Andrew Wyeth.



Appendix H - Franco Mangnani's composite perspective landscapes.



Legnanino
1967 Oil on canvas; 18 x 21 in.

