

**AGREEING ON A WAY FORWARD: MANAGEMENT OF  
PATIENT REFUSAL OF TREATMENT DECISIONS IN VICTORIAN  
HOSPITALS**

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## **DOCTOR OF PHILOSOPHY DECLARATION**

I, Debra Lee Griffiths, declare that the PhD thesis entitled “Agreeing on a way forward: Management of patient refusal of treatment decisions in Victorian hospitals” is no more than 100,000 words in length, exclusive of tables, figures, appendices, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Signed:

Date:

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## ABSTRACT

The purpose of this study is to investigate and develop a substantive theory, of the processes adopted by nurses and medical practitioners when patients with serious illness refuse medical treatment. The study seeks to identify the main constraints confronting nurses and medical practitioners and to explain the key factors that moderate the processes of dealing with refusal decisions. Using a grounded theory method, a sample of 18 nurses and 6 medical practitioners from two public hospitals in Melbourne were interviewed. In addition, observations and documentary evidence were utilised.

The basic social psychological problem shared by nurses and medical practitioners is conceptualized as *Competing Perspectives: Encountering Refusal of Treatment*, which reflects the diverse perceptions and beliefs that confront participants when patients decide to forgo therapy. In utilizing the grounded theory method of analysis, it is recognised that participants deal with this problem through a basic social psychological process conceptualized as *Endeavouring to Understand Refusal: Agreeing on a Way Forward*. This core variable represents the manner in which participants, to varying extents, deal with the situations they face and it incorporates the various influences which moderate their activities. *Endeavouring to Understand Refusal: Agreeing on a Way Forward* comprises a series of three transitions. The first involves a struggle for participants to come to terms with, or even recognize that patients are rejecting treatment. The second transition illustrates the varied responses of participants as they interact with patients, relatives and each other, in order to clarify and validate decisions made during episodes of care. The third transition reflects the degree to which patients and family members are incorporated into treatment decisions, and highlights a shift in emphasis, from a focus on the disease state, to the patient as a person with individualistic thoughts and wishes.

The remaining social processes evident in the study consist of four categories. The first, *Seeking Clarification*, embodies exploration undertaken by participants and their recognition that treatment is actually being refused. The second category, *Responding to Patients and Families*, demonstrates the level of expertise of

participants communicating, and their ability to encourage reciprocity in the professional-patient relationship. The third category, *Advocating*, highlights the extent and manner in which patient and family wishes are promoted to members of the treating team. The fourth category, *Influencing*, reveals the ability of participants to utilize a degree of authority or power in order to shape particular outcomes.

The findings also indicate that over arching the core variable and categories are various contextual determinants that moderate the way nurses and medical practitioners deal with patient refusal of treatment. These determinants are categorized into three main influences: *The Context of Work*, describes the of the environment and organisational factors pertinent to public hospitals; *Beliefs and Behaviours*, illustrates the perceptions of, and values held, by four key groups involved in decisions, namely, nurses, medical practitioners, patients, and family members; and *Legal and Ethical Frameworks*, examines the existing principles that support or guide professional practice in situations where patients with serious illness refuse medical treatment.

## KEY TO TRANSCRIPTS

Categories	All category and subcategories names are highlighted using italics
Direct quotations	Direct quotations from the literature are presented in regular font style
Exemplars	Italics are used when presenting exemplars from participants' interviews
Pseudonyms	all names used to refer to study participants, including names that appear in exemplars and hospitals are pseudonyms
Dr	indicates the participant is a registered medical practitioner in Victoria
Nse	indicates the participant is a registered nurse (Division 1) in Victoria
15/23	prefix 15 = the participant interview number 23 = the page number in the interview transcript
[square brackets]	researcher's comments, added to provide clarity or explanation
...	words omitted from a single sentence
....	words omitted from one or more consecutive sentences

## OPERATIONAL DEFINITIONS

In this study the following definitions apply:

**Active/aggressive treatment** includes any medical procedures designed to keep the patient alive. Treatment may or may not be intended to be curative.

### CLASS OF MEDICAL STAFF

**Consultant** refers to the most experienced and senior medical practitioners, who are in charge of specific therapeutic units and delegate work to the more junior members of the medical team. They are qualified in their area of medical specialty and include physicians and surgeons.

**Registrar** is a medical practitioner with greater than three years post graduation experience. In public (government owned and funded) hospitals the consultants rely on registrars as the next most experienced practitioner. Registrars work with, and to some extent, supervise less experienced residents.

**Resident** is the least experienced medical practitioner in the public hospital system. Residents have less than three year's post graduation experience and rely on the direction and support of consultants and registrars.

## **CLASS OF NURSING STAFF**

- Nurse unit manager** is the nurse in charge of a ward or unit, usually with more than four year's post graduation experience.
- Graduate nurse** refers to a recently graduated nurse, commonly with less than one years experience post graduation.
- Ward or unit** refers to the organisational structures within the acute hospital areas. The words are used interchangeably throughout this study unless a distinction is made when an area is referred to specifically, such as the intensive care unit. They both encompass designated areas where groups of patients are located and nurses are appointed to work in specific wards or units.
- Palliative care** is treatment intended to manage the symptoms of illness the emphasis is not to cure.
- Medical treatment** means all procedures, investigations and therapy ordered with the intention of investigating, diagnosing or treating patients with serious illness.
- Refusal of treatment** encompasses behaviour, which denotes a withholding of acceptance or consent. The behaviour usually refers to patients, but can include relatives and indicates an unwillingness to proceed with proposed therapy, or accept a particular treatment or procedure.

- Serious illness** refers to a significant illness that has major life changing tendencies. A decision to refuse specific medical treatment is likely to notably impact on the patient's well being, including his or her life span.
- Therapeutic unit** is an arrangement of work according to a speciality area of medical practice, such as orthopaedics, neurology or intensive care. Other units are delineated according to foci, and are commonly medical or surgical in nature. For instance, the title "General Medical Unit 1", denotes a medical team that deals with a range of medical illnesses. This structure serves to indicate the appointment and groupings of medical teams. Ward or unit areas may admit patients from more than one therapeutic unit.

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**PART A: INTRODUCTION TO THE STUDY**



# **CHAPTER 1**

## **INTRODUCTION TO THE STUDY**

### **1.1 INTRODUCTION**

This thesis presents a study into how nurses and medical practitioners respond to patients who refuse medical treatment. The study involves registered nurses and medical practitioners and takes place in two public hospitals within a 100 kilometre radius of Melbourne, in the state of Victoria. Strauss and Corbin's (1998) approach to grounded theory is used as the methodological framework for the study, and interviews, observations and documentary sources are used to collect data. The thesis is divided into two parts. Part A comprises general background information, including the methodology and methods utilised in the study, and Part B presents the findings, including the theory generated from the study.

In this chapter, the background to the study provides some insight into, and impetus for, this research project. The research question and the research aim are then stated. This is followed by a brief account of how the outcomes of the study add to knowledge and clinical practice. Finally, an overview of the structure of the thesis is presented.

### **1.2 BACKGROUND TO THE STUDY**

There is a need for a study that explicates the processes that nurses and medical practitioners go through when patients, with serious medical illness, refuse treatment. The need for such a study is premised on the recognition that there is a paucity of Australian knowledge, research of clinical practice, and of the methods of decision making in this area. By exploring these facets an understanding of the integral role health professionals play in health outcomes can be gained, not as neutral "purveyors of scientific expertise", but as participants purposely engaging in, and spearheading various social processes with patients (Luftey, 2005). In particular, this study examines how health professionals actually come to acknowledge and then deal with patient refusal decisions.

Concerns have been raised by eminent authorities regarding confusion with the legislation and lack of respect for patient wishes in this area. Julian Gardner, the former Public Advocate of Victoria<sup>1</sup>, acknowledges that problems exist when health professionals are reluctant to respect patients' wishes in relation to unwanted treatment (Julian Gardner, personal communication, November 30, 2005). Mr Gardner believes that this situation illustrates the shortcomings of current health care practice.<sup>2</sup> The issue of health care practice and patient wishes being ignored has also come to the attention of the Health Services Commissioner, Ms. Beth Wilson. The Commissioner's role is legislatively established to:

- (i) deal with complaints from patients using health care services in Victoria, and
- (ii) to suggest ways in which health service providers may improve the quality of health care (Health Services Conciliation and Review Act 1989, p.1).

Ms. Wilson confirms that her office receives complaints, particularly from patients' substituted decision makers, who claim that the patients they represent have reached the end of their lives and want treatment to cease, but commonly their medical practitioners disagree, insisting that treatment continue. Ms. Wilson states: "The substitute decision makers believe that their opinions are not being respected; that there is a degree of medical arrogance at play a kind of 'we know what's best' attitude" (Beth Wilson, personal communication, October 4, 2005).

Davies (2002) reports that family members of patients express alarm that their loved ones have actually stated their decisions to refuse certain treatment, or have made

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<sup>1</sup> The role and powers of the Public Advocate are established by the *Guardianship and Administration Act 1986* (Vic). The role of the Public Advocate is to support services and actions that promote the rights of people with disabilities and protect them from exploitation and abuse. Under this Act 'disability' means intellectual impairment, mental disorder, brain injury, physical disability or dementia. Potentially a number of patients receiving treatment in hospitals come within the meaning of a person with a 'disability' and therefore medical treatment and associated decisions have attracted the interest and involvement of the Public Advocate.

<sup>2</sup> This was highlighted in part, in the Supreme Court decision of BWV (2003), when the patient had not wanted artificial feeding to continue. However, the health professionals were unsure of their legal position regarding this request and were unwilling to withdraw the treatment. The Public Advocate, Mr Gardner was requested by the patient's family to assist them in carrying out the patient's wishes. The Public Advocate sought judicial advice due to the surrounding uncertainty of health professionals' practice and the Victorian law.

attempts to plan for unwanted health care in the future however, hospital staff refuse to abide by patients' decisions. Medical practitioners and nurses inform family members that it is not legally possible for treatment to be changed or withdrawn. Davies (2002) cites an example where a family member sought independent legal advice confirming that, as his grandmother's substituted decision maker, he was within his rights to demand that certain treatment be withdrawn. The senior medical executive of the hospital refused to implement his requests. This event indicates that the senior medical executive of the hospital did not understand their legal roles (Davies, 2002).

The researcher, a nurse and a lawyer, has been involved in the education of practising health professionals and undergraduate students for more than a decade and has encountered numerous instances highlighting misunderstanding and uncertainty on the part of health professionals in relation to their professional obligations. The anecdotal experience of the researcher suggests that there is little clarity in the minds of a considerable number of health professionals regarding routine practice in the event patients refuse therapy. Professionals emphasise the desire for patient consent and consider refusal of therapy only in situations where patients are dying and can not express their wishes, or in situations when patients wish to prematurely leave the hospital. It appears that a gulf exists between the utilisation and implementation of legal principles and everyday clinical practice. Indeed, anecdotally the law is something to avoid for many health professionals as it conjures negative connotations. From this researcher's perspective, the actual process of identifying treatment parameters is not overtly discussed, yet medical and nursing staff deal with patients everyday in hospitals, who are seriously ill but not necessarily at the end of their life, or wanting to prematurely discharge themselves.

In the past few years in Victoria there have been efforts to deal with the specific issue of patients making plans for future health care. A program, originally designed in the United States,<sup>3</sup> has been implemented.<sup>4</sup> The focus is on advance care planning,

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<sup>3</sup> The program 'Respecting Choices' was developed by Dr Hammes from La Crosse, Wisconsin.

<sup>4</sup> The Austin Hospital in Melbourne implemented the 'Respecting Patient Choices' program in 2003. See Sections 2.5.1 and 2.5.2 for further discussion of this program.

including the appointment of a substituted decision maker. However, there remains little understanding of the underlying decision making processes in hospitals, particularly who or what influences decisions when patients refuse therapy and how health professionals respond. This information is imperative, arguably, before programs can be properly formulated and implemented because the underlying way two key health professional groups deal with patients in hospitals, namely nurses and medical practitioners, is unknown.

### **1.3 RESEARCH QUESTION AND AIMS**

Given the background to this study, the research question asks: What processes do nurses and medical practitioners go through when patients, with serious medical illness, refuse treatment? The aims of the study are:

- (i) to identify and explore the processes that nurses and medical practitioners undertake in order to respond to patients' refusal of treatment decisions, in acute care settings, and
- (ii) to identify and explain what factors effect nurses' and medical practitioners' utilization of these processes.

### **1.4 SIGNIFICANCE OF THE RESEARCH**

The study will shed some light on the manner in which nurses and medical practitioners work, together or unaided, when patients refuse treatment. This may assist in the identification of implications for future clinical practice in order to allow and encourage patients and their families to be pro-active when treatment options and decisions are to be made. This includes the ability for competent patients to refuse current care, or at least establish agreed treatment parameters, and the use of the substitute decision-making mechanism established by existing legislation. Ascertaining how nurses and medical practitioners manage patients' decisions to refuse treatment emphasises the limits of patient autonomy and the subsequent right to self-determination in the acute care environment. The results of this research have the potential to impact on the clinical practice of nurses and medical practitioners in hospitals, and as a consequence, protect patient autonomy regarding treatment.

Patients and their families should feel confident that hospitals will offer treatment with the respect and inclusion of patients' consent, including their decisions to restrict therapy.

There are also potential benefits in uncovering a substantive theory, which outlines the processes adopted by nurses and medical practitioners in dealing with patients' refusal of treatment decisions. The theory has the potential to raise awareness among the two professional groups and to provide an understanding of their individual and collective roles. It is anticipated that the theory will assist in identifying and strengthening the work of nurses and medical practitioners, by enabling them to take a comprehensive approach to patient refusal decisions, not only concentrate on decisions for future health care, but consider the direction of overall care from the outset of the relationship. Identifying and exploring the behaviour of nurses and medical practitioners highlights clinical practice as it relates to the legislative framework. The findings may demonstrate the discrepancies in practice in relation to the legal principles and suggest that in many situations current practices are insufficient to encourage and acknowledge patients' wishes, regarding refusal of treatment and boundaries of acceptable treatment.

## **1.5 STRUCTURE OF THE THESIS**

The remainder of the thesis is presented in eleven chapters. In Chapter 2, the context of refusal of treatment is presented. A review is undertaken of the concepts relevant to this topic, including the emergence of patient rights, the existing legal framework, advance directives, and factors impacting on medical and nursing work. In Chapter 3, the methodological basis utilised in the study is discussed, and an analysis of the qualitative approach of grounded theory is addressed. In Chapter 4, the methods of the study are outlined and discussed. In Chapter 5, an overview of the findings of the study is expounded by providing a diagrammatic overview of the findings that give rise to the theory. A concise synopsis is then presented to introduce the core problem, core process, categories and the contextual determinants. The chapter also provides a summary of the basic social psychological problem; *Competing Perspectives: Encountering Refusal of Treatment*. In Chapter 6, the key factors that serve to influence the work and behaviour of the nurses and medical practitioners is

presented as the three contextual determinants: *The Context of Work, Beliefs and Behaviours*, and *Legal and Ethical Frameworks*. Each determinant is identified and explained. In Chapter 7, the core category or basic social psychological process; *Endeavouring to Understand Refusal: Agreeing on a Way Forward*, is discussed. In Chapters 8 to 11, the four categories are identified and discussed in turn. The four categories are: *Seeking Clarification*, in Chapter 8; *Responding to Patients and Families*, Chapter 9; *Advocating*, Chapter 10; and *Influencing*, Chapter 11. Finally, in Chapter 12, an overall discussion of the findings is addressed, as well as the limitations of the study, and implications for clinical practice, nursing and medical education, research, and the legislation.

## **CHAPTER 2**

### **THE CONTEXT OF PATIENT REFUSAL OF THERAPY**

#### **2.1 INTRODUCTION**

The purpose of this preliminary review of the literature is to provide the background and context to the study. Insight into the surrounding issues helps to promote theoretical sensitivity by means of highlighting sensitizing cues regarding the phenomenon being studied (Strauss & Corbin, 1998). The current study seeks to identify the processes nurses and medical practitioners employ to ensure that patient parameters of treatment, namely, refusal of treatment decisions, are identified and managed. The literature does not specifically examine how health professionals interact and manage treatment decisions for patients who refuse therapy, rather there are several topics of relevance that overlap the present study, and these assist in providing theoretical sensitivity.

In grounded theory the literature can be considered data (Holloway, 1997) and in this study, it was accessed during and after other data collection methods. The literature therefore forms part of the constant comparative process and was accessed in a cyclic simultaneous fashion.<sup>5</sup>

The review begins with some considerations for those supplying and receiving health care and then addresses six themes of relevance to the present study. The themes include:

- (i) the acknowledgement of patient rights and roles;
- (ii) the legal position;
- (iii) the focus on anticipating future therapy;

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<sup>5</sup> The literature has been sourced from numerous electronic data bases including CINAHL, APAIS, AMI, AGIS, Biomed Central, LexisNexus, Proquest, Medline and the Cochrane library. The parameters set for the literature review included the past 12 years.

- (iv) medico-legal knowledge;
- (v) health professionals and communication; and
- (vi) education and work practices of the two professional groups.

## **2.2 CONSIDERATIONS IN HEALTH CARE**

Health care has evolved from the original ideal of the beneficent physician making decisions on behalf of patients, to the acceptance of the right of patients to autonomy (Thomas, 2001). This shift assumes that patients control the manner and delivery of their health care. Authors from the legal profession presume that the law is quite clear and reasonably straightforward if patients retain both mental capacity and the ability to express a refusal of treatment (Staunton & Chiarella, 2008; McIlwraith & Madden, 2006; Forrester & Griffiths, 2005; Devereux, 1999). The legal perspective presupposes that patients can and do exercise their autonomy in health care. It is argued that it is more difficult for patients if they wish to anticipate therapy at some future date but lose the capacity to make or communicate such decisions (Thomas, 2001). Therefore, interest has firmly focused on situations where patients will be unable to communicate their wishes at some future point in time. But what of the perceptions and roles taken by the health professionals who provide the important information that allow such decisions to be made, and what role do these individuals actually play when patients have mental capacity or lose this capacity? These questions become more prominent with the proposition that with improvements in medical knowledge and technical success, health professionals still tend to concentrate on the technology, rather than the patient (Taylor & Cameron, 2002). As Gibbs highlights, “the achievements [of institutionalized medicine] have been so significant that, at times, death seems avoidable. But, as more patients are hooked up to more and different machines the stress of patients, families and health professionals, essentially increases.” (1986, p.56)

From the perspective of patients, Emanuel, Barry, Stoeckle, Ettelson and Emanuel (1991) found that many elderly patients express fears of over zealous intervention of life sustaining treatment when they are seriously ill, which would prolong their



suffering and compromise their quality of life. McCue (1995) contends that many patients express a fear that when they become seriously ill they will lose control of treatment decisions and this might lead to prolonged treatment and an impersonal death. It has also been argued that patients who can not clearly express their wishes, when they are admitted to hospitals, may be subjected to invasive procedures and extensive resuscitation against their will (Taylor, Ugoni, Cameron & McNeil, 2003). Johnson, DaCosta and Turale (2002) also found that, “prolonging the dying process with inappropriate measures” was the nurses’ “most disturbing ethical/human rights issue” (p.31). Moreover, there is some evidence that patients modify their preferences in response to life sustaining treatment, due to the likelihood that it will result in functional or cognitive impairment. Mazur and Merz (1996) state that patients usually prefer death over survival, if survival is accompanied with a significant degree of cognitive or functional impairment.

When a patient chooses to withdraw from medical treatment, continuing to help that patient is a legitimate role for health professionals. Decisions to withdraw treatment in some clinical settings are not uncommon, even if the withdrawal means the patient’s life will be shortened. In palliative care such decisions are the norm. They are commonly reached by mutual agreement between the patient and the clinicians and treatment then focuses on the process of the patient being kept comfortable, rather than the pursuance of further active or life sustaining treatment (Sensky, 2002). The increasing use of technologies capable of sustaining life means that such decisions are likely to become more common but also more complex (Sensky, 2002).

### **2.3 THE ACKNOWLEDGMENT OF PATIENT RIGHTS AND ROLES**

A number of factors have influenced the development of patient rights, including the acceptance of the autonomous rights of patients and their consequent involvement in health care decisions. As early as 1914, Justice Cardozo stated that, “Every human being of adult years and sound mind has a right to determine what will be done with his own body: and a surgeon who performs an operation without his patient’s consent commits an assault” (*Schloendorff v Society of New York Hospitals*, ¶93). Other sources raising the focus of “rights” relating to health care include the United

Nations Universal Declaration of Human Rights (1948)<sup>6</sup> and the World Health Organization's Constitution that states, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (World Health Organization, 2006, p.1). With these influences, the emergence of consumer organizations and legal structures in the last few decades in Australia have shaped expectations for patients, and simultaneously the responsibilities of health professionals.<sup>7</sup>

Currently, in Australia a national *Charter of Patient Rights* is in the process of formulation (Australian Commission on Safety and Quality in Health Care, 2008). Of the eight "rights" in the draft *Charter of Patient Rights*, three are of potential relevance to this study. They include: the right to clear communication in language that can be understood, particularly when [treatment] plans change; the right to thorough information regarding services, treatment and care; and the right to participation, where patients are involved in decision making about their care, including being informed and discussing the options available (Australian Commission on Safety and Quality in Health Care, 2008).

The effect of the change in emphasis, to that of recognizing the rights of patients, firmly places them as active participants in the delivery of health care services (Deber, Kraetschmer, Urowitz & Sharpe, 2007). The shift has occurred in the practitioner-patient relationship, from its former emphasis on paternalism, to a new recognition of the importance of an informed, autonomous patient (Coulter, 1999). This change in the locus of decision making, from the practitioner to the patient, has arguably been reinforced by the legal requirement of consent and the numerous bodies and organizations promoting the importance of patients' participation in the process. For treatment decisions, determining which, or what information is relevant, is guided by the legal and ethical obligations placed on health professionals.

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<sup>6</sup> The Declaration states that people have the right to a standard of living adequate for their good health and well being (Articles 1 and 25).

<sup>7</sup> For instance, the Consumers Health Forum Incorporated is an independent national organization in Australia, representing and promoting health consumers' interests. There are also statutory bodies dealing with a range of issues for those receiving health care, including health care complaints, privacy, insurance, and human rights and equal opportunity.

Typically, the content covered in health care decisions should include a description of the medical condition, all treatment options including the associated procedures, potential benefits and side effects of each, and this information should be complete, balanced and as accurate as possible to enable patients to make decisions (Feldman-Stewart et al., 2006). This has resulted in significant emphasis being placed on obtaining patient consent.

With the recognition of patients as active players in treatment decisions, interest has turned to patients, rather than their disease, as the focus (Bensing, Verhaak, van Dulmen & Visser, 2000). This has created debate regarding the differing roles health professionals and patients can take in the clinical relationship and decision making. Roter (2000) highlights the two paradigms: the physician model and the consumer model. The most prevalent, but not necessarily most desirable or efficient model of decision making, is the physician model, where practitioners dominate agenda setting of goals and decision making in relation to information and services, and the patient's voice is largely absent (Roter, 2000). This view is premised on the assumption, often incorrect, that practitioner and patient share the same values and preferences. Conversely, Roter (2000) argues that the patient model represents consumerism, where the roles are reversed. Patients set the goals and agenda of the consultation and take sole responsibility for decision-making. A cooperative practitioner then accommodates patient demands for information and technical services and the relationship resembles a market place encounter. The problem with both paradigms is the divergent expectations of practitioners and patients. This is evident when relationships cannot be negotiated or modified as they may well come to a dysfunctional standstill (Roter, 2000).

The notion of shared decision-making emerges as a way to recognize practitioner knowledge and patient empowerment in many situations (Whitney, McGuire & McCullough, 2004). It is a collaborative approach, in which patient and practitioner contribute information as a prerequisite to sharing the treatment decision (which may be to do nothing), and both parties agree to the decision (Edwards & Elwyn, 2006). Charles, Gafni and Whelan (1999) describe shared decision making as a spectrum between the physician as "perfect" agent and the "truly" informed consumer patient.

Physicians can act as perfect agents if they are fully aware of the patient's values, preferences, opinions and goals, and then combine this with their clinical knowledge and experience to guide the interaction and decision. Patient consumers can then make an informed choice if they are given sufficient clinical knowledge and combine this with their values and preferences. This form of patient-practitioner interaction requires shared information from both parties and can achieve a range of health care benefits (Benbassat, Pilpel & Tidhar, 1998; Griffin, Kinmonth, Veltman, Gillard, Grant & Stewart, 2004). Clinicians and patients also generally indicate positive responses to sharing decisions (Davis et al., 2003; Edwards, Elwyn, Atwell, Wood, Prior & Houston, 2005).

## **2.4 THE LEGAL POSITION: THE RIGHT TO REFUSE TREATMENT**

The right of a competent patient to refuse medical treatment is largely settled at law (Manning, 2002). There are a number of common law countries<sup>8</sup> where the courts have upheld that a competent person may reject life-sustaining treatment.<sup>9</sup> A series of cases, most importantly *Airedale NHS Trust v Bland*, in the United Kingdom in 1993, has also confirmed that in certain circumstances, patients who are unable to communicate can have medical treatment withdrawn (Forrester & Griffiths, 2005). During the 1970s and 80s this issue was considered less clear and with the emergence of individual rights, consumer organizations and the "right to die" movement, individuals became increasingly concerned about the number of impaired patients who were kept alive for prolonged periods with medical technology (Brown, 2003). The debate highlighted the fact that many of these patients may have refused treatment if they had been competent, or if a legal framework existed for them or their family members, to claim their common law right to refuse treatment (Brown, 2003). Several countries, starting with the United States, Canada and Australia,

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<sup>8</sup> Common law countries refers to those countries or states where the legal system embodies both parliamentary law and the common law. The common law emerged in the United Kingdom and countries retaining this system have been historically associated with the United Kingdom. Examples of these countries include Canada, the United States and Australia.

<sup>9</sup> The courts in Australia, Britain and the United States have made it clear that a patient's right to autonomy does not extend to demanding life-prolonging treatment, when the health professionals consider it clinically inappropriate and this includes when an advance preference is given by a patient (Thiagarajan, Savulescu & Skene, 2007).

introduced legislation in the 1980s and 1990s. In contrast, the United Kingdom has only recently enacted legislation, as a result of an international convention.<sup>10</sup>

In Victoria, from the early 1980s there were moves to formalise a right for individuals to refuse medical treatment.<sup>11</sup> The Parliamentary appointed Social Development Committee<sup>12</sup> (the Committee) were directed to consider public submissions, make recommendations and report to Parliament on this matter. In particular, the Committee's terms of reference were prefaced to have regard to the "greatly increased technological capacity to sustain life" and the terms of reference included, among other things, to consider whether it was desirable and practical for the Government to take legislative or other action establishing a right to die (Social Development Committee, 1986, p.6.). The Committee also considered under what circumstances, if any, a person had a right to die, the right of an individual to direct his or her death, including the form that direction should take, and the right of an individual, who was incapable of giving a direction, to be allowed to die (Social Development Committee, 1986).<sup>13</sup>

The resultant work of the Committee was the enactment, by the Victorian Parliament, of the *Medical Treatment Act* 1988 (Vic) (the MTA) to clarify the law relating to the right of patients to refuse medical treatment (MTA, section 1(a)). The preamble of the MTA includes several statements providing insight into the purpose of the legislation. Most noteworthy is the Victorian Parliament's recognition that it is desirable "to give protection to the patient's right to refuse unwanted medical

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<sup>10</sup> The relevant international Convention is titled: International Protection of Adults. The British legislation is the *Mental Capacity Act* 2005 (UK). It relates to persons who lack mental capacity, and sections 24-26 of that Act specifically relate to advance decisions to refuse treatment.

<sup>11</sup> The Health Advisory Council reported to the Victorian Minister of Health in 1983 on this topic.

<sup>12</sup> The Social Development Committee was appointed pursuant to the *Parliamentary Committees Act* 1968 (Vic), section 4E. The functions of the Committee were threefold: To inquire into, consider and report to the Parliament of Victoria: (1) any proposal or matter concerned with the social development of the people; (2) how the life of individuals, families and communities may be improved; and (3) the role of Government in promoting the welfare of the people of Victoria. This Act has been repealed by the *Parliamentary Committees Act* 2003 (Vic).

<sup>13</sup> There were several other aspects the Committee were asked to address, including what was an acceptable definition of death, protection for health professionals who allow an individual to die, and to report on the relevant literature and judicial decisions.

treatment”, “to state clearly the way in which a patient can signify his or her wishes in regard to medical care”, and “to encourage community and professional understanding of the changing focus of treatment from cure to pain relief” (MTA 1988, Preamble, 1). The MTA now sets out two procedures for this to occur. Firstly, it provides for a competent adult patient<sup>14</sup> to complete a Schedule One: *Refusal of Treatment Certificate*, to indicate what treatment would be considered unreasonable, and if necessary, to give specific instructions as to the types of palliative care the patient would accept (MTA, sections 1(b) & 5).<sup>15</sup> Secondly, the MTA allows for a competent adult to appoint an agent (also called an attorney, sometimes referred to as a proxy decision-maker), to make decisions regarding treatment, on behalf of the patient (MTA, section 5A(2)). This is achieved using a Schedule Two: *Enduring Power of Attorney (Medical Treatment)*, document.<sup>16</sup> The agent’s power only comes into effect when the competent patient becomes incapable of making decisions. In exercising this power, if the agent believes that the proposed treatment would be unacceptable to the patient, the agent can refuse medical treatment on behalf of the patient. This requires completion of a Schedule Three: *Refusal of Treatment Certificate Agent or Guardian of Incompetent Person* (MTA, section 5B(3)).<sup>17</sup> The important feature of the legislation is that it allows adult patients to indicate a refusal of medical treatment, both when competent and incompetent, even if this has the effect of shortening or ending the patient’s life. The MTA makes provision for the offence of medical trespass, highlighting that a medical practitioner must not knowingly provide medical treatment that has been refused (MTA, section 6).<sup>18</sup> Therefore, the non-provision of treatment in reliance on a MTA Schedule negates any criminal or disciplinary responsibility or civil liability (MTA, section 9).<sup>19</sup> However, it remains unclear whether current practice in Victoria meets the specific requirements of the legislation.

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<sup>14</sup> An adult is a person who has attained 18 years of age and the individual is assumed to be competent to decide unless there is some evidence of a disturbed state of mind.

<sup>15</sup> See Appendix A.

<sup>16</sup> See Appendix B.

<sup>17</sup> See Appendix C.

<sup>18</sup> To the author’s knowledge this section has never been invoked.

Brown, Fisher, Brumley, Ashby and Milliken (2005) highlight the fact that little research has examined the utility of the provisions of the *Medical Treatment Act* (MTA) and whether it achieves its objectives. The researchers found that 78 per cent of the respondent patients in palliative care settings in rural Victoria, were not familiar with the legislation. The researchers conclude that despite the relatively lengthy existence of the legislation (20 years), it is rarely used and remains poorly understood. Brown et al. (2005) suggest that in order to achieve the objectives of the MTA, patients require face-to-face support and explanation, as written materials will not suffice. Making end-of-life decisions involves a process and it is the conversation that is important rather than the completion of forms (Brown, 2003). Furthermore, the researchers argue that medical practitioners and nurses need to understand the provisions of the legislation so they can assist patients in discussing their treatment, early in the therapy regime. The nurses who participated in Brown's study were provided with an educational workshop about the research project and the provisions of the MTA. As a result of their participation in the study the nurses found that they gained confidence in discussing information with patients and their families.

When patients decide not to accept specific treatments this should be documented clearly and comply with the existing legal framework (Forrester & Griffiths).<sup>20</sup> The situation becomes even more critical when patients become incompetent, when clinicians rely on the patients' appointment of an agent, to make the decision. Evidence of decisions that consist of remote, general, spontaneous or causal comments are unlikely to support the claim of decisions, whether they are made by patients or agents (*Matter of Jobes*, 1987). There has been no research undertaken to identify the manner in which nurses and medical practitioners document patients' or Agents' decisions in relation to the *Medical Treatment Act*, despite there being specific documents (Schedules) to complete.

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<sup>19</sup> For further, detailed explanation of the features of the MTA, see Chapter 6, Section 6.5.1.

<sup>20</sup> Section 5E Medical Treatment Act requires that the Board or proprietor of a hospital or nursing home must take reasonable steps to ensure that a copy of any refusal of treatment certificate applying to a patient should be kept in the patient's record.

While the technology exists to allow patients to be kept alive, it is questionable whether health professionals actively encourage patients to consider treatment options, or how treatment parameters are determined. This was a key reason for the enactment of the MTA. It is also important to note that the MTA does not require an adult to be terminally ill instead, refusal of treatment must relate to a current medical condition. There are numerous studies examining advance directives and advance care planning however, there are no studies examining precisely what health professionals actually do when patients or their families refuse treatment and how this reflects the provisions of the MTA. Heland (2003) described nurses' experiences in an intensive care unit when patient treatment parameters should have been discussed. She expressed concern that staff did not talk to patients regarding decisions to limit, withdraw or not offer curative treatment, because the staff found the discussions confronting and the medical practitioners were fearful of their legal obligations. This is suggestive of staff being unaware of both their patients' and their own legal position. Thus, the clinical practice of health professionals may be haphazard and fall short of patient expectations and the law.

## **2.5 THE FOCUS ON ANTICIPATING FUTURE THERAPY**

There is a substantial body of literature examining advance directives, where jurisdictions provide for individuals to specify a desire to detail certain treatment at a future point in time, and these decisions are usually made at the end of patients' lives. The topic area of advance directives, therefore, provides insight into those situations where decisions regarding treatment are made, including associated issues such as their implementation, likelihood of patients' wishes being respected by health professionals, and issues surrounding the appointment of proxy decision-makers. These facets are of relevance to the current study, given the mechanisms of the MTA.

An advance directive (sometimes called a living will) is an account or plan of an individual's preferences for future health care (Silveria & Schneider, 2004). The advance directive can include identified limits of therapy, or wishes to refuse specific types of care. The directive is made in anticipation of a time when the patient is not able to express or participate in decisions relating to therapy. The directive can take



differing forms. It may be a legal document in the form of a power of attorney where a proxy decision maker is appointed (MTA Schedule Two), or the patient might formally record therapy preferences, as required by the MTA (Schedule One), or less formally, including an entry in patient files by the treating medical practitioner, following a verbal discussion with patients (Prentergast, 2001). This latter position recognizes the individual patients' right at common law to refuse treatment, even where there is no legislation.

The United States was one of the earliest countries to enact national legislation dealing with advance directives, followed by several Australian states and Canadian provinces (Brown, 2003), and this is reflected in the available literature. The United States *Patient Self-Determination Act* 1990 mandates all health care institutions, including hospitals, receiving Medicare or Medicaid reimbursement, to develop written policies regarding advance directives, advise patients on their right to refuse care, and educate medical staff and the community about advance care planning (Emanuel, Weinberg, Gonin, Hummel & Emanuel, 1993). It was originally hoped that the United States legislation would increase the use of advance directives and this would facilitate communication between health professionals and patients, while preventing unwanted treatment or over treatment (Prentergast, 2001), thereby respecting the right of patients to make autonomous decisions.

Following the enactment of the *Patient Self-Determination Act*, a 28 million dollar multi-centered trial, the *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment* (SUPPORT) was established (SUPPORT Principle Investigators, 1995). The trial comprised two distinct phases: the first phase was to identify the shortcomings of end-of-life care, and the second phase of the study was to design and evaluate suitable interventions to improve patient care. In the first phase, the investigators found poor communication and decision-making processes, and consequently poor end-of-life care.<sup>21</sup> The second phase of the SUPPORT study comprised an intervention using a nurse facilitator to work with patients and families

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<sup>21</sup> For instance, cardiopulmonary resuscitation and intensive care therapy were often provided in the patient's final months of life, despite the fact that the patient or relatives preferred the provision of general comfort, rather than life prolonging treatments (SUPPORT Principle Investigators, 1995).

to elicit and document patient preferences, and to assist communication between patients and medical staff. However, the investigators found that there were no differences between the treatments provided and the control groups in any of the SUPPORT outcome measures.<sup>22</sup> The attempts in the trial to facilitate communication and outcomes, regarding patient choices at the end-of-life however, did not necessarily translate into more effective care reflecting patient wishes (SUPPORT Principle Investigators, 1995).

Subsequent research studies examined why the SUPPORT study had failed to demonstrate a difference to patient care (Danis et al., 1991, Teno et al., 1997; Teno, Stevens, Spernak & Lynn, 1998; Ditto et al., 2001). In relation to advance directives the data highlight a range of reasons. Danis et al. (1991) found that advance directives were at times limited by inattention to them, or by decisions to place priority on considerations other than patients' refusal of therapy. Danis et al. (1991) also found that while advance directives were generally consistent with treatment outcomes, the presence of the written advance directive did not facilitate this consistency. The researchers speculate that the high rate of consistency was achieved because the interview process involved all participants and caregivers, and included forethought and communication of patient wishes amongst family members and health care professionals (Danis et al., 1991).

Evidence indicates that advance directives are not readily available to medical staff when needed and often do not guide medical decision-making beyond identifying a substitute decision maker, or recording general preferences of patients (Teno et al., 1997). When the directives are available they are often not read (Teno et al., 1994) or if they are read, physicians often find them too vague to be helpful (Teno et al., 1998). Even when specific preferences were recorded, care was potentially contradictory in half of the cases (Teno et al., 1997). Researchers report that physicians were rarely involved in counseling patients about completing advance

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<sup>22</sup> On the basis of the first phase the investigators identified five major outcomes to be measured: (1) incidence and timing of not for resuscitation orders; (2) patient-physician agreement on preferences for resuscitation; (3) days the patient spent in an intensive care unit in a coma or ventilated before death; (4) the presence of pain; and (5) hospital resources used (SUPPORT Principle Investigators, 1995).

directives or discussing them (Emanuel et al., 1993, Teno et al., 1997). Emanuel et al. (1993) state that there are several reasons for these findings, notably they include the fact that the teaching hospitals are busy and there is reduced time for, and emphasis on, inquiries in advance care planning, and the responsibility for making inquiries and providing information was assigned to admitting personnel and nurses, not physicians, who are usually integral to therapy plans. The findings suggest that there is an absence of communication between patients and health care professionals and that directives commonly do not provide specific instructions. In addition, the researchers highlight that one third of those patients with proxy decision-makers had not appointed their next of kin. This illustrates the importance of health professionals consulting patient's written documents, rather than assuming that family members know patient preferences (Emanuel et al., 1993).

The involvement of specific health professionals in the identification of patient preferences regarding therapy is considered relevant. One study demonstrates that most physicians did not know when their patients had completed advance directives, as they were not primarily involved in these discussions. The physicians were unaware of their patients' wishes and were therefore unable to incorporate them into care (Virmani, Schneiderman & Kaplan, 1994).

When patients seek to record their own advance directives the wording chosen to describe preferences and the associated knowledge of health care and illness, can be dependent upon the efforts of individual patients to be informed (Eisendraft, & Jonsen, 1983). The reliance on individual patients' perceptions, in the absence of wider consultation and guidance, has been identified as problematic. Eisendraft and Jonsen (1983) highlight the difficulty for health professionals when interpreting the precise wording of living wills and suggest that this may actually impede decision-making. Where patients do not seek pertinent information and/or the recording of their preferences is unclear, there is a real possibility that decisions made may be contrary to a patient's wishes. This might be the case if the document is completed without informed discussion between patient and physician.

In many studies examining the low rates of use, and the difficulties of implementing advance directives, the research focus shifted in the late 1990's to consider other

aspects of advance directives. For instance, the role of physicians was investigated, where the researchers found that physicians spoke twice as much as they listened, and were not inclined to explore patient attitudes or values (Tulsky, Fischer, Rose & Arnold, 1998). Haidet et al. (1998) examined hospitalized patients with terminal colon cancer at a stage in their illness where they were mentally competent and suffered few functional disabilities. In 59 per cent of patients and physicians who indicated that they had discussed issues relating to prognosis, the physicians incorrectly understood patient preferences in relation to cardio-pulmonary resuscitation 30 per cent of the time.<sup>23</sup> The results of the study indicate that one reason advance directives failed was due to the poor approach and emphasis placed on physician-patient communication.

There is further evidence that the mere appointment of proxy decision-makers will not necessarily enhance carriage of patients' plans regarding future care. Patients do not automatically or extensively discuss their preferences with their proxy (Seckler, Meier, Mulvihill & Paris, 1991). Even when patients and their proxies are required to discuss treatment preferences agreement can be poor (Ditto et al., 2001) and the proxy decision makers' predictions of patient preferences are more closely aligned with their own than that of the patient (Fagerlin, Ditto, Danks, Houts & Smucker, 2001).

Singer et al. (1998) sought to identify patient perspectives with respect to future planning for care at the end of patient lives. From the data, the researchers identified five domains of end-of-life care that were of interest to the respondent patients. The domains included: avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, adequately managing pain and symptom control, and strengthening relationships with loved ones (Singer et al., 1998). Importantly, the findings indicate that it is not helpful to approach advance care planning with a mere checklist for specific treatments. The researchers conclude that while dialogue should include specific therapy options, it is only after a broader exploration and

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<sup>23</sup> The specific breakdown for the medical professionals in this group was: 35% for oncologists, 26% for surgeons and 12% for general medicine physicians.

discussion of patients' values and experiences of illness, that clear planning can begin (Singer et al., 1998).

Health professionals have sometimes been understandably reluctant to honour competent refusals, especially if life-threatening. There has been a marked tendency to avoid doing so, sometimes on questionable grounds (Manning, 2002). For example, where health professionals have disagreed with the patients decisions there have been questions raised by the treating staff that the patient lacks competency. If patients are declared incompetent the health professionals are then free to impose the treatment options they consider necessary.<sup>24</sup> It has also been argued that the use of anticipatory directives create problems for clinicians where they fail to guide clinical decision making or when the advance directive rules out treatment which the medical practitioner believes is in the patient's best interests (Biegler, Stewart, Savulescu & Skene, 2000).

### **2.5.1 A shift in emphasis: The process of advance care planning**

The negative data from the numerous studies exploring advance directives has encouraged a move to broaden the approach of determining patient preferences regarding health care, particularly at the end-of-life. The focus has shifted to the development and evaluation of programs designed to educate health professionals and patients to consider advance care planning (Hammes & Rooney, 1998).<sup>25</sup> Advance care planning is a process involving discussion, reflection, and communication of treatment preferences for end-of-life care (Miles, Koeppe & Weber, 1996). Hammes and Briggs (2005) argue that the process is not merely the completion of an advance directive, rather wider considerations are necessary because the skills required to initiate and continue conversations regarding end-of-life decisions, are far more complicated. Health professionals need to take time to explore patient understanding, values and experiences (Hammes, 2001). This requires skills in active listening and facilitation (Briggs, 2002). The process requires

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<sup>24</sup> See Chapter 8, especially 8.3.1 Determining patient competence and 8.4 Discussion.

<sup>25</sup> Dr Hammes developed a widely published '*Respecting Choices*' program in La Crosse, Wisconsin following his research study in the mid 1990s.

the ability of health professionals to initiate conversations for differing patients, providing information that is unique to each situation, and assisting patients to weigh the benefits and burdens of therapy, and to then translate these into specific treatment decisions (Hammes, 2001).

From the patient's perspective the process ideally comprises several features, including:

- (i) from the patient's perspective, a good understanding of the medical issues and choices available, as well as the identification of relevant personal goals and values,
- (ii) reflection on what choices best represent what is important to the patient, and
- (iii) a clear communication and interaction with others who are likely to be involved in those future decisions.

This includes the selection of a suitable proxy decision-maker (Hammes & Briggs, 2005). It is an informative decision making process, requiring interaction between the health professionals, in particular the medical practitioner and the patient, rather than a mere one-off signature on a consent form (Emanuel, Danis, Pearlman & Singer, 1995). It is also important to ensure discussions are ongoing throughout the continuum of care. This requires health professionals to review therapy plans with patients or proxies on a regular basis (Hammes & Briggs, 2005).

A randomized controlled trial was conducted in Canadian nursing homes in which the implementation of an educational program concerning advance care planning was studied (Molloy et al., 2000).<sup>26</sup> The study highlights a number of findings and confirms that given the opportunity, competent residents and family members of incompetent residents, are willing to complete advance directives. The advance directives in the intervention nursing homes (those with the educational program), addressed the issues of life threatening illness, cardiac arrest and feeding options for

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<sup>26</sup> The program was called '*Let Me Decide*' advance care planning.

reversible and irreversible conditions. As part of the advance planning, a personal statement was also completed by residents, in the intervention nursing homes, allowing individuals to specify which disabilities, as a result of their illness, they would accept or reject. The directives from these homes were found to be more comprehensive and specific when compared to directives completed in the control nursing homes (those without the educational program). Overall, the researchers found in the intervention homes there was a reduced hospitalization rate and implementation of aggressive care, for residents who did not want it. The researchers conclude that the educational program involving staff, residents and family members did result in clear instructions that were ultimately respected (Molloy et al., 2000).

Vinen (2002) argues that whatever the process adopted by health professionals there is a need for patients to be encouraged to focus on planning in terms of outcomes, rather than the acceptance or refusal of specific treatments. Considerations could include acceptability of treatment in terms of quality of life, burdens of treatment and the probability of a good, or poor outcome. Lynn (2000) contends that much of the research in this area assumes that the course of care for patients results from decisions, which arise from discussions between patients or proxy decision makers, and physicians. She suggests that while this might happen, it is probably not the usual explanation for the medical treatment actually provided. Instead, Lynn suggests, the pattern of treatment is probably perpetuated in repeated types of care for patients, with a similar illness. In addition, she observes that teams of health professionals have learnt to do advance care planning more to prevent automatic responses to predictable emergencies, rather than focus on the enhancement of patient autonomy. Lynn argues that advance planning however, might be a good feature of care, to avoid emergency treatment in favour of more appropriate responses, although she believes that educating health professionals to promote discussions regarding end-of-life care is largely ineffective on its own. Further testing of processes and consideration of what could be done, and why it matters to patients, requires ongoing investigation (Lynn, 2000). This perspective highlights the limitations of research that considers advance care planning, and illustrates the need to extend knowledge further, to consider other aspects, including professional-patient interaction when determining acceptable therapy boundaries.

### 2.5.2 The Australian context

Due to the paucity of existing data in Australia in relation to advance directives and associated issues, there have been calls for further research to be undertaken (Biegler, 2001, Vinen, 2002). As the Australian population ages <sup>27</sup> there will be increasing numbers of older patients presenting for acute care management. Taylor and Cameron (2002) contend that currently, many of those patients who are admitted to acute care hospitals are debilitated and infirm, some suffering senility [*sic*], many with little apparent quality of life. Despite this they have been treated with life sustaining treatment, including feeding tubes, permanent urinary catheters, internal defibrillation devices and inappropriate resuscitation attempts (Taylor & Cameron, 2002). These patients generally have a low rate of completing advance directives, or the directives are not accessible to staff, or they have been disregarded. Taylor and Cameron (2002) argue that the time is overdue for serious research and debate about these issues in Australia.

Taylor, Ugoni, Cameron and McNeil (2003) focused on patients' perceptions and use of advance directives. The study revealed that only 7.9 per cent of the patients attending a large Melbourne hospital's emergency department had an advance directive of some kind. Despite this low rate, 82.6 per cent of patients thought that an advance directive was a good idea (Taylor et al., 2003). The study concluded that other issues regarding advance treatment decisions, that would assist in providing quality patient care, include:

- (i) research into the preparedness of medical practitioners to discuss advance directives with their patients,
- (ii) the difficulties of accessing advance directives in a time of crisis, and
- (iii) the legal issues relating to acting or not acting on a patient's advance directive (Taylor et al., 2003).

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<sup>27</sup> 12% of the Australian population is aged 65 years and over and this proportion continues to increase (Australian Bureau of Statistics, 1998).



In a study exploring end-of-life decisions made by medical practitioners in Australia with the same decisions made in the Netherlands, Kuhse, Singer, Baume, Clark and Rickard (1997) raise the question as to why Australian medical practitioners intentionally make decisions regarding their patients without consulting them, even when patients are competent. The researchers (Kuhse et al., 1997, p.1001) contend that:

... it may be that, because the existing laws prohibit the intentional termination of life, doctors are reluctant to discuss medical end-of-life decisions with their patients lest these decisions be construed as collaboration in euthanasia, or in the intentional termination of life.

Although, as the researchers in one study reflect, merely teaching medical practitioners about the law is not sufficient to change behaviour, they also require practical experience discussing advance care planning with their patients (Markson Fanale, Steel, Kern and Annas, 1994). At the Austin hospital in Melbourne, an attempt was made in 1999 to introduce a policy to support the use of recording advance care plans and enduring medical powers of attorney (Lee, Heland, Romios, Naksook, & Silvester, 2003). Despite the policy, evaluation of its use demonstrated an almost complete lack of implementation. Consequently, staff at the hospital implemented the Wisconsin program developed by Bernard Hammes, with certain modifications to suit the Victorian legal context (Lee et al., 2003). The program is called the Respecting Patient Choices (RPC) (Austin Health, 2004). Evaluation of the RPC program found that patients wanted to discuss their illness and future therapy options, but they expected medical practitioners to initiate the conversations with them (Lee et al., 2003). The researchers found that 70 per cent of patients introduced to the RPC program went on to document preferences for therapy in the future and that these were easily located in patient file. The program prepares nursing and allied health staff to facilitate discussions with patients and relatives.<sup>28</sup> Interestingly, medical practitioners are not the target group educated to initiate

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<sup>28</sup> The *Respecting Patient Choices* program developed at the Austin Hospital in Melbourne is working on collaborative projects in other Victorian hospitals, nursing homes and hostels. It has also been delivered to health services in other Australian states (Austin Health, 2004). There is, however, modest literature available regarding further evaluation of the program.

discussions with patients, rather they are provided with education about the program and its relevance to clinical practice (Lee et al., 2003).

Seal (2007) reports on nurses in a South Australian acute care hospital, pre and post experience of the implementation of the RPC program. She found that pre-implementation of the RPC program, respondent nurses expressed job dissatisfaction due to the inappropriateness of the end-of-life care delivered, and the respondents believed that they were not encouraged to ensure patients could exercise self-determination in related decisions. Post implementation of the RPC program a significant number of respondents agreed that they were more confident that patients could exercise self-determination and that treatment was perceived to be congruent with patients' wishes (Seal, 2007).

The emphasis on research associated with advance care planning has resulted in an important, but relatively narrow focus, of determining and documenting patient preferences at the end-of-life. It relates to future care and the appointment of proxy decision makers. Additional research studies need to consider other aspects, such as the relationship between professional practice and relevant law, professional-patient communication, and importantly, the manner in which decisions are formulated in various health care settings. These are also essential facets of patient decision making and apply not just at the end-of-life but during all professional-patient interactions.

## **2.6 MEDICO-LEGAL KNOWLEDGE**

Published research in Australia from either the legal, medical or nursing professions concerning the practice of health professionals, their knowledge of existing legal principles and how these might impact on clinical practice, are sparse. In 1991 in South Australia, a survey was conducted to identify general practitioners' attitudes to and knowledge of the *Natural Death Act 1983 (SA)* which indicated that only 74 of the 117 respondents were aware of the legislative provisions for advance directives (Ashby, Wakefield & Beilby, 1995). Forty-one of the 74 practitioners had discussed formulating advance directives with their patients, the topic actually initiated by patients in most instances. The respondents expressed a number of concerns about

advance directives, including the difficulty of raising the topic with patients and their families, and the possibility of having a negative impact on the clinical relationship and creating differences of opinion between practitioners and family members. The authors conclude that lack of knowledge of the existing legislation has prevented the effective use of advance directives in that State (Ashby et al., 1995).<sup>29</sup>

Darvall, McMahon and Piterman (2001) sought to examine general medical practitioners' knowledge of legal standards relevant to clinical practice. One area examined included respondents' knowledge of the appointment of an Agent within the provisions of the *Medical Treatment Act* in Victoria. The study found that only 7 per cent of the respondents believed that they had "much" or "complete" understanding of the relevant law (Darvall et al., 2001). The study identified the number of times a medical practitioner had discussed a medical enduring power of attorney with patients in the previous 12 months, more than 55 per cent of respondents had not discussed this issue with patients and less than 15 per cent of respondents indicated that a medical enduring power of attorney had influenced their treatment of a patient. The researchers conclude that there is a strong possibility that significant levels of ignorance or uncertainty about legal expectations will result in high levels of non-compliance, which may result in negative outcomes in terms of patients' health. It is also possible that inadequate knowledge will ensure that medical practitioners fail to play a key role in the implementation of the legislation.<sup>30</sup> The researchers conclude that the role of medical practitioners discussing medical enduring powers of attorney with patients has not been achieved in practice (Darvall et al., 2001).

Minimal levels of knowledge concerned with practitioners' awareness of relevant law and its application to clinical practice, have been identified in research studies elsewhere. Goldstein, Vallone, Pascoe, Hunter and Winograd (1991) sought to

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<sup>29</sup> The *Natural Death Act* 1983 (SA) was superseded by *Consent to Medical Treatment and Palliative Care Act* 1995 (SA) which contains more detail regarding advance directives and the ability to appoint a medical power of attorney.

<sup>30</sup> The MTA specifically and consistently refers to medical practitioners throughout. It is clear the MTA was premised on the basis that this group of professionals would play a key role in assisting patients in the area of refusal of medical treatment.

identify levels of awareness of health professionals in California regarding durable (enduring) powers of attorney. The study reported that health professionals were ill prepared to inform patients about making decisions for future care. The findings indicate that one-third of nurses and physicians were unaware of the existing legislation and for those physicians who had “heard” of the legislation, knowledge was limited. The study recommended the formulation of educational programs to address specific problems, including provision of relevant information to practitioners, and strategies for dealing with past problems relating to durable powers of attorney (Goldstein et al., 1991). McCrary, Swanson, Perkins and Winslade (1992) examined the adequacy of physicians’ knowledge of Texas legislation regarding terminally ill patients and investigated whether improved legal knowledge diminishes legal defensiveness in clinical decision-making. The study findings indicate that less than one third of physicians were able to demonstrate adequate knowledge although, the results show that physicians with the greatest training, expertise and legal knowledge regarding the treatment of terminally ill patients, are the least likely to demonstrate “legal” defensiveness when interacting with their patients (McCrary et al., 1992).

In contrast, a study in the state of Arkansas in 1989 examined physicians working in general practice, family medicine and internal medicine (Davidson, Hackler, Caradine & McCord, 1989). A subjective assessment of their knowledge in relation to advance directives legislation revealed that slightly less than two-thirds of the 790 respondents believed that their knowledge was reasonably good (Davidson et al., 1989). It is unclear however, whether the subjective assessments by the respondents corresponded to their actual knowledge. For instance, in the Victorian study by Darvall et al. (2001) when respondents subjectively rated themselves about their knowledge of the medical treatment legislation, they were almost equally divided, into those who believed that they had some understanding and those who believed that they had little or no knowledge. Nonetheless, the Victorian study findings reveal that respondent medical practitioners demonstrate modest use of the legislation (Darvall et al., 2001). This suggests that subjective evaluation of respondents does not necessarily equate with objective knowledge in clinical practice.

## 2.7 HEALTH PROFESSIONALS AND COMMUNICATION

The ability of health professionals, particularly medical practitioners, to discuss difficult choices with seriously ill patients, is pertinent when considering patients accepting or rejecting therapy. Corke, Stow, Green, Agar and Henry (2005) investigated the difficulties medical practitioners face in discussing treatment options with patients with acute life threatening illness.<sup>31</sup> They found that medical practitioners explained the medical situation reasonably well but generally failed to consider the extent to which the illness was affecting the life of the patient. Nor did they consider the therapy options in the context of the patient's fears or hopes. When the respondent practitioners provided advice it was in favour of intervention and the researchers believed that this was because they failed to explore the patient's feelings, values and fears. The researchers suggest that where medical practitioners limit consideration to a disease process, in the absence of considering the individuality of the patient, it is probable that they will only feel comfortable promoting intervention (Corke et al., 2005). Interestingly, the respondents in the study were more inclined not to offer advice to the patient, the researchers propose that one reason was due to the respondents' beliefs that this was inappropriate.

Pochard, Grassin, Kentish-Barnes and Azoulay (2003) contend that medical education has shifted to emphasise respect for patient autonomy and that this has restricted medical practitioners interaction with patients, to the mere provision of information. Schneider (1998) argues that limiting the delivery of any information to patients might create considerable difficulties, especially for patients unable or unwilling to make decisions. Emanuel and Emanuel (1992) propose a range of approaches, from the provision of information to patients who are able to make autonomous decisions, to a more directed approach, which may be appropriate for certain patients presenting with the same illness. The emphasis in whichever approach needs to be moderated and based on the professional being able to recognise the differing personalities and needs of patients. The findings of Heyland,

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<sup>31</sup> The study involved observation of physician-patient interviews based on a medical scenario involving high risk surgery in a hypothetical patient (played by an actor). The 30 trainee medical practitioners of 3-5 years experience represent the equivalent to registrar participants in the present study.

Trammer, O'Callaghan and Gafni (2003) support the notion that patients with the same or similar illness have differing needs, particularly in treatment relating to end-of-life decisions.

Anselm et al. (2005) examined the barriers to communication regarding end-of-life care perceived by physicians,<sup>32</sup> residents and nurses. Four key barriers were identified, at slightly differing proportions for each group and these include: the patient barrier, system barriers (the hospital), provider barriers (the health professionals themselves), and dialogue barriers (the topic of death). All three professional groups identified patients as the key source of many barriers to communication regarding decisions relating to end-of-life treatment (46% nurses, 43% physicians and 40% residents). The health professionals cited exclusion by patients and family, tension between patients and family members, varying mental capacity of patients to understand, and inappropriate timing of discussion, as obstacles to effective communication with patients. The system barriers include issues associated with the hospital, such as available time and insufficient skill or support to enable them to discuss sensitive matters with patients and relatives. While the three professionals groups did identify themselves and the nature of the conversation as barriers, proportionately they considered these two factors as less of an impediment (Anselm et al., 2005). The researchers conclude that the views expressed by the physicians, residents and nurses might reflect real and important barriers to communication with patients, but they state that the findings might also represent a defensive attitude, where the respondents attribute blame to factors extrinsic to themselves (Anselm et al., 2005).

## **2.8 EDUCATION AND WORK PRACTICES**

In acute health settings decision making relating to therapy, especially end-of-life care, is now seen as teamwork in which medical practitioners and nurses work together to reach a decision that reflects the attitudes and values of patients and relatives (Hilden, Louhiala, Honkasalo & Palo, 2004). Both professional groups

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<sup>32</sup> The physicians in the study were senior medical practitioners, called consultants in the present study.

work closely with patients and with each other. However, the educational programs of nurses and medical practitioners vary. The different medical and nursing approaches suggest differing attitudes to health.

The medical model concentrates largely on health as an absence of disease, whereas nursing models of health encompass a far broader concept; identifying it as a continuum reflecting a person's ability to interact with the environment and society (Briggs, 1995). Fowler (1989, p.958) explores this idea stating, "What becomes a life not worth living for an individual is directly related to that person's value system and life experiences and this will vary from individual to individual." This idea recognises that patients or those close to them are best suited to decide what constitutes an adequate quality of life and therefore outcomes of health care. In adhering to the medical model, medical practitioners narrow a patient's sources of knowledge and may ignore the personal source, focusing largely on disease and dismissing any value judgment a patient may make, say, based on spiritual beliefs (Briggs, 1995). Accordingly, there is a need to understand the processes that nurses and medical practitioners utilize to assist patients when deciding upon treatment options.

The medical-nursing difference is explored by Brink who highlighted that, "When faced with an ethical decision nurses usually decide on the basis of autonomy, while physicians decide on the basis of do no harm" (1992, 264). The traditional medical model is one in which the disease processes predominate, the emphasis being largely on the cause and effect of the disease (Clifford 1989). Despite recognition some decades ago of the need to expand the model of medical education to encompass not just biological, but psychological and social factors (Engel, 1977), recent studies suggest that medical and nursing education and practice have some way to go before the current models move from the theoretical to the practical in these areas.

Astin, Sierpina, Forys and Clarridge (2008) found that medical students and residents rate their education and training in psychosocial factors, both in terms of diagnosis and treatment, as inadequate. The researchers argue that there is a need to improve the quality of medical education to address the interplay of biological, psychological and social factors and their influence, and importance on health care delivery.

Calvert and Skelton (2008) highlight the importance in undergraduate medical education of the integration of quality of life principles and their application in facilitating physician-patient communication and in the promotion of patient centered consultations. The researchers state that there are limited opportunities for undergraduate medical students to study and implement health-related quality of life principles to their patients. Seely and Mount (1999) point out that modern medical practice aims at prolonging life with little attention paid to the experience of illness and patients' quality of life, with the exception of palliative medicine. Easson, Crosby and Librach (2001) examined the key textbooks used for medical students and surgical hospital staff and found that the texts offered a comprehensive study of epidemiology, prognosis, medical treatments and disease progression. However, there was no information relating to patients' spiritual, psychological and social issues and communication issues were also not included.<sup>33</sup> These topic areas are essentially absent in the surgical literature despite rapidly accumulating medical literature about end-of-life care. The researchers conclude that the content of textbooks reflect a medical tradition where the investigation, diagnosis, cure of disease and prolongation of life are the most frequently measured endpoints. The material utilized to educate medical practitioners in surgery should provide the essentials of good practice and thus should include information relating to quality of life issues and end-of-life discussions and care (Easson et al., 2001).

Traditionally, nursing and the models of health in nursing education have embraced the ideas of "health" as well being involving multiple dimensions, as opposed to "health" as a mere absence of disease (Saylor, 2003). During the early 1900s nursing education was dependent upon the medical profession to teach biological knowledge and pathology (McCarthy, 1972) and this aligned many nursing programs with the medical approach. The nursing literature however, reflects a growing discontent with the manner in which nursing was dominated by the medical style, particularly the lack of recognition of psychological and social dimensions of health (Wynne, 1997). The nursing models subsequently developed, have attempted to move away from the biomedical view of health, to a more open approach (Brink, 1992). While the

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<sup>33</sup> Ferrell, Virani and Grant (1999) also concluded that many nursing texts were limited in their coverage of end-of-life care.



biological aspects are important, nursing education and models of care recognise that other aspects of patients lives such as the psychological, social, cultural and spiritual are equally important when delivering care and understanding patients (Wywialowski, 1997). Nevertheless, while nurses in differing contexts can recognize the uniqueness of individual patient needs, they do not always possess an ability to meet those needs. McCaughan and Parahoo (2000) found that nurses in their study reported higher competence in providing physical care than psychosocial care. Botti et al. (2006) found that experienced nurses expressed educational deficits in the areas of skills allowing for psychosocial care and communication.

The manner in which nurses and medical practitioners interact and share work in health care institutions is also an important determinant of patient care and decision-making (Tjora, 2000). It has been demonstrated that collaborative partnerships in patient management can have a positive impact on patient outcomes (Coombs & Ersser, 2004). Early studies identify that nursing strategies (Rushing, 1962) and the dynamics of the “doctor-nurse game” (Stein, 1967) demonstrate that nurses often play a crucial role in shaping medical decisions and ultimately, care.

Contemporary models of work distribution suggest a more collaborative decision-making process between nurses and medical practitioners, which allows nurses to exercise more independence in making or challenging health care decisions (Porter, 1991; Wheelless, Wheelless & Riffle, 1989) and this ultimately impacts on patient care. Hospitals where the organization of nursing services promotes high levels of nurse autonomy and relatively good relationships between medical and nursing staff have better patient outcomes (Sochalski & Aiken, 1999). Studies of dilemmas faced by nurses in making autonomous decisions and/or having problems in their relationships with medical practitioners continue to be highlighted (Goodman, 2004). McCallin (2001) concludes that inter-professional relationships have been studied without linkages to a broader context. Furthermore, Weber, Stockli, Nubling and Langwitz (2007) contend that there has been little recent research on communication between physicians, nurses and patients in acute care hospitals. How the professionals actually interact and work together and whether patient outcomes are improved, are issues requiring further consideration. The close working patterns and

relationships between nurses and medical practitioners indicate that it is necessary to examine the practices of both groups in order to understand how patients' refusal of treatment decisions are managed.

## **2.9 SUMMARY**

The literature identifies several areas of relevance to the current study. The acknowledgement of patients' rights highlights the shift in emphasis from health professionals largely directing treatment and making decisions, to models allowing patients to decide, or at least share decision making. The introduction of legislation in many jurisdictions recognises that with development in technology patients should be free to make decisions about treatment preferences, including the right to refuse therapy. The research studies demonstrate the limitations of concentrating on the implementation of advance directives. There is a need to take a broader approach to consider patient values and include these in treatment discussions, hence, the move to advance care planning. These areas are highly pertinent to the present study as they illustrate the importance of developing a process in relation to patient decisions. However, these areas largely concentrate on patients, the identification of future treatment preferences and the appointment of proxy decision makers.

The limited literature addressing medico-legal knowledge provides a brief snapshot, mainly of medical practitioners and their understanding of the legal principles in the area of advance directives and relevant law. The studies suggest that the level of awareness of practitioners of existing legal principles is generally less than adequate, although one study revealed that sufficient legal knowledge positively influenced clinical decision-making. Importantly, it appears there is a difference between the subjective assessment of practitioners and their actual medico-legal knowledge, and their use of the legislative frameworks.

The literature addressing professional-patient communication offers insight into the limitations and barriers perceived by health professionals when discussing difficult information and treatment options with patients. The emphasis appears to be weighted to discussions relating to technical aspects of care and a general failure of practitioners to recognise the differing needs of patients who present with similar

illnesses. The literature highlights the inadequacies of both nurses and medical practitioners in their communication abilities when discussing psychosocial issues with patients, despite these areas being considered highly pertinent to influencing patient perceptions of illness, and possibly decisions. Levels of communication skills can be related to the education and work practices of health professionals, which influence and shape professionals way of thinking relating to health and illness. The literature demonstrates that attitudes to health can differ between nurses and medical practitioners, despite the fact that they are required to work closely together, and with patients, in acute care hospitals.

Notwithstanding the roles of each professional group, there has been little recognition or studies to examine precisely what happens when decisions are made by patients to forgo therapy. The emphasis has focused upon the implementation of specific procedures, namely advance directives or planning, at the end of patients' lives. This ignores the fundamental roles, beliefs and practices of health professionals and their influence on the entire process. A number of questions have been left largely unanswered. For instance, because medical practitioners and nurses work closely together it is important to consider their work practices and relationships, and how each discipline guides and influences therapy plans and decisions. There must also be some understanding of their perceptions of health care, distinguishing supposition from the reality, including the role of patients and family in deciding therapy boundaries. Other relevant inquiry requires examination of specific environments, given that health care occurs in a range of settings. The literature reveals that studies investigating the actual practices of nursing and medical staff, and their interactions with each other in relation to patient decisions regarding treatment, are wholly absent. In addition, there is scant consideration of how existing legal principles impact on health care practice. The current study directly relates to the examination of medical practitioners and nurses in relation to their patient treatment decisions, especially decisions to refuse therapy and to identify how they are managed. The analysis and findings of the current study will also highlight clinical practice in the broader context of the existing legal framework, and demonstrate the adaptability or workability of the legislation for those practising in acute care.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 INTRODUCTION**

An important component of any research study requires careful consideration of the methodology as it underpins the principles and philosophy utilized by the researcher. The methodology will guide the assumptions and nature of the research study and forms the basis for the research procedures and strategies. This chapter begins with a brief consideration of the preference for a qualitative methodology for the current study, and then examines the tenets of qualitative research, namely the ontological, epistemological and the methodological considerations relevant to the chosen research design. This is followed by a discussion of the principal philosophical feature of grounded theory methodology, namely symbolic interactionism. The chapter then presents a discussion of grounded theory, including a critique of this methodology. The chapter concludes after consideration of the Strauss and Corbin approach to grounded theory and its application as the most appropriate methodology to inform the current research study.

#### **3.2 THE PREFERENCE FOR A QUALITATIVE METHODOLOGY**

Traditionally, science has been located in methodology which is quantitative in nature (Guba & Lincoln, 1994). The study of phenomena has been justified in the specific belief that to measure, analyse, and replicate the knowledge gained is the only legitimate manner to proceed. However, researchers have been challenged to explain phenomena that defy measurement, particularly human phenomena (Streubert, 1995). The tradition arose out of the need to understand the various parts of the human system that were not amenable to study through measurement (Streubert, 1995). The difficulty in studying human phenomena, including the inability to measure it, has led researchers to develop other methods that have been characterized as qualitative research methods. The use of qualitative methods to study human phenomena is based in the social sciences, namely anthropology and sociology.

Quantitative empirical researchers dispense with ideas that do not reflect an objective approach to the formation of knowledge. The aims of this type of science are prediction and control and are less helpful when the subject of the inquiry is unable to be made objective (Streubert, 1995). In the qualitative method of research, subjectivity is acknowledged and valued as part of the inquiry. The qualitative researcher's aim is to create knowledge which affords an understanding and interpretation of phenomena within a particular context. This method of research offers an opportunity to study and create meaning that will inform the human experience (Holloway, 1997). The purpose of the current study is to examine the behaviour of registered nurses and medical practitioners within the specific context of patients' refusal of treatment decisions.

The reason for choosing a qualitative methodology in this study is that qualitative methodologies develop understanding of human experiences which are important for health (and other) professionals, who focus on communication and interaction (Holloway & Wheeler, 1996). It is also significant when legislators are formulating legislation that is designed to apply to the daily lives of individuals. The nature of a qualitative approach lends itself to the research problem as it can be used to explore substantive areas about which little is known, to gain original understandings (Stern, 1980). This is the case for the current study where there is a paucity of knowledge and research regarding health professionals' behaviour, vis-à-vis their patients' refusal of treatment decisions and the existing law.

### **3.3 TENETS OF QUALITATIVE RESEARCH**

Qualitative researchers approach their studies with a certain worldview which comprises a set of beliefs or assumptions that guide the inquiry (Creswell, 1998). In order to highlight the underpinnings of qualitative research one must consider three interrelated constructs which define the qualitative research process: the ontology, epistemology and the methodology (Denzin & Lincoln, 2003). In choosing a particular research framework the researcher collects empirical materials relevant to the question and then analyses and writes about them. This is undertaken within a framework or set of assumptions, which are related to the nature of reality (the ontology issue), the relationship of the researcher to that being researched (the

epistemological issue) and the processes of the research (the methodological issue) (Creswell, 1998). These beliefs shape how the qualitative researcher views the world and how it should be understood and studied.

### **3.3.1 Ontology and qualitative research**

Ontology is a philosophical stance concerned with the nature of being and existence (Holloway, 1997). Ontology refers to assumptions that a particular approach to social enquiry makes about the nature of the social reality. This includes claims about what exists and what units comprise the social reality and how these units interact (Blaikie, 1993). The philosophical perspective has a direct bearing on the manner in which the research is conducted, including the validity and reliability obtained in the results.

A feature of qualitative research, including grounded theory, is its realist ontology (MacDonald & Schreiber, 2001). A realist ontology purports that the objects of enquiry exist and act independently of scientists and their activity. A social reality is viewed as a socially constructed world in which social behaviour is the product of the cognitive resources social actors create (Blaikie, 1993). Realism pursues explanation as a primary object, to discover the connections between the phenomena by acquiring knowledge of the underlying structure and mechanisms at work. This includes considering the existence of types of unobservable entities and processes that may be unfamiliar to the researcher. The researcher must go beyond “mere appearances” of things to their natures and essences. Hence research with a realist approach provides an account of the structures and mechanisms which causally generate observable phenomena and enable a description which explains them (Blaikie, 1993).

Realism is evident in the writings of Glaser and Strauss when they emphasize that there is a real world that can be studied and understood.

But a firsthand immersion in a sphere of life ... a social world ... different from one's own yields important dividends. The field worker who has observed closely in this social world has had, in a profound sense, to live there. He has been sufficiently immersed in this world to

know it, and at the same time has retained enough detachment to think theoretically about what he has seen and lived through. (1967, p.226)

This notion of constructed reality is believed by Lincoln and Guba (1985) to be meaningful because it promotes the notion that there are multiple realities. This is a logical position as it supports the idea that there is more than one way to know something and that knowledge is context bound (Streubert & Carpenter, 1995). To believe in a single reality tends to limit an understanding of being, particularly the function of human beings. Thus, while reality changes with the experiences of the individual and the social context in which the individual exists, the reality may also change over time. Strauss and Corbin believe in, “a reality that cannot actually be known, but is always interpreted” (1990, p.22). Hence the reality of social inquiry is relative, being the product of an interpretation, the researcher’s construction (Annells, 1997).

### **3.3.2 Epistemology and qualitative research**

Epistemology is the theory of knowledge and epistemological considerations deal with beliefs about the nature of knowledge (Holloway, 1997). Hitchcock and Hughes (1995) state that assumptions about different forms of knowledge, access to knowledge and ways of acquiring knowledge are key epistemological concerns. Epistemology is defined as, “the branch of philosophy which investigates the origin, nature, methods and limits of human knowing” (Barnhart, 1970, p.12), and in qualitative research considers the relationship of the researcher to that being researched.

Approaches to qualitative research have to some extent been influenced by developments in the quantitative sphere of research. Early qualitative considerations were concerned with the assumptions relating to the natural sciences, which include epistemological considerations such as positivism. Positivism is an approach to science which is based on a belief in universal laws, with an insistence on objectivity and neutrality (Thompson, 1995). A positivist approach follows the natural sciences in which theories and hypotheses are tested. Comte [1798-1857], the French philosopher, suggested that the new and emerging social sciences should proceed in

the same way as natural science by adopting the natural science methods, as opposed to theological explanations of phenomenon (Holloway & Wheeler, 1996). Most importantly, Comte identified society as a phenomenon that can be studied and understood logically and rationally, that sociology could be as scientific as biology or physics. Prior to Comte's revelation, religious paradigms predominated to explain the differences or changes of societies, the state of social affairs was viewed as God's will. Comte separated his inquiry from religion. He believed that religious belief could be replaced with scientific objectivity (Babbie, 1998).

Therefore, a purely positivist approach to research is the quest for objectivity, to avoid personal biases in the research process. A positivist approach directs the researcher to investigate human behaviour in terms of universal laws, in the belief that behaviour can be predicated on the basis of these laws. This assumption considers that numerical measurement, statistical analysis and the search for cause and effect, are the basis of all research (Holloway & Wheeler, 1996). However, many writers now agree that whether it is natural or social science, neither can be truly "value free" (Creswell, 1998; Thompson, 1995; Leininger, 1985).

A competing assumption with positivism is the interpretive view of how research should proceed. This approach focuses on interpretation and the creation of meaning by human beings and their subjective reality (Holloway & Wheeler, 1996). The interpretive paradigm, sometimes referred to as naturalistic, is a consequence of postmodern thinking which emphasizes the value of deconstruction, that is, taking apart old ideas and structures and reconstructing them in new ways. For the interpretive researcher reality is not a fixed entity but rather a construction of the individuals participating in the research. Reality exists within a context and there may be many constructions of that reality. Epistemologically, this approach assumes that knowledge is increased when the distance between the researcher and the participants in the study is minimized. This allows for the voices of those researched to provide an understanding of the phenomenon of interest from their perspective (Polit & Beck, 2004)

Leininger (1985, p.6) stresses that knowledge of people consists of more than "what can be seen, sensed and measured", that is, human beings should be approached



within the whole of their life context not as individuals in a vacuum. A significant contributor to this approach was Weber [1864-1920], who believed that social scientists should be concerned with the interpretive understanding of human beings, and that meaning can be found in the intentions and goals of the individual (Blaikie, 1993). Weber argued that understanding in the social sciences is inherently different from explanation in the natural sciences. The numerically measured probability is quantitative only and he emphasized that social science concerned itself with the qualitative. He believed that researchers should treat people as human beings and try to gain access to their experiences and perceptions by listening to them and observing them (Turner, 1982). For Weber, the social sciences “aim at the interpretive understanding of social behaviour in order to gain an explanation of its causes, its course, and its effects” (Weber, 1964, p.29). Moreover, the behaviour to be studied is social action which includes:

All human behavior when and insofar as the acting individual attaches a subjective meaning to it. Action in this sense may be overt, purely inward, or subjective; it may consist of positive intervention in a situation, of deliberately refraining from such intervention, or passively acquiescing in the situation. Action is social insofar as by virtue of the subjective meaning attached to it by the acting individual (or individuals), it takes account of the behavior of others and is thereby orientated in its course (Weber, 1947, p.88).

Postmodernists and poststructuralists have in more recent times contributed to the understanding that there is no clear view into the inner life of an individual. The examination is always filtered through the lenses of language, gender, social class, race and ethnicity (Denzin & Lincoln, 2003). Moreover, postmodernism posits that there is no single truth on which to base any theory or system of beliefs, there is no grand theory that offers a “universal explanation” (MacDonald & Schreiber, 2001). However, Lyotard (1984) argues that researchers can still make judgments without resorting to grand theories by considering the specifics of context and situation within which the human action occurs. Lyotard advocates the “little narrative” which

represents human action, located within its own time and place (MacDonald & Schreiber, 2001, pp.39-40).

The essence of these two epistemological assumptions, positivism and interpretivism can be seen in grounded theory and have significant implications for the research methodology used. Commonly, each approach determines the research as either quantitative or qualitative however, despite the philosophical differences there can be a blend of the two reflected in the research method. The interpretative approach is clearly guiding the nature of human knowing. Milliken and Schreiber (2001) argue that the epistemology of grounded theory begins with who is the knower and this is in contrast to quantitative methods in which the researcher is the expert. In grounded theory the researcher defers to the expertise of the participants, it is the researcher's responsibility to investigate the socially constructed roles of the participants who have the experience of the phenomenon of the study (Milliken & Schreiber, 2001). However, assumptions relating to positivism can be seen to influence the methodological assumptions of grounded theory, in its quest for reliability and validity.

### **3.3.3 Methodology and qualitative research**

The methodology refers to the philosophy and principles on which researchers base their procedures and to the basic assumptions that they hold about the nature of the research in which they engage (Holloway, 1997). Harding states methodology is "a theory and analysis of how research does and should proceed" (1987, p.3). In particular, methodology comprises the ideas underpinning the entire process of the research, how data is collected, analysed and reported. Strategies of inquiry unite the researcher to specific methodological practices of collecting and analysing data. Grounded theory as a strategy has developed from a specific history, and as with other interpretative paradigms, has a specific method of implementation (Denzin & Lincoln, 2000).

Charmaz (2000) argues that grounded theory, as developed by Strauss and Corbin, has relied upon objectivist assumptions. The notion of objectivity is important as it presupposes that the researcher does not let his or her own values or political stance

impinge on the matter studied. For the outcome to be a more accurate reflection of the research enquiry it is implicit that the researcher's values and background interfere least, as biases are excluded as far as possible to obtain the "truth". A significant proponent of a particular objectivist approach is Habermas.<sup>34</sup> Habermas claimed that the subject matters of the natural and social sciences are fundamentally different. He stated the natural sciences used "sense experience" while the social or hermeneutic sciences used "communicative experience" (Blaikie, 1993, p.52).

He [Habermas] argued that no system of basic concepts comparable to that established [in the natural sciences] for the investigation of moving bodies and observable events was in principle possible, in the study of society. This is because societies are differently constituted as objects of possible knowledge. They form a network of intentional actions and statements about intentional actions that are not reducible to statements about observable events. The investigator must gain access to his data through an understanding of meanings (Connerton, 1976, p.5).

Habermas rejected the objectivist notion of positivism in which the world is conceived as a universe of facts, independent of the observer. Rather he accepted that social and cultural reality is already pre-interpreted by the participants as a cultural symbolic meaning system, which can change over time (Blaikie, 1993). In this form of research the researcher is a "disengaged observer" who stands in a subject-to-object relationship to the subject matter (Stockman, 1983, p.143).

A further methodological consideration of qualitative research recognized in grounded theory is the tradition of hermeneutic phenomenology. Researchers using hermeneutic phenomenology<sup>35</sup> gather data from language, texts and actions. They return to the data frequently and ask the participants what the data means to them.

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<sup>34</sup> Habermas' intellectual origins were in hermenutics, which focuses on the interpretation of the experience shared by human beings and on empathetic understanding. Originally developed as a term for interpreting biblical texts, it was believed that human consciousness and interpretation construct reality and therefore texts can be interpreted in different ways (Holloway, 1997).

<sup>35</sup> Phenomenologists explore the structures of consciousness in human experiences and describe the meaning of the lived experience in relation to a concept or phenomenon (Creswell, 1998).

Each time researchers return to the participants' environment they gain more understanding and knowledge about it and the understanding continues to develop. In this process the participant creates the information and the researcher is the interpreter, together they create the data. The meanings of the participant and the researcher are integrated with each other and in this way the researcher gains an understanding of the context which provides meaning to the data (Holloway, 1997). This remains in keeping with an interpretivist epistemology in which to understand the part (the sentence, utterance, or act) the researcher must grasp the whole (the complex of intentions, beliefs, and desires or the text, language etc.) and vice versa (Schwandt, 2000).

The researcher undertaking grounded theory methodology is challenged to discover ways to investigate how individuals live and make meaning of their worlds. Glaser and Strauss (1967) established a framework and particular strategies in order to achieve this. Researchers were encouraged to go out into the worlds of their participants and actually learn, first-hand. Milliken and Schreiber (2001) believe that grounded theory is an important methodology as it brings the philosophical underpinnings of symbolic interactionism and the conduct/process of the research together extremely effectively.

### **3.3.4 Symbolic interaction as the basis for grounded theory**

Emerging from the interpretive paradigm, symbolic interactionism forms the basis of much social, interpretative research and forms the theoretical framework for grounded theory (Schwandt, 1994). Symbolic interactionism is one of the few theoretical features that could be said to be largely an invention of the twentieth century (Denzin, 1992). The epistemology of grounded research is based in symbolic interactionism and the methodology is the link between the epistemology and the conduct of the research. From this perspective, it follows that grounded theory methodology emanates from symbolic interactionism (Milliken & Schreiber, 2001).

Symbolic interactionism, a term developed by Blumer [1900-1987] in 1937, is an approach which concentrates on the interaction of human beings and the roles that they have or adopt (Holloway, 1997). Blumer drew on the earlier work of George

Herbert Mead [1863-1931], who viewed the individual as a social, rather than a psychological phenomenon (Holloway, 1997). Mead believed that members of a society affect the development of an individual's social self by their expectations and influence. Initially, individuals model their roles and behaviour on those people who are important in their lives, "significant others", thereby learning to behave according to others' expectations. However, the individual can eventually perform in a variety of social roles simultaneously, "generalised other", which Mead believed compared to a team game. The members of the team can anticipate the behaviour of other team members and can thus play their own role (Holloway & Wheeler, 1996). Observing this interacting behaviour forms a source of data in grounded theory.

Symbolic interactionism focuses on the processes of interaction between individuals and social roles (Holloway & Wheeler, 1996). It has become a theoretical perspective that highlights the relationship between individuals and society, and is mediated by symbolic communication (Milliken & Schreiber, 2001). Interactionists assume that human beings create the worlds of experience they live in. They achieve this by acting on things in terms of the meanings things have for them. These meanings emanate from interaction and they are shaped by self-reflections that individuals bring to their particular situations. This self-interaction "is interwoven with social interaction and influences that social interaction" (Blumer, 1981, p.153). Symbolic interaction (the merger between self and social interaction) is the primary means "by which human beings are able to form social or joint acts" and these joint acts, including their formation, conflict and dissolution constitute "the social life of a human society" (Blumer, 1981, p.153). A society therefore consists of the joint or social acts "which are carried out by the members" of that group (Blumer, 1981, p.153).

Manis and Meltzer (1972) believe individuals construct their behaviour and during the implementation of that behaviour, they form an elaborate process of perceiving, interpreting, choosing and rejecting potential lines of conduct. As such, human behaviour is influenced but not determined by the predictability of interactions (Milliken & Schreiber, 2001). Thus, if individuals base their conduct on their interpretations of meanings it becomes important to ascertain the individuals'

meanings, in order to understand and explain that behaviour (Manis & Meltzer, 1972). Ultimately, to understand human conduct researchers must study the individuals' overt and covert behaviour. This is the chief methodological implication of symbolic interactionism that is directly addressed through the use of grounded theory (Milliken & Schreiber, 2001).

Individuals in symbolic interactionism are considered active, creative beings who can plan, project, create actions and then revise them. Individuals engage in self-reflexive behaviour and deal with a world that they must interpret in order to act, rather than respond to specific environmental stimuli (Holloway & Wheeler, 1996). The individual's ability to interpret the behaviour of others allows that individual to choose from a variety of social roles. Thus, the members of a particular culture or group are able to analyse the language, appearances and gestures of others and behave accordingly to those interpretations. Based on these perceptions the individual's behaviour is justified in a particular context. Grounded theory therefore emphasizes the importance of context when understanding an individual or collective behaviour (Holloway & Wheeler, 1996).

Denzin (1989) links symbolic interactionism to naturalistic, qualitative research methods arguing that researchers must go into the world of interactive human beings in order to understand them. In so doing, researchers can then see the situation from the perspective of the individuals, rather than their own. This insight can be revealed by interviews and observations. In this manner individuals can be observed during the process of their usual work and their interaction and negotiations with others in that setting (Holloway, 1997). This current study is most suited to this form of theoretical inquiry as the processes of nurses and medical practitioners negotiating refusal decisions with their patients is gained by observation and interview, whilst the participants are located in their everyday work environments.

### **3.4 THE EMERGENCE OF GROUNDED THEORY**

Grounded theory was initially developed by Glaser and Strauss as a means to enable the "systematic discovery of theory from the data of social research" and was initially presented in their text, *The Discovery of Grounded Theory* (1967). The

methodology developed as a response to the overwhelming belief held by positivist researchers that qualitative research was unscientific because it rejected the tenets of quantitative research, such as hypothesis testing and verificational techniques, and appeared to embrace interpretation. However, the backgrounds of the two researchers proved significant in the new and emerging method. Glaser was trained in quantitative research methods and Strauss came from the Chicago school of thought which had a long history of qualitative research approaches. The methodology of grounded theory was conceived as a response to develop scientific propriety to qualitative research (Smith, 1997). For Glaser and Strauss, the generation and testing of theories are equally important and the two activities are intimately related (Blaikie, 1993).

Grounded theory, as developed by Glaser and Strauss, has been used to study a broad range of phenomena by researchers in fields as diverse as education, social work, psychology, sociology, business management and nursing (Strauss & Corbin, 1994).

Stern found grounded theory to be useful in nursing research because the:

Nurse scientists who use grounded theory find it ideal for tracking nursing problems, for finding the solution to those problems and for applying the findings to nursing settings. Because the scientist generates constructs (or theory) from the data source rather than applying a theory constructed by someone else from another data source, the generated theory remains connected to or grounded in the data. (1985, p.149)

### **3.4.1 The features of grounded theory**

Grounded theory is a general methodology for developing theory that is grounded in data which is systematically gathered and analyzed (Strauss & Corbin, 1994). The notion of “grounded” refers to the collection of factual data, from which the theory is then generated (Stern, 1985). This method of research can be used to generate theory from data but it can also be used to modify existing theories. Glaser and Strauss (1967) believed that preconceived ideas relating to a phenomenon prevent the development of the research, because imposing a particular framework might impede the awareness of major ideas or concepts that emerge from the data. Grounded theory

can be used successfully where little is known about the research topic or area to be studied (Stern, 1985).

Grounded theory is used to develop two types of theory: substantive and formal. Substantive theory is generated in specific contexts and relates to a specific social process such as patient care or race relations, which can also be studied empirically. Substantive theories provide explanations for the social processes of the participants in relation to the particular phenomenon studied. They focus attention on concepts such as the complexities of people undergoing change, the influence of social interactions on outcomes and ways by which the social environment influence human experiences (Benoliel, 1996). The substantive theories produced through grounded theory offer explanations of the social processes of participants. Formal theory is developed at a higher level of generality and involves concepts that can be applied to a number of substantive areas, such as authority and power or social mobility (Glaser & Strauss, 1967; Blaikie, 1993). Both the substantive and formal theories must be grounded in the data.

Substantive theory can be used to create new formal theories or to reformulate existing formal theories (Glaser & Strauss, 1967). However, substantive theory can not be formulated merely by applying the ideas from an established formal theory. Ideally, the researcher should study an area or phenomenon without any preconceived theory that may dictate the relevant concepts and hypotheses (Glaser & Strauss, 1967). A substantive theory generated from the data must first be formulated in order to see which formal theories are applicable for furthering additional substantive formulations. Glaser and Strauss believe that it is incorrect to directly apply a formal theory to a substantive area expecting it to supply all of the necessary hypotheses. The consequence is a forcing of the data and a neglect of any relevant concepts that may emerge. The grounded theory approach, allowing substantive concepts to emerge first in their own right, then enable the researcher to ascertain which if any existing formal theory may assist to generate the substantive theories (Glaser & Strauss, 1967).

The formal and substantive theories generated in grounded theory are described as “middle range” theories. These contain limited insights into the real world but are



particularly useful for linking theory with practice and may be empirically tested (Fawcett, 1995). “Grand theories” on the other hand, are usually more explicit in their aims and formulations although more encompassing of a wide range of phenomena and the theoretical starting points are easier to examine, however, they can not be empirically tested (Fawcett, 1995).

Further characteristics of grounded theory are the processes of induction, deduction and verification (McCann & Clark, 2003). The process of induction requires the researcher to use a ground-up approach, instead of theoretical ideas coming from sources such as existing theories or the researcher, which are then tested (as is the case in deductive research strategies). The theory must be perceived in relation to the data. Moreover, the researcher must keep an open mind and remain flexible to ensure that the theory emerges from the data (McCann & Clark, 2003). It is only after the initial data collection that hypotheses can be formed, and verification of the hypotheses occurs from further collection of data. In grounded theory verification involves “looking for evidence in the data to verify our statements of relationship” while “also looking for instances of when they might not hold up” (Strauss & Corbin, 1990, p.108). Anells contends that the verification process is not one of finding proof but rather a seeking of support for relationships between concepts. The verification of hypotheses is undertaken throughout the course of the research study, not at the completion of it, or through further quantitative research (1997). Empirical verification of the hypotheses occurs through further data collection (Charmaz, 1990; Holloway & Wheeler, 1996). The theory can then be tested allowing the development of predictions through the deductive process. When the researcher derives hypotheses from the data it involves interpretation. This Strauss and Corbin believe to be the deductive process (1998).

In the current study, the grounded theory is conceptualised from the data obtained using inductive, deductive and verification processes which identify concepts and categories and demonstrate the links between them. These processes identify and explain the phenomenon under study, that is, the processes used by nurses and medical practitioners when dealing with patients’ refusal of treatment decisions in the context of acute care delivery. The theory describes and explains how the

concepts and categories relate to a specific phenomenon. Grounded theory methodology was chosen for the current study because the research question seeks to understand and explain the practice of nurses and medical practitioners in a particular context, namely patients' refusal of treatment decisions and how this relates to the existing legal framework. There have been no Australian studies of this kind and the grounded theory methodology is particularly useful where there is little formally known about the research topic or area to be studied (Stern, 1980).

In grounded theory, in order to build a theory the approach is to identify concepts and elucidate how they are related to a phenomenon. The concepts are necessary to categorize the data (Blumer, 1981). The concepts actually form the components of the theory and are abstract generalizations. As data are collected concepts are identified and are then arranged into categories and subcategories, from which theory is then developed (Charmaz, 1990). A theory in this context is specific and limited in range, compared with a conceptual model which is general and abstract, providing a broad perspective of the phenomenon. In a middle range theory there is examination of the interrelationship between and within concepts that enables an explanation of what is occurring (Fawcett, 1995).

Strauss and Corbin (1994) refer to the process of concept identification as theoretical conceptualization, where researchers conceptualize the data after identifying the behaviours and interactions between the participants. The researchers observe the patterns of "action and interaction between and among the participants (social units)" (Strauss & Corbin, 1994, p.278). The emphasis is not on creation of theory about the individual participants, rather researchers are concerned with identifying process, in the sense of changes in patterns of action and interaction, and with changes of conditions which are either internal or external to the process itself (Strauss & Corbin, 1994). This entire process provides the basis of an explanatory structure, allowing the researcher to make predictions.

Grounded theory methodology is designed to guide researchers to produce theory that is "conceptually dense", which refers to the richness of the concept development and relationships, these rely on researchers' familiarity with the data (Strauss & Corbin, 1994) and are presented in discursive form: "They are embedded in a thick

context of descriptive and conceptual writing” (Glaser & Strauss, 1967, p.31). Strauss and Corbin (1994) believe that a discursive presentation captures the conceptual density and communicates a description of the substantive content of the study, far better, than does the natural science form of propositional presentation. To obtain conceptual density, McCann and Clark (2003) state that grounded theory methodology requires an “emic” or insider approach when the researcher is collecting and analyzing the data. This requires researchers to have an empathetic understanding or view of the insider, participants’ perspective, discovering and exploring the meanings they provide to their experiences, perceptions and feelings (Stern, 1994). The researchers’ views are provided with the realization that meanings may be frequently unclear or ambiguous while evolving (Holloway & Wheeler, 1996). The researchers then take an “etic” perspective to explain the participants’ meanings and provide an explanation for events and actions which enable the description of the phenomenon (McCann & Clark, 2003; Harris, 1976).

Grounded theory methodology in the current study requires the researcher to be immersed in the data, the culture and setting (McCann & Clark, 2003). Immersion in the data will allow the researcher to identify conceptually dense categories, which enable a thorough and clear portrayal of the situation (Denzin, 1989). The researcher, as a nurse, possesses theoretical sensitivity to take an “emic” approach regarding data collection and analysis. This requires an empathetic understanding, exploring the meanings the participants give to their ideas, feelings, experiences and perceptions (McCann & Clark, 2003), and the researcher is sensitized to the research environment, the acute care hospital. The insider’s perspective must be gained with the realization that meanings are frequently ambiguous and unclear, while they are also dynamic and constantly evolving (Addison, 1992). The data are then examined from the “etic” perspective to interpret and provide meaning of the participants to enable explanation for the actions and interactions. This results in conceptually dense theory with many conceptual relationships and these relationships are embedded in a context of descriptive and conceptual writing. The resultant theories are grounded in the data, and not predetermined by any theoretical perspective (Cutcliffe, 2000).

Grounded theory, unlike many qualitative methodologies, comprises seven key distinctive features, which assist the research process. They are:

- (i) theoretical sensitivity
- (ii) theoretical sampling
- (iii) constant comparative analysis
- (iv) coding and categorizing the data
- (v) theoretical memos and diagrams
- (vi) literature as a source of data
- (vii) integration of theory

### **3.4.2 Theoretical sensitivity**

In grounded theory the researcher must have theoretical sensitivity, which refers to the insight, qualities and awareness of the researcher. Strauss and Corbin state that it means “having insight into, and being able to give meaning to, the events and happenings in the data” (1998, p.46). Sensitivity is developed over time, from reading the literature and can include the experience of the researcher. In addition, the researcher must have “the ability to maintain analytical distance while at the same time drawing upon past experience and theoretical knowledge to interpret what is seen, astute powers of observation, and good interactional skills” (Strauss & Corbin, 1990, p.18). Theoretical sensitivity guides the researcher to ensure that the data are examined from all perspectives (Holloway, 1996). The researcher in this study is an experienced nurse and has gained some sensitivity examining the literature. The researcher is also a lawyer who has been involved in education about the law of nurses and medical practitioners, where the ideas for this study originally emerged. The legal experience of the researcher provides insight into and some degree of sensitivity to, a potentially controversial and difficult phenomenon, that of patients’ refusal of treatment and how they behave in these circumstances when this occurs.

### **3.4.3 Theoretical sampling**

In grounded theory, theoretical sampling means the sampling continues throughout the study and is not planned prior to commencement of the study. Participants are not chosen on the basis of their representativeness, but because of their knowledge of the phenomenon under scrutiny (Smith, 1997). It means that essentially the sampling occurs on a theoretical, rather than a statistical basis (Finch & Mason, 1990). According to Glaser, theoretical sampling is:

The process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides which data to collect next and where to find them, in order to develop his theory as it emerges. In this process the developing of theory controls the process of data collection. (1978, p.36)

Theoretical sampling is a form of purposeful sampling, with sampling becoming more focused “until all categories are well developed” (Strauss & Corbin, 1998, p.215). Sampling and analysis occur concurrently, with analysis guiding further data collection and includes looking for negative or deviant cases, which do not support a particular hypothesis. When these are found the researcher must modify the hypothesis or justify why it is not applicable. A degree of consistency is important in this form of sampling as comparisons are made systematically with each category, ensuring that each is fully developed. Strauss and Corbin believe that a certain degree of flexibility is also required, as the researcher must be able to take advantage of all incidents, including those not planned, while out in the field (Strauss & Corbin, 1998).

In the current study once the area of interest was identified, the researcher made some sampling decisions relating to the recruitment of participants and the setting for the study. As the data were collected and analysis occurred, further decisions were made regarding sampling participants. This was dependant upon the identification of concepts and the development of emerging categories and subcategories, as the researcher moved from data analysis back into the field to collect further data.

The sample size is considered satisfactory only when the key concepts that have been identified from the data have reached saturation, that is, when no new data emerges (Smith, 1997). This means that no new or relevant data appear during data collection. When a category is well developed in terms of its properties and dimensions and the relationships among the categories are well established, this demonstrates variation (Strauss & Corbin, 1998). The quality of the data are more important than the frequency with which it recurs. This is important because a researcher must gather data until all categories are saturated or the theory will be unevenly developed, lacking precision and density (Strauss & Corbin, 1998). This ensures that the collection of data becomes more focused and specific as the process develops.

#### **3.4.4 Constant comparative analysis**

The concepts identified in the study are the basis of analysis, they form the building blocks of theory. All procedures are established to identify, develop and relate the concepts (Strauss & Corbin, 1998). This is evident in constant comparative analysis where the researcher collects some data and then pauses to commence data analysis, before collecting more data, to pause again to allow analysis to continue (Schneider, Elliot, LoBiondo-Wood & Haber, 2003). Glaser and Strauss (1967, p.105) identified four stages which make it a continuously growing process where the researcher:

- (i) compares incidents applicable to each category,
- (ii) integrates categories and their properties,
- (iii) delimits the theory, and
- (iv) writes the theory.

From these steps the process of constant comparison is understood. The researcher compares each section of the data with every other, throughout the study looking for similarities and differences. The data are coded and categorized and from this, the key concepts are developed. The researcher then searches for major themes which link ideas to form a “story line” for the study (Holloway & Wheeler, 1996, p.101). According to Blaikie (1993), the process is cyclical, rather than linear, from the

constant comparative analysis the emerging categories guide the focus of the study and further data collection. This progression of comparative analysis occurs until, in this study, the processes of nurses and medical practitioners dealing with patients' refusal decisions, arrives at a theory with sufficient abstraction and detail.

#### **3.4.5 Coding and categorizing the data**

Coding and categorization constantly continues throughout the research. The coding is the process by which the concepts are identified and named during the analysis. Concepts are the conceptual labels which are assigned to discrete events, ideas, incidents, or action/interaction, the researcher identifies as being significant to the phenomenon. (Strauss & Corbin, 1990, 1998). When coding, the researcher can begin to examine data comparatively and the concepts reveal how the phenomena might be related to each other (Strauss & Corbin, 1998).

Strauss and Corbin use a coding pattern they refer to as their "paradigm", which is an organizational model or perspective, taken toward data in such a way that structure and process are integrated (1998). When coding, the paradigm influences the perspective taken toward the data. This is an analytical stance that helps to systematically gather and order data so that structure and process are well integrated (Strauss & Corbin, 1998). It provides understandings of causal, conditional and intervening factors related to the context of the phenomenon. The coding process also allows the researcher to develop concepts as they emerge from the data.

From the identified concepts data are transformed into more abstract categories. A category is a classification or group of concepts that stand for phenomenon. Categories arise from the constant comparative analysis, which involves questioning the data and identifying the properties of the concepts. In grounded theory method the researcher has flexibility in what manner coded categories are relationally linked to each other, to assist in the theory formation (Schneider, Elliot, LoBiondo-Wood & Haber, 2003). It is important that theory development is not limited to just one pattern of integrating categories.

Categories involve grouping the concepts, conceptualizing data, and this process results in a more abstract concept, known as the category (Strauss & Corbin, 1998).

The category may signify an event, issue or relationship and it should relate in some way to other categories. Thus, the researcher compares event with event, event with category, category with category, searching for similarities and differences. This enables identification of the components of each category, and links that can be made between categories (Hutchinson, 1993). The conceptual categories ultimately allow the researcher to build the theory. Before an understanding of how the concepts and categories emerge, an explanation of the coding process is paramount. There are three types of coding to be utilized in grounded theory method, which allow for the emergence and development of concepts and categories. They are: open, axial and selective.

#### **3.4.5.1 Open coding**

Open coding is the process of breaking down data into discrete parts. The researcher is seeking to find events, happenings, objects, and actions/interactions that are found to be conceptually similar in nature or related in meaning, they are then grouped together (Strauss & Corbin, 1998). Each separate idea is labeled and similar ideas are named with the same label (Holloway, 1997). The text must be opened to expose the thoughts, ideas, and meanings contained therein. Data are then closely examined and compared, this allows for fine discrimination and differentiation among categories. Without this first analytical step the rest of the analysis and the communication that follows could not occur (Strauss & Corbin, 1998).

Open coding requires the researcher to look for process, as data are gathered, from observational notes, interviews or relevant written documentation. The procedure entails using words or phrases that describe what happened in the field of study (McCann & Clark, 2003). Raw data are analysed using line-by-line coding. This is important in the beginning of the study because it allows the researcher to generate categories quickly and to develop those categories through further sampling. Coding can also be done by sentence and by paragraph. This approach to coding can be used at any time but is especially useful when the researcher has several categories and wants to code specifically in relation to them (Strauss & Corbin, 1998). If a new concept or category is identified the researcher may need to revert to line-by-line coding. This detailed form of analysis forces the researcher to concentrate on the



data to avoid undue influence created by preconceived beliefs regarding the phenomenon (Charmaz, 1990).

There are two types of coding used at this stage: in vivo codes and sociological constructs. The in vivo codes may consist of words or phrases that have been used by the participants themselves to describe the phenomenon (Strauss, 1987). They provide the life and interest of the study and reflect the reality of the participants because the participants themselves use this language or expression (Holloway & Wheeler, 1996). Using in vivo codes prevents the researcher from imposing his or her own words, and possibly preconceived ideas on the data. Sociological constructs are developed from the substantive data collected in the field and the researcher's expertise and scholarly knowledge (McCann & Clark, 2003). These augment a mere scholarly conceptualization of the analysis than in vivo codes however, they lack the degree of imagery of the latter form of coding (Strauss, 1987)

#### **3.4.5.2 Axial coding**

This is a technique used by Strauss and Corbin (1990, 1998) where the data having been fractured and deliberately broken down during the open coding process, is then reassembled. The data is re-examined and collapsed into categories or higher level concepts (Schreiber, 2001). The researcher begins axial coding when he or she notices similarities in the concepts, identified during the open coding phase. The researcher constantly compares the open codes against existing and new incoming data and identifies categories, which are then compared with data and codes. As the researcher develops categories there may be further development requiring the use of subcategories. Subcategories like categories, also have properties and dimensions but rather than standing for the phenomenon itself, subcategories answer questions about the phenomenon such as when, where, why, who, how, and with what consequences, thus giving the concept greater explanatory power. Identification of subcategories becomes more obvious as data collection proceeds (Strauss & Corbin, 1998).

As axial coding proceeds the concepts are elevated to provisional categories, then categories are grouped together to build major categories, where links are made between a category and the subcategories. This ensures that the researcher goes from

specific incidents to abstractions, which are then checked against the incidents in an iterative process (Schreiber, 2001). Schreiber states that when these comparisons are made the researcher may “identify gaps in the data where further information is required” (2001, p.70). The process requires inductive and deductive analysis where the researcher asks questions and makes comparisons with the data (McCann & Clark, 2003). As the researcher becomes more familiar with the data, coding may occur at two levels simultaneously, from open to axial coding.

During the course of the coding process working hypotheses or propositions are generated. These must originate from the data and the process of checking hypotheses continues throughout the research. Holloway (1997, p.85) contends that “if negative or deviant data which does not support a particular proposition is found, the researcher must modify the hypothesis or find reasons why it is not applicable”. The process of coding and categorizing stops when no new information relating to a category can be identified, the category is fully described (with all of its variations and processes) and links between categories are firmly established (Strauss & Corbin, 1990, 1998).

#### **3.4.5.3 Selective coding**

The third level of coding is selective coding which is coding for the main phenomenon, the core category. In grounded theory this is the key category which links all categories. At this stage theoretical coding requires the researcher to comprehend the data theoretically, rather than descriptively (Stern, 1980). This means applying a variety of analytical schemes to data to enhance their abstraction (Streubert & Carpenter, 1995). Moving from descriptive to theoretical explanations requires the researcher to examine all the variables that may impact on data analysis and findings (Stern, 1980). During the process of modifying concepts and categories the researcher uses memos to maintain the researcher’s ideas as the theory emerges (Streubert & Carpenter, 1995). The researcher’s knowledge and academic experience assist this process where coding takes place using theoretical sorting. The intent of the sorting is to re assemble the data back, into a meaningful whole. At this time any categories requiring further development are refined (McCann & Clark, 2003)

The selective coding process involves the linking of all categories around the core category and the core category only begins to emerge after constant comparative analysis with the data. Strauss and Corbin (1998) believe that the process of integration of the core category with the other categories is similar to axial coding, requiring an abstract level of thinking. The core category represents a thread, which is woven into the entire research study, providing a story line (Holloway & Wheeler, 1997). The core category is broad in range and is able to integrate and explain the relationship between the other categories. It is also able to explicate the variation in events identified in the course of the study (Strauss, 1987). After the emergence of the core category the researcher begins the steps of concept modification and integration. Through the use of theoretical codes, the conceptual framework moves from a descriptive to a theoretical level (Streubert & Carpenter, 1995). The core category must have analytical power.

The core category or resulting theory should have two features: firstly, it should be comprehensive but not unwieldy, allowing for clear conceptual links in the coding process; and secondly, it should facilitate an explanation of the variations in the categories (Hutchinson, 1993; McCann & Clark, 2003).

Strauss (1987, p.36) and Strauss and Corbin (1998, p.147) identify the major characteristics of a core category:

- (i) it must be the central element of the research, where all other categories can be related to it;
- (ii) it must be able to provide explanation which is logical and consistent, there must be no forcing of the data;
- (iii) it must recur frequently in the data;
- (iv) it easily connects with other categories, as the concept is refined analytically it grows in depth and explanatory power;
- (v) in the process of identifying, describing and conceptualising the core category, the general theory of study develops more fully;

- (vi) the core category is able to explain variation as well as the main point made by the data.

#### **3.4.5.4 Coding modification and integration**

Theoretical codes provide direction to the process of examining data in the theoretical rather than the descriptive terms (Stern, 1980). This means applying a variety of analytical schemes to data to enhance its abstraction. Moving from descriptive to theoretical explanations allows the researcher to examine all the variables that may impact on data analysis and findings (Stern, 1980). During concept modification and integration, memoing is used to retain the researcher's ideas which are pertinent to the emerging theory (Streubert & Carpenter, 1995).

#### **3.4.6 Theoretical memos and diagrams**

Memos comprise a continuous log of analytic information. Diagrams form the visual memos. They are used to depict the relationships among concepts (Strauss & Corbin, 1990, 1998). In grounded theory memos are written records that contain the products of analysis or direction for the researcher. They form a useful store of ideas throughout the entire analytical process and are meant to be analytical and conceptual, rather than merely descriptive. Any thoughts the researcher has about the nature of the phenomenon, new codes and categories, relationships between categories or with existing theoretical models, even general ideas should be written up immediately and filed (Smith, 1997).

Memos can take many forms, including code notes, theoretical notes or operational notes. As the research proceeds, memos become abstract, they contain clues to integration particularly if the researcher has systematically identified the properties of concepts as well as their dimensions (Strauss & Corbin, 1998). Memos are usually sorted by categories and then reviewed. By reviewing and sorting memos according to categories they can highlight linkages and assist the researcher to integrate data (Strauss & Corbin, 1998). Memoing involves both inductive and deductive processes. When data is conceptualized it is inductive, and when the researcher is identifying categories and links between categories and subcategories, it becomes a deductive process (Hutchinson, 1993).

Strauss and Corbin (1998) believe that writing memos and drawing diagrams are important elements of analysis and should never be considered superfluous, no matter how time consuming they may be. They should be utilized from the beginning of analysis and continue throughout the entire research process. Despite the fact that the memos and diagrams may only be viewed by the researcher (and supervisors in this current study), they remain important documents because they record the progress, thoughts, feelings and directions, of the research and researcher. They record the understanding of the entire research process as they can be traced back to the researcher's thought and decision making processes throughout the study (Smith, 1997). Memos and diagrams can be utilized in demonstrating an audit trail from data to category.

#### **3.4.7 Literature as a source of data**

In grounded theory the researcher is seen to bring considerable background and professional knowledge of the literature to the research process. If the researcher is unfamiliar with the area of study, the researcher may undertake a preliminary search of the literature in order to assist identification of the area of to be researched. The researcher however, should not be so enmeshed in the literature that the research is confined or stifled by it (Strauss & Corbin, 1998).

During the research itself the researcher may find further documentation in the form of reports, manuscripts and the like, which are pertinent to the area studied. Strauss and Corbin (1998) refer to this information as literature that can be used to enhance, rather than constrain theory development. When categories have been found, the researcher can examine the literature for confirmation or refutation of these categories. This assists the researcher to identify other theories, or links to existing theories. In this situation the literature becomes part of the data (Holloway & Wheeler, 1996).

Strauss and Corbin (1990, 1998) highlight the uses of technical and non-technical literature.<sup>36</sup> The technical literature can be used to enhance sensitivity to subtle nuances in the data, and before beginning a project the literature may assist in the formulation of questions during the initial observations. Concepts developed from the literature can provide a source for making comparisons to data, and literature can provide knowledge of many theoretical perspectives as this will influence the particular stance the researcher will take.<sup>37</sup> When the data have been collected and the research is being written, the literature can be used to confirm findings or illustrate where the literature lacks depth or partially explains the phenomenon (Strauss & Corbin, 1998). The non-technical literature may be used for the same purposes as the literature however, Strauss and Corbin (1998) also suggest that it may be used as primary data or can be used to supplement interviews and observations.

#### **3.4.8 Integration of theory**

As a result of the coding processes, memoing, the construction of diagrams and the appropriate use of literature, the successful grounded researcher must develop and refine the theory. To be credible, a grounded theory must have explanatory power and clear links between the categories and specificity. In a quality study the categories are tightly linked to the data and the theory does not merely describe static situations, but accounts for the processes which occur (Holloway & Wheeler, 1996). Glaser and Strauss considered that these processes would produce a theory that will fit and work, that is, its concepts will be appropriate, it will be meaningful and relevant and it will be able to both explain and to predict the phenomenon studied (Blaikie, 1998). Thus, the generation of the theory arises during the process of the research rather than preceding it. This means that theorising is an ongoing evolving process (Glaser & Strauss, 1967). Strauss and Corbin (1990, 1998) are less pragmatic

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<sup>36</sup> Technical literature includes reports of research studies and philosophical discussions written by scholars. Nontechnical literature includes biographies, diaries and records that can be used as primary data (Strauss & Corbin, 1998, p.35).

<sup>37</sup> For instance, a phenomenologist might study the meaning of various types of experience, whereas a Marxist may consider investigating power, while a researcher interested in symbolic interactionism may investigate interaction and structure and the relationship between them (Strauss & Corbin, 1998, p.50).

regarding these features of fit, work, relevance and meaning and claim that qualitative researchers should select the standards of qualitative research namely validity, reliability, efficiency and sensitivity (Polit & Hungler, 1999).

Given that a key feature of grounded theory is to produce a theory from the data, Strauss and Corbin (1990) contend that a good grounded theory must demonstrate four main criteria: fit, understanding, generality and control. Thus, if the theory is grounded or generated from the data, it will fit or be clearly integrated and able to explain the area of the research, in this instance, acute care hospitals and the behaviour of nurses and medical practitioners when dealing with patients' refusal of treatment decisions. The theory in this study should demonstrate the context in which nurses and medical practitioners function and the roles they adopt during interaction. It should be relevant to professionals working in the specific acute care environment. Furthermore, the theory must be true to real life and should be clearly understandable to both the participants and other professionals, including academics interested in health care and the law.

#### **3.4.9 Critique of grounded theory**

There are a number of factors to consider when assessing the value of grounded theory methodology. The wide use of grounded theory methodology has caused some researchers to argue that the diverse interpretation of grounded theory procedures are representative, but there may be problems with the designs or confusion regarding the method. The use of grounded theory in conjunction with other methods, or use of selective procedures of this methodology researchers find expedient, make it difficult to compare studies, particularly when studies have adhered to all of the procedural processes and subsequent detail advocated by either Glaser or Strauss (Babchuk, 1996). Charmaz (2000) recognizes that the approaches of Glaser and Strauss are to some degree conflicting, but states that both have positivistic underpinnings. She contends that both Glaser's and Strauss and Corbin's position "endorse a realist ontology and positivist epistemology, albeit with some sharp differences" (2000, p.513). Nevertheless, Charmaz (2000) believes that Strauss and Corbin move into postpositivism, because they give voice to their participants, acknowledging their view of reality. However, this position, she argues, is

ambiguous as they move between objectivist and constructivist assumptions. This is also the view of MacDonald and Schreiber (2001) who believe that with Strauss and Corbin, researchers can find support for any ontology they wish.

Furthermore, the concepts of reality, truth and validity in grounded theory, while mentioned by the originators, are not sufficiently elaborated by either Glaser or Strauss and Corbin's position. For example, like Glaser, Strauss and Corbin maintain that "fit" is a criterion for judgement of a theory. A theory should be true to the data, repeating from Glaser and Strauss' earlier work that "fit" indicates some kind of close correspondence. Strauss and Corbin contend that "fit" is a powerful condition for understanding and usefulness, yet Lomborg and Kirkevold (2003) state this leaves the reader with a vague feeling that Strauss and Corbin's position is realistic, because correspondence normally refers to a realist position, although their use of the concept "fit" is ambiguous. As Glaser does not enter the discussion on the ontological or epistemological level his position remains vague. Consequently, it is uncertain how the researcher should ensure the quality of a theory or how a given grounded theory can be critiqued (Lomborg & Kirkevold, 2003). Lomborg and Kirkevold (2003) consider that a valid theory is a theory that corresponds to the phenomenon studied and the concept of "fit" is a simple way to express the correspondence to social reality. It also serves the central function of allowing for external validation of social research processes. Despite the fact that there are many interpretations of a given social subject not every theory will "fit" the subject of the study. Therefore, the concept "fit" does provide some guidance when evaluating a theory.

One important difficulty is the ostensible conflicting approaches taken by Glaser and Strauss regarding the rules and procedures they outline in their various publications, subsequent to their first collaborative work in *The Discovery of Grounded Theory*. The main focus of Glaser's critique of Strauss' version of grounded theory is that it tortures the data through "heaps of rules and fracture methods that are hard to remember and follow, and yield low-level abstract description" (Glaser, 1992, p.81). Glaser asserts that too many rules impede effective analysis and serve to only produce a description of behaviour rather than a grounded theory in a substantive



area. However, Babchuk (1996) argues Glaser's belief that the researcher must simply trust in the emergence of themes from the data and allow the data to control him, is problematic by Glaser's insistence that grounded theory relies on a series of steps which must be strictly adhered to. Glaser states that "one must study thoroughly the methods set out in [the texts] *Discovery* and *Theoretical Sensitivity* and be prepared to follow them" (1992, p.17). Conversely, Strauss and Corbin advocate flexibility in the method stating that "individual researchers invent specific procedures (1994, p.276), and "while we set these procedures and techniques before you, we do not wish to imply rigid adherence to them" (1990, p.59). However, they continue to assert that the procedures of grounded theory must be taken seriously "otherwise researchers end up claiming to have used a grounded theory approach when they have used only some of its procedures or have used them incorrectly (Strauss & Corbin, 1990, p.6).

The differences between Glaser and Strauss in how they view the procedures and processes of grounded theory become difficult when attempting to assess the value of grounded theory studies. In addition, to ensure that a study meets the requisite standard, the time line this research requires in order to demonstrate the procedural steps have been adequately followed, is lengthy. To demonstrate the method properly the length and format and the amount of detail regarding analysis is important and not always suitable for conference or journal publication, but rather books and doctoral dissertations (Smith, 1997).

The terms used in grounded theory methodology have arguably created some confusion with research design. For example, grounded theory uses non-probability sampling and theoretical sensitivity. For concepts and categories to emerge during data analysis sampling continues until each category is saturated. There are no limits placed on the number of participants or data sources. Therefore, the selection of the participants and other sources of data is a function of the emerging hypotheses and the sample size a function of theoretical completeness (Cutcliffe, 2000). Sampling in grounded theory is described as theoretical rather than purposeful because it is determined by the emerging theory. However, Cutcliffe (2000) argues other authors of qualitative research do not make this distinction, in fact there is evidence some

authors suggest that theoretical and purposeful sampling are interchangeable (Lincoln & Guba, 1985). This apparent uncertainty only serves to confuse novice qualitative researchers. Hutchinson (1993) argues that participants are initially chosen to provide a relevant source of data, thus the sample is purposefully chosen, but this is superseded by theoretical sampling as the data/theory highlight the direction which sampling needs to follow.

A further issue to consider when critiquing grounded theory is the role of the researcher. Qualitative research invariably requires interaction between the researcher and the world that they are studying. Nevertheless, it is how this interaction affects the emerging theory which remains an issue for debate. Morse (1994) contends that this has created conflicting advice concerning the application of the researcher's prior knowledge and experience. It is important that the researcher is aware of his or her own personal perceptions, values and beliefs and can conduct the research without allowing these to overpower the research process. If this is not addressed, the scientific endeavour will be unsuccessful as the researcher perceives an image of his or her perceptions and not the social reality. Hence there is a need for the grounded theory researcher to acknowledge prior experience and knowledge and to bring this into the open, to discuss how this affects the research process and subsequent theory. Cutcliffe (2000) contends that by allowing an interplay between the researcher's knowledge and beliefs, and the data, allows the researcher's creativity to explore the categories and the theoretical links. In grounded theory, checking for representative data that is not purely from the researcher, can occur by exploring the emerging concepts and categories in further data collection. If the belief or hunch belongs to the researcher and is not part of the environment studied this will have little or no meaning for the participants and can be discarded (Cutcliffe, 2000).

#### **3.4.10 Justification for the Strauss and Corbin approach**

Since Glaser and Strauss first published grounded theory methodology in 1967 there have been further publications from each author which, after scrutiny of the literature, indicate each has taken a different approach to this qualitative method.

Therefore it is important that the researcher make clear which methodological approach has been taken and why it was chosen.

Stern (1994) highlights the fact that Glaser and Strauss had distinctly different academic backgrounds which has influenced the development of grounded theory methodology. Glaser's background was in statistical analysis and he insists that the theory should be allowed to emerge, whereas, Strauss' background was the Chicago school of sociology which has its origins in the symbolic interactionist tradition. Strauss prefers a more prescriptive approach to theory development. In particular, as the data are examined the approaches vary considerably. The Strauss approach is to stop at each word and ask "What if?", whereas Glaser keeps his attention on the data and asks "What do we have here?" (Cutcliffe, 2000). The Strauss approach (now the Strauss and Corbin approach), is preferred for the present study because this approach brings every contingency that could relate to the data, whether it immediately appears in the data or not (Stern, 1994). It is also the preferred approach as the prescriptive nature of the research process provides the neophyte researcher, as is the case in this study, with clear methodological direction.

The origins of the Strauss and Corbin approach to grounded theory methodology is influenced by the pragmatist and interactionist writings of Mead, Blumer, Park and Dewey. The ideas from these writers have shaped the philosophical direction of this methodology to include the following features:

- the need to get into the field of study to truly understand it;
- the importance of theory, grounded in empirical reality;
- the nature of experience as continually evolving;
- the active role of the individual in shaping the world in which they live;
- the emphasis on change, process, variability and complexity of life; and
- the interrelationships among conditions, meanings and action. (MacDonald, 2001, p.138)

For Strauss and Corbin an important aspect of the research question is establishing the boundaries around what is to be studied. The research question should allow flexibility to explore a field or problem in depth however, the initial question begins broadly and is narrowed down and becomes more focused during the research process (Strauss & Corbin, 1998). This allows the research problem to be a workable size for the novice researcher and also provides direction for the researcher. The question in the current study has been formulated to encompass the boundaries to be studied, yet is sufficiently flexible to explore the behaviour of nurses and medical practitioners in a specified situation, with a depth of understanding as to just what goes on in circumstances when patients refuse treatment.

MacDonald (2001) contends that the systematic features of grounded theory allow theory to meet the canons of good scientific research including significance, generalizability, precision, rigor and verification. The researcher alternates between collecting and analyzing data, which allows emerging concepts to direct sampling and also allows verification of provisional hypothesis. Strauss and Corbin believe that the purpose of grounded theory is to specify the conditions that give rise to specific types of action/interaction relating to a phenomenon. Thus, the theory is generalizable only to those specific situations (Strauss & Corbin, 1990). They also contend that all theories are temporally limited and always provisional. Thus, there can be no time and context free generalizations of grounded theory. However, when a further study is undertaken to the extent that situations and conditions in the new context are similar to the context in which the theory was developed, then the grounded theory may be generalizable (Strauss & Corbin, 1994; 1998).

In terms of the use of literature, the approach preferred is for the researcher not to be too enmeshed in the literature as it may stifle and constrain the theory. The researcher may begin with a cursory examination of the literature to develop sensitivity and then return as a concept emerges as relevant. The initial examination of the literature will assist in the generation of ideas, which may be related to the theory (Holloway & Wheeler, 1996). It is important that each concept earns its way into the theory. Strauss and Corbin (1998) refer to the use of both technical and non-technical literature as being relevant and usable. The researcher in the current study

has utilized both types of literature as a source for developing sensitivity and as a source of data, the patient records did provide useful insight into the actions of the nurses and medical practitioners after a patient has refused treatment.

Strauss and Corbin (1990) claim that grounded theory can be evaluated when the process is made explicit. This is most suitable as a precise process provides a useful guide for the novice researcher. The criteria they developed include direction about the sample and the reasons for the choice, the description and indicators of the major categories, the concepts on which theoretical sampling proceeds, the demonstration of hypotheses and an explanation, including the reasons for the choice, of the core category (Holloway & Wheeler, 1996). The methodological process allows the theoretical ideas to emerge and assist in understanding the phenomenon. In the current study this will be useful when educating nurses and medical practitioners when they are dealing with patient refusal decisions and further, may assist in evidencing the specific legal principles required.

Lastly, the preference for the Strauss and Corbin approach relate to the researcher's theoretical sensitivity. This approach considers the researcher's personal characteristics to be important to assist with sensitivity and they include insight, awareness of subtleties and the capacity to identify relevance (MacDonald, 2001). The current researcher is a nurse with extensive experience in the acute care setting which enhances the development of theoretical sensitivity. The researcher is also an educator of both nurses and medical practitioners in the area of medico-legal aspects of practice which provides some insight into the existing legal expectations and the practice dilemmas of these professionals. The methodology suggests some clear strategies to deal with ensuring a balance between the researcher's own knowledge and perceptions and the reality of the phenomenon. These include questioning, detailed analysis of the words and phrases used by the participants, flip-flop technique and systematic comparison of phenomena (MacDonald, 2001).

### **3.5 SUMMARY**

Before a research study commences the researcher must carefully choose the most appropriate research strategy and have a clear understanding of the key philosophical

components of the methodology utilized. The current study examines the behaviour of nurses and medical practitioners in a specific situation with the aim to uncover an understanding and insight into the practice of these health professionals. Hence a qualitative research design was considered most appropriate and in particular, the methodology of grounded theory. The Strauss and Corbin version of grounded theory was preferred in this study given its key features, including an ability to explore a phenomenon in depth with explanatory power, which will provide a significant contribution to future clinical practice and educational programs.

## **CHAPTER 4**

### **METHODS**

#### **4.1 INTRODUCTION**

This chapter discusses the methods of study used to investigate the research question: what processes do nurses and medical practitioners employ when patients refuse treatment? The chapter commences with a discussion of the main ethical considerations. A description of the selection and recruitment of participants is provided, and a discussion of the three data collection methods – interviews, observations and documentary sources – then follows. Finally, a summary is presented about the processes of data collection and analysis, including entering the field and sampling, and the analytical framework utilised in this study.

#### **4.2 ETHICAL CONSIDERATIONS**

There are seven key ethical issues pertinent to the study:

- (i) ensuring informed consent and voluntary participation;
- (ii) respecting the participants' right to withdraw from the study;
- (iii) maintaining privacy, anonymity and confidentiality;
- (iv) minimising harm to the participants;
- (v) the presence of patients;
- (vi) reporting alleged unethical or illegal conduct; and
- (vii) providing proper data storage, access and disposal.

#### **4.2.1 Informed consent and voluntary participation**

Informed, voluntary consent is an explicit agreement by the participants, which is given without inducement or threat and it is based on information any reasonable person would want to receive, before agreeing to participate (Sieber, 1992). The process of informed consent is based firmly within the principle of respect for autonomy and means that participation is voluntary, and that participants are not only aware of the benefits of the research, but also the risks they take (Holloway, 1997).

The nature of qualitative research is its flexibility, as it focuses on meanings and interpretations of participants and it enables the researcher to develop ideas that are grounded in the data (Holloway & Wheeler, 1996). This can create problems because the researcher is not able to inform participants of the exact path of the research therefore, informed consent is an ongoing process of informed participation (Ford & Reutter, 1990). Moreover, the literature search indicates that the area of refusal of treatment is commonly associated with advance directives and planning at the end of patients' lives and this might raise emotional and legal concerns for participants.

In the current study, with the above issues in mind, prior to informed consent being obtained, verbal and written explanations were given to participants regarding the study. Following this phase a number of individuals agreed to participate. Further verbal explanations were given and clarified upon request, with potential participants, when the researcher was observing previously recruited participants during the observational period. This allowed individuals time to consider whether they would join the study. There was considerable emphasis placed on the voluntariness of their participation and at no stage was coercion or inducement used to persuade individuals to take part. It was made clear during the verbal explanation that refusal to participate in the study would not be detrimental to anyone in any way, and this proved to be the case. Furthermore, participants were informed that they were free to choose whether to answer specific questions during the interviews and to decide, without explanation, whether to exclude the researcher from periods of observation. The researcher appreciated the sensitive nature of the study and excused herself from observing at times, making this decision before being asked by participants.



#### **4.2.2 Withdrawal**

If participants decided to withdraw their consent at any stage during the study, either before or during the interviews, or whilst being observed, they were free to do so. It was clearly expressed in the written and verbal details that no reason or explanations were required if participants chose to withdraw from the study and that deciding to withdraw would not have any detrimental affect on their employment position. If a participant requested, any tape recordings, transcripts or field notes would be destroyed. However, this did not eventuate as no participant withdrew from involvement in the study.

#### **4.2.3 Privacy, anonymity and confidentiality**

The interviews were held in a suitable mutually agreed private setting, as directed by the participants. The time of the interview was always scheduled to suit the participant, and this occurred both during and outside working hours. The interviews were undertaken in separate rooms on the hospital premises, in an area where interruptions were minimised. Alternatively, interviews were conducted in the private offices of some participants. The observations occurred within the work environment, on the wards and unit, where participants worked. These areas were mutually agreed upon.

Assurances were given to participants by the researcher that any information gained during the interview or observations would be held in the strictest confidence. In addition, the researcher guaranteed the anonymity of participants in any reports or publications generated as a result of this study.

#### **4.2.4 Minimising harm to the participants**

This study would not create any physical risk of harm to participants. However, the nature of qualitative interviews can provoke distressing memories (Holloway & Wheeler, 1996). This must be considered in light of the topic area itself, where it could be perceived that patient refusal of treatment and how informants or their colleagues deal with it, could evoke emotional distress for participants. In addition, Platt (1981) contends that in interview situations informants are often in a position of

inequality. This is particularly the case when participants perceive they are not equal peers with the researcher.

In anticipation of the event of stress being caused as a result of involvement in the study the researcher had in place a clear list of strategies. Throughout the study, care was taken with all questions asked by the researcher, mainly to avoid distress and it was made clear to participants that they were not required to answer questions if they did not wish to do so. In particular, at the close of each interview and observation period, time was taken to de-brief participants in order to identify and eliminate any uncertainties or unresolved issues. Smith (1992) argues the researcher's role is one of investigation rather than one of counselling or educating. At both hospital sites experienced counsellors had been recruited in readiness, should a participant feel distress regarding an interview or an observational session. The other approaches to ensure that the researcher's duty of care was properly exercised, should a participant become distressed included:

- (a) ceasing an interview or period of observation;
- (b) offering to remain with the participant;
- (c) providing basic emotional support, listening and empathising;
- (d) allowing the informant to decide whether to continue with the interview or period of observation; and
- (e) if necessary, and with the informant's consent, arrange to take them to the counsellor or request the counsellor to attend for support.

On one occasion during an interview a participant demonstrated an intense degree of frustration and anger when recounting a situation where she believed that a patient had been greatly disadvantaged in relation to certain therapy decisions. The researcher halted the interview and basic emotional support was provided. The researcher asked the participant if she wanted to cease the interview. It was determined that the participant wanted a short break to make a coffee. This request was undertaken and when the coffee was made the participant was again given the

choice about continuing or ceasing the interview. The participant wished to continue and at the close of the interview time was spent discussing the difficult situations arising for health professionals when patients or relatives refuse therapy. She left the interview stating that she was glad that the topic area was “finally” being examined. Debriefing provides the researcher with the opportunity to emphasise the value of the study (Sieber, 1992).

#### **4.2.5 The presence of patients**

The presence of patients in the field, particularly during the observation phase of data collection also posed ethical problems. It was necessary to plan for possible situations if there were concerns individual patients were too ill, or were distressed when discussing therapy options or refusing treatment. It was agreed before observation commenced that the researcher would seek guidance from senior ward staff as to the appropriateness of the researcher remaining and it was also agreed that staff could request the researcher to leave at any stage. The senior staff were best suited to determine the patient’s welfare in these circumstances.

It was also necessary for the researcher to be introduced to patients when observing participant nursing and medical staff and a truthful account of the study provided, but the notion of informing patients that the researcher was studying refusal of therapy, when this might not occur, was considered to be improper and could inadvertently bias the professional-patient relationship. It was decided to tell patients that the researcher was studying how nursing and medical staff interact with their patients regarding treatment decisions. No data would be collected from patients, although use would be made of information written by nursing and medical staff in the patient file regarding any issues relating to refusal of treatment or therapy boundaries.

#### **4.2.6 Unethical and illegal conduct**

The current research study examines how nursing and medical staff manage refusal of therapy decisions and there is existing legislation that presupposes certain requirements. There was also the possibility that during the course of the fieldwork the researcher might observe unprofessional conduct on the part of participants or

associated third parties. In fieldwork it is important to consider that alleged unethical or illegal conduct might be reported or observed and it was necessary to be clear from the outset how this was to be handled. Unethical or illegal conduct has the potential to endanger participants or others (including patients) and compromise the role of the researcher.

It was planned that should a situation arise that might be considered alleged unethical or illegal conduct, the researcher would firstly explain her role and clarify with the participant, his or her actions. There was always a possibility that the participants' actions might be observed out of context, or there might be a reasonable explanation to explain the behaviour. If the researcher was not satisfied with the explanation from the participant, it was planned that she would suggest that the participant seek assistance, and if necessary, either assist the participant to obtain professional support and/or involve particular senior staff at the hospitals. This required a two-tiered approach. The study was designed to include a wide range of participants, including senior medical and nursing managers. Before the fieldwork commenced executive medical and nursing personnel were identified at both hospitals, as suitable individuals to be consulted and involved, should the researcher consider that alleged unethical or illegal conduct occurred. It was also determined that, where appropriate, should less experienced nursing or medical participants be involved, the senior nurse or medical practitioner of each unit would be consulted and involved. This was made clear to participants at the outset of their involvement. In the written participant information a statement that information would be kept confidential except as required by law was included. However, to avoid frightening the participants it was also made clear that any involvement of senior personnel would be to provide assistance and guidance, rather than punishment.

There was one occasion necessitating the researcher to intervene, involving two staff, a resident and nurse, who were both relatively inexperienced. During a period of observation of the nurse, a patient assessed as being incompetent to make decisions, was urged and physically assisted to complete a consent form by the resident. The nurse did not intervene, yet she appeared uneasy. The researcher asked the nurse some questions, to which the nurse responded that she was concerned by the actions

of her colleague, but was not sure what to do. The researcher intervened and directed her to the senior unit manager, who immediately addressed the situation with both the nurse and resident. The participant nurse later thanked the researcher for her assistance, as the inexperienced nurse did not know how to deal with the dilemma and felt unable to discuss the situation with the resident.

#### **4.2.7 Data storage, access and disposal**

All data, including tape recordings, transcriptions, field notes and related material were dated and coded to avoid identification of participants or third parties, in the event of loss or theft. The participants were informed that, apart from the researcher, the study supervisors<sup>38</sup>, and a transcript typist, no other individual was permitted access to the data. Tape recordings were used for transcription purposes and these were stored on computer diskettes, protected by a password. All tapes, diskettes and written notes generated, were placed in a locked filing cabinet, the key being held by the researcher. On completion of the study, data will be stored in accordance with the protocol of the Faculty of Health, Engineering and Science, and will be destroyed after the mandated period, as required by Victoria University Human Research and Ethics Committee, which are based on the National Health and Medical Research Council Statement on Ethical Conduct in Human Research (2007).

### **4.3 OVERVIEW OF THE HOSPITALS**

The two hospitals (hereafter referred to as Conrad and Berkley) involved in the study, are acute tertiary level public hospitals, located in the State of Victoria. The Department of Human Services,<sup>39</sup> categorize Conrad as a regional hospital, and Berkley as a metropolitan hospital. They are both located within 100 kilometres of the city of Melbourne. The size of the two hospitals ranges between 300-400 beds and they are teaching hospitals with university affiliations. They are involved in the education of both medical and nursing professionals. The hospitals service

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<sup>38</sup> Professors Terence McCann and Helen Baker.

<sup>39</sup> Is the government of Victoria's health department.

communities of diverse socio-economic status, which allow the topic and phenomenon in question to be adequately studied.

Conrad and Berkley hospitals provide a wide range of general and specialty medical and surgical services, with intensive care and emergency departments. At Berkley hospital, three wards participated in the study; they comprised two medical wards and one surgical ward. The areas of specialty of the wards included neurology, cardiology and orthopaedics. The patients were usually admitted to each ward from the emergency department, although some were admitted for elective procedures. The capacity of each ward was between twenty-eight and thirty beds. Each ward at Berkley hospital had between one and four different medical teams or units admitting patients. At Conrad hospital, the intensive care unit participated. The unit comprised up to eighteen beds and patients from all areas of the hospital, requiring high acuity care, were treated in this unit. Patients frequently came from the emergency department or post operatively, from the theatre complex. In addition, participants from each hospital worked in the areas studied, but some also on occasion, worked in other wards in each hospital.

#### **4.4 SELECTION AND RECRUITMENT OF PARTICIPANTS**

There were two groups of individuals involved in the study: nurses and medical practitioners. The aim of the study was to identify the processes utilised by nurses and medical practitioners when managing patients' refusal of treatment decisions in acute care hospitals. There are many different health professionals working in hospitals however, medical practitioners are responsible for the overall therapy plan, and nurses provide direct patient care. In effect, the two professional groups work closely with patients, and each other. In order to understand how therapy plans are formulated the input of both groups was considered paramount.

Purposive sampling was initially used to guide the selection criteria, thereafter theoretical sampling was used to select potential participants. The resulting number of participants included eighteen nurses and six medical practitioners. The numbers of nurses in hospital environments outweigh those of medical practitioners, and this is reflected in the differing numbers of participants in each group.

The selection criteria for participants were kept to a minimum, to reflect the variation of experience of both nursing and medical staff working in public hospitals. Staff involved in direct patient care and therapy decisions include a wide range of individuals from nurses and medical practitioners who are newly graduated, to the senior nursing and medical staff in charge of the wards and unit, and medical teams. The inclusion criteria were as follows:

For nurses:

- Registered nurses (Division One) <sup>40</sup> in the State of Victoria;
- Currently practising in acute care hospitals;
- Employed either on a full-time or part-time basis.

For medical practitioners:

- Registered medical practitioners in the State of Victoria;
- Currently practising in acute care hospitals;
- Employed either on a full-time or part-time basis.

Research can involve sensitive subject matter where potential risks exist for participants because of the nature of the study. There are four main situations where research can be threatening:

- (i) if it poses an “intrusive threat” to participants because it concentrates on issues that are sacred, private or provoke fear;
- (ii) if information is provided in the study that can be stigmatising or incriminating;

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<sup>40</sup> There are two levels of registered nurses in Victoria. Those individuals registered in Division One include nurses with a Bachelor of Nursing degree or equivalent qualification. Those individuals registered in Division Two are nurses with a Certificate Four qualification or equivalent, commonly referred to as enrolled nurses. This study only includes Division One registered nurses.

- (iii) if there are political implications from the findings, which may lead to controversy; and
- (iv) if there is an inherent risk to the researcher in carrying out the study (Gibson, 1996).

In the current study, the focus did include sensitive subject matter, refusal of therapy, which could include consequences, such as a shortened life span, and such decisions occur within an existing legal framework. Mindful of this, the researcher took care in the recruitment and involvement of participants, in particular to avoid coercion.

Ethical approval was obtained from the Victoria University Human Research Ethics Committee and the equivalent ethics committees of the two hospitals, Conrad and Berkley, to conduct the study. Ethical approval from the hospitals' Human Research and Ethics Committees was the necessary prerequisite to allow the study to proceed. However, even before submissions were made to these committees the researcher met with the senior executive nursing and medical personnel at both hospitals, to inform them of the intention to undertake the research project, and to seek their input and feedback. These meetings were useful to highlight the study, but also to ascertain issues or problems that senior executive staff might perceive, given the sensitive nature of the project.<sup>41</sup> At these meetings specific units and wards were identified as being suitable for the study<sup>42</sup>, however at the suggestion of the executive personnel, once ethical approval was obtained a further meeting was arranged to include the senior ward and unit managers. At these subsequent meetings the study was explained and questions were answered. As a result, approval was obtained from a number of senior managers to gain access to their units and wards in order to recruit participants. At Conrad hospital the intensive care consultant granted permission for the unit to be involved.

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<sup>41</sup> As the meetings transpired, the senior executive staff were supportive of the study and provided some insightful comments, which assisted the researcher in the preparation of the ethics committee documentation.

<sup>42</sup> For instance, the paediatric wards were not suitable and it was decided that it was not necessary to include the maternity units.



Once access was gained to particular areas in each hospital, the researcher approached the recruitment of participants in three stages. In the first stage, the researcher attended each unit and ward to explain the study to the nursing and medical staff and to answer questions. These meetings provided the researcher with the opportunity to outline the purpose of the study and the conditions of consent, as well as answer questions. This meeting also allowed staff to meet the researcher and be made aware of her presence in their working environment, even if they did not intend participating. As senior managers were in attendance at many of these meetings, the researcher made it very clear that there was no pressure on any staff member to take part in the study. At these meetings there was always more nursing staff present, although there were some medical staff. At the end of these explanatory meetings it was explained that individuals could offer to participate, by completing the prescribed documentation. In fact, a few staff did approach the researcher to acknowledge their interest and desire to participate in the study. The study package<sup>43</sup> was provided to these individuals. In the second stage of recruitment, the researcher spent periods of time immersed in the field at each hospital and during these periods the nursing and medical staff became familiar with the researcher and she could repeat her explanation regarding the study and answer any questions. This often resulted in one-on-one conversations with individual staff members. The third stage was necessary to concentrate on the medical staff, as they were not situated in the wards at Berkley hospital, and exposure to them was limited. This was not necessary at Conrad hospital in the unit where both nursing and medical staff attended the explanatory meetings. During the time the researcher was immersed in the field, the nursing managers of each ward made it a point to introduce the researcher to each medical team, or individual medical staff, as they attended patients in that particular area. This allowed the researcher to provide explanation regarding the study to them and answer questions in much the same manner as occurred in the second stage of recruitment.

Eighteen nurses and six medical practitioners took part in the study. Tables 1 and 2 show the demographic information about the nurses and medical practitioners. The

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<sup>43</sup> See Appendix D for study package – Information Letter and Consent Form.

data highlight that a broad range of both professional groups took part in the study, from the most senior nursing and medical staff, to the most junior.

**Table 1: Demographic information about nurses**

Gender	Female 14		Male 4	
	Age (years)	<b>20-29</b> 6	<b>30-39</b> 3	<b>40-49</b> 3
Post Grad academic qualifications**	<i>Certificate</i> 3	<i>Diploma</i> 8	<i>Masters</i> 3	
Additional qualifications (non nursing)	<i>Diploma</i> 2	<i>Bachelor</i> 4		
Years of experience	<b>1-4</b> 5	<b>5-10</b> 3	<b>11-15</b> 2	<b>15+</b> 8

\*\* Of the 14 nursing participants with post-graduate qualifications, only four were working in the wards, the remainder were located in the intensive care unit.

**Table 2: Demographic information about medical practitioners**

Gender	Female 2		Male 4	
	Age (years)	<b>20-29</b> 2	<b>30-39</b> 2	<b>40-49</b>
Post Grad academic qualifications	<i>Masters</i> 1	<i>Fellowships</i> 2		
Additional qualifications (non nursing)	<i>Bachelor</i> 1			
Years of experience	<b>1-3</b> 2	<b>4-10</b> 2	<b>10+</b> 2	

#### **4.5 OBJECTIVITY, SENSITIVITY AND SUBJECTIVITY**

In grounded theory, the methodology requires the researcher to collect data and analyse it in alternating sequences (Strauss & Corbin, 1998; Corbin & Strauss, 2008). The problem that arises during this process is the researcher's immersion in the data, which requires a balance between objectivity, subjectivity and sensitivity, and this is necessary to avoid bias. Objectivity is necessary to reach an accurate and impartial interpretation of events, while sensitivity is required to understand the meanings in the data and identify the concepts and the connections. It is important that the researcher maintains a level of critical subjectivity; the researcher must be self-critical and explicit (Reason & Heron, 1995).

In qualitative research, objectivity means having an understanding, while recognising that the researcher's understandings are sometimes based on values, the level of education and experience, and these might be quite different from those of the participants (Cheek, 1996). To maintain objectivity the researcher kept an openness, a willingness to listen and observe what the participants did and then represented this as accurately as possible (Strauss & Corbin, 1998; Corbin & Strauss, 2008). One technique to assist with objectivity was to gather data utilising several points of reference. In this study three methods were employed to collect data: participants were interviewed, there were periods of observation, and patient files were examined. Data were collected in order to gain insight into multiple and varied representations of the phenomenon. For instance, inexperienced nursing and medical staff were sometimes unsure of what to do when patients refused therapy. Occasionally their first responses demonstrated a tendency to ignore the refusal and if patients equivocated, participants would seek out their peers to discuss the matter. This contrasts with more experienced staff who were more likely to recognise and explore patients' cues. Therefore, it was important that data were collected from respondents with varying degrees of experience and insight. Data were also collected from different areas of the acute care sector, from medical and surgical areas to the specialised intensive care area. The differing settings allowed for variations of behaviour to enable insight into how respondents negotiated situations, to allow the meaning of differing behaviour to emerge. The more persons, places and events that are interviewed or observed, the more the researcher is able to check interpretation

against alternative explanations of events, while also discovering properties and dimensional ranges of concepts (Strauss & Corbin, 1998; Corbin & Strauss, 2008).

Another analytical strategy involved occasionally checking the researcher's assumptions with respondents. This enabled the researcher to explain to participants what she thought was going on and then ask participants if that is what matched their experiences. For instance, when patients indicated a refusal of therapy to a nurse at the bedside it was more common for that nurse to engage the support of other nurses, rather than go directly to one of the medical staff with that information. This appeared to represent a professional division along hierarchical lines. The researcher was uncertain as to the reasons for this; was it for convenience, or adherence to expected practice by unit managers, or did the nurses "feel" they could not go directly to medical staff? Many nursing respondents confirmed that this was how they dealt with the situation because they believed that they were more likely to successfully promote patient decisions with the medical staff if more nurses, especially senior ones, were aware and involved, and the notification to other nurses enabled different nurses to approach patients and clarify, and then confirm patient wishes.

To foster theoretical sensitivity, researchers must constantly challenge their personal theories and biases against the data (Schreiber, 2001). Qualitative researchers must, however, attempt to disregard their own wishes to achieve a more rigorous outcome (Holloway, 1997). In order to achieve this, during the fieldwork the researcher compiled notes, including thoughts about analysis, method and points requiring clarification. A range of strategies can be used during the study to enhance self-reflection (Olshansky, 1996) to check interpretations and allow the researcher to gain clearer insight into the phenomenon, yet distinguish these from the researcher's own beliefs. In addition, time was allocated to discuss responses with the researcher's supervisors, and at various stages of the study, findings were presented to peers. Theoretical memos were also extremely useful as they provided an internal dialogue for the researcher to raise tentative ideas and provisional categories and then compare findings (Strauss, 1987). Memos guide the researcher away from the data to

allow abstract thinking, then when returning to the data, to ground these abstractions into reality (Strauss & Corbin, 1998; Corbin & Strauss, 2008).

Insights into the data do not occur haphazardly. Researchers often have a familiarity with the topic and literature before they begin the research project (Strauss & Corbin, 1998). Charmaz (2006) argues that sensitising concepts and disciplinary perspectives can be used as tentative tools for developing ideas about processes the researcher finds in the data, but they provide a place to start, not to end. Being sensitive to the area of study provides vantage points that can intensify examination of the research topic, but it can also result in the ignoring of other aspects and thus allow a degree of bias (Schreiber, 2001). The knowledge and theories with which researchers have familiarity inform the research in many ways, even if they emerge unselfconsciously (Sandelowski, 1993). In order to minimise the possibility of introducing bias into the study, it is necessary to examine at the outset the researcher's preconceived assumptions about the phenomenon under study.

Three broad factors influenced the researcher's assumptions regarding the topic studied. The first influence was her professional experience as a registered nurse in Australia and the United Kingdom. Working in the acute care sector, alongside other nurses and medical practitioners, assisting patients with therapy and decisions was commonplace. The second influence was the researcher's education in the law, particularly at the post graduate level, the existence of specific medico-legal principles, designed to impact on the practice of health professionals. The third influence was the researcher's academic experience, researching and teaching the law in the context of health care delivery to a range of health professionals.

#### **4.6 DATA COLLECTION METHODS**

To explain and describe a theory, of the processes nurses and medical practitioners utilise when patients refuse therapy, required the development of multiple methods and sources of data collection. This provided rich sources of data, and when analysed, proved to be sufficiently precise and dense for a theory to be grounded. The three main methods of data collection included interviews, observations and examination of patient files. There were two groups of participants studied:

registered nurses and medical practitioners. In addition, these participant groups were examined at two acute care public hospitals in the State of Victoria. The data collection commenced in December 2005 and was completed by March 2006.

#### **4.6.1 Interviews**

Individual face-to-face interviews were used for all participants. They were conducted in private, in offices or rooms in the hospitals, commonly adjacent to the wards or units where the observations were also taking place. The decision to use interviews was influenced by the nature of the research question, the aims of the study and the methodology being used. The appeal of the use of interviews is the desire to conduct a “conversation with purpose” (Burgess, 1984), to comprehend the experiences and perceptions of the participants. In the present study, the format of the interviews was conversational and loosely structured. An aide-memoire<sup>44</sup> was used to guide the conversation and support the relatively inexperienced researcher. This approach was also selected because of the little prior information about the topic, permitting a degree of flexibility in following the participants ideas, as they told their stories (Polit & Hungler, 1995).

There are differing opinions as to the length of interviews. Field and Morse (1985) advise that they should not be longer than 60 minutes, whereas Holloway and Wheeler (1996) maintain that the duration should be determined by the informant. The interviews were generally of 60 minutes duration, as had been previously agreed. Nonetheless, several participants were willing to extend the time, several lasting between 60-90 minutes. This occurred in interviews where the participants wished to share multiple stories and demonstrated little difficulty discussing their experiences.

The interviews commenced with a few structured questions to elicit demographic information, including years of experience, current position held, and qualifications. Once that information was gained the interview proceeded with broad open-ended questions, and then began to focus on specific questions to clarify details and to learn

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<sup>44</sup> See Appendix E for the aide-memoire.

about the participant's experiences and reflections (Charmaz, 2006). The researcher found that some participants were initially uncertain about the topic being studied, given its potentially sensitive nature, and how their roles would be considered. As one participant (Nse 12/1) stated: "I'm not sure exactly which situations you want me to discuss. Maybe I haven't had too many, really". It was useful to then ask participants to recount past situations, where patients had refused therapy, and that provided a focal point for them and prompted their recollections and experiences. The researcher also noted that once a few participants had been interviewed, other potential participants who had previously stood back and kept their distance, recognised that the interview process had not generated problems for those who were involved. The potential participants then approached the researcher to be interviewed.

#### **4.6.2 Observations**

The role of observing participants is to examine and explore a culture from the inside. Jorgenson (1989) states participant observation allows a direct and experiential observational access into the "insiders" world of meaning. The social world is examined and this approach of data collection augments a symbolic interaction perspective because it comprises data collected through observation and interaction (Adler & Adler, 1994). Prolonged observation generates more in-depth knowledge of a culture or subculture and does not just involve observing, but also listening to the individuals being studied (Holloway & Wheeler, 1996). In the present study, participant observation was included as there was little prior information available regarding the phenomenon studied and it was inaccessible to the public.

Observations occurred in several different wards and an intensive care unit, and occurred before and after the interviews. The researcher was accustomed with hospital environments, although she was unfamiliar with each of the specialty areas, and the two hospitals involved. This minimised the researcher's risk of familiarity with the culture studied however, having general experience as a health professional did assist the development of researcher-participant relationships. Observing and interviewing the participants enabled the researcher in comparing and contrasting

what they said, with what actually happened in practice. Further questions could then be introduced and points of clarification made.

The researcher spent considerable time “entering the field” and this included time in the staff rooms and at focal points such as ward desks, where staff met, discussed patients and organised treatment. To become immersed in the work of the participants it was important for the researcher to be present, and she spent extended periods of time in the various environments. The period of observation included three to four days each week, for three months. The time spent in each hospital reflected the number of participants and wards studied. The researcher varied the times she visited the different settings, from mornings to afternoons and during four weekends.

The type of observation was dependent on the specific situation, the opportunities available and what the participants permitted. When observing nursing staff, time was spent listening to the nurses’ handover<sup>45</sup> at change-of-shifts and then as staff became familiar with the researcher, more time was spent with individual nurses at patient bedsides and moving around the ward. On several occasions, once the researcher had been present for some time, she found that the nurses sought her out and requested her to observe interactions, including meetings or conferences where staff would discuss a patients’ treatment plan with close family members. This allowed the researcher to observe interaction and conversations between nurses, patients and family members and with nurses and medical staff.

Observation of the medical practitioners initially began when the researcher was invited to accompany them on their medical rounds as they moved from one patient consultation to another. At times the medical staff visited patients with a large group of associated health professionals and at other times they would come individually, or in small groups, to discuss matters with patients, or the nurses. The main variation

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<sup>45</sup> A handover is a traditional part of nursing practice and occurs when one group of nurses hands over the work of the ward to the next group. In this study it was practised in two ways, depending on the preference of each ward or unit manager. The first, involved individual nurses providing information to the oncoming nurses, regarding the specific patients they were caring for. The second approach involved one senior nurse, providing all patient information to the oncoming staff.



of the participant observation role was noted in the intensive care unit at Conrad hospital. Due to the different structure of the unit, where there is one nurse for each patient and medical staff constantly present, the researcher spent time with individual nurses at patients' bedsides. The medical practitioners frequently came to the nurse at the bedside to discuss matters with the nurse or the patient. The interactions observed generally involved fewer staff members, commonly one or two nurses and one medical practitioner on many occasions. While there were family conferences, they were more frequent in the intensive care unit than any of the wards and this enabled nursing and medical staff to be observed before, during and after the event. The identification of participants and the ability to observe them working allowed the researcher to observe many dozens of interactions with fellow nurses and medical practitioners who were not participants. Verbal permission was requested with any third parties, before the researcher remained to observe the interaction, but it is noteworthy that this significantly broadened the range of observational data gained in the study. There were few occasions where third party health professionals did not agree. In situations involving discussion with relatives, due to the sensitive issues sometimes discussed, the researcher withdrew her participation on a number of occasions.

During the observations, natural conversations occurred frequently as the researcher asked questions and clarified points of practice. This always occurred away from patients and relatives, as soon as possible after the observational event. Field notes were also made at times during observations, or later, after a period of observation, when the researcher had reflected on what she had seen and wanted to check with the individual participants involved. Moreover, once the categories, sub-categories and theory were emerging the researcher checked these with the participants from time to time, in order to verify her findings and to ensure that she had not inappropriately incorporated her own values.

#### **4.6.3 Documentary sources**

The third method of data collection involved the examination of patient files when nursing or medical staff recorded any issues relating to refusal of procedures. Hammersley and Atkinson (1995) suggest that researchers use these, because

documentary sources provide information that observation or interviewing cannot. The patient files would normally be limited to the staff responsible for patient care, and therefore they would not be easily accessed to those outside this domain. As the researcher was engaging in participant observation and simultaneously able to examine the notes made by participants, she could interpret the meaning of the written text in context and study the situation and conditions in which the information was recorded, to try and establish the writer's intentions. Hammersley and Atkinson (1995) warn that written documents can be misleading and create biases because they are often written for individuals in power. However, the written content can be considered useful for the present study because it can provide valuable data that might reveal insights not otherwise available to the study. This is discussed in the findings and discussion in later chapters.

#### **4.7 DATA MANAGEMENT**

Fieldwork data were collected from three sources:

- (i) Twenty-four interviews were held, all were tape recorded.
- (ii) Data were collected during the observations and this included natural conversations and notes made during the 3 month (3-4 days per week) period.
- (iii) Time was taken to examine in excess of 100 patient files when notes were sometimes made by the participants.

The documents resulting from the fieldwork were collected for analysis in the form of hard copy. An experienced audio typist typed the tape recordings. Each participant was identified by a pseudonym. The notes made by the researcher were always labelled with the location, the time and the specific individuals involved.

The interview transcripts were read as the audio-tapes were played, to ensure accuracy of transcription. The participants had, during the interviews, referred to a number of technical terms when discussing specific diagnosis and treatment and a number of these required correction to ensure the context of the phrases were maintained. The transcripts were then read at least twice, before coding commenced

to ensure that the data was accurate and for the researcher to thoroughly familiarise herself with the data.

#### 4.8 DATA ANALYSIS

Open coding was completed by hand using different coloured highlighter pens. As conceptual labels emerged from the highlighted text, the labels were inserted in the margin, in pencil. The researcher preferred this approach to the use of a computer. The open coding process began to fragment the data, to conceptualise it. Each idea in the data was given a label and similar ideas given the same label (Table 3).

**Table 3: Fragmentation of data and the application of a conceptual label**

Data	Conceptual label
... she [patient] kept taking that tube out. We could clearly see what she was telling us. (Nse 01/5)	Interpreting signals

The conceptual labels were then linked to abstract categories, their properties and dimensions were then identified. For example, the conceptual label “Interpreting signals” was grouped with several other conceptual labels, and through the process of abstraction, the category *Seeking Clarification* was identified (Table 4). *Seeking Clarification* exemplifies the process of discovering and identifying what patients are actually telling staff, particularly what it is that they are rejecting.

**Table 4: Conceptualisation of the category *Seeking clarification***

- Determining patient competence
- Ascertaining whether there was a refusal
- Interpreting signals
- Allowing time to reflect
- Considering prior information
- Identifying acceptable treatment modalities

Axial coding was also employed to fragment and reassemble the data, broken down through the open coding process. This was achieved by categorising the data and making links between a category, its subcategories, and strategies. These were grouped together in a new form to build key categories (Table 5).

**Table 5: The categories of the study**

- Seeking Clarification
- Responding to patients & families
- Advocating
- Influencing

The selective coding involved the process of integrating and refining all of the categories. It was only possible to identify the core category by linking all of the categories around a category that explained the phenomenon. The properties and dimensions of the core category slowly emerged. The core category *Endeavouring to understand refusal: Agreeing on a way forward* allowed the researcher to refine a conceptual theory to explain all of the categories and their interrelationships. This process is explicated in the later chapters of this study.

Despite the numerous descriptions of using grounded theory and the various methods of coding, the process did not proceed in an orderly manner. While the researcher commenced with open coding and followed this with axial coding, there was overlap as they were utilised simultaneously. Selective coding occurred when the categories started taking shape and this required an ongoing process to continually refine the categories. The entire process was one of an evolving nature as the following two examples reveal.

Initially, when identifying the properties and dimensions of the categories the researcher had some difficulty teasing these out, and in some categories there were only a few conceptual labels. For instance, in the category *Seeking Clarification* it became apparent that there were additional strategies utilised by the participants. Further distinctions could be made between the activities of participants. For example, there was more going on in the strategy *Identifying acceptable treatment modalities* where participants engaged in purposeful conversation to discover the extent to which certain procedures were acceptable. The researcher found that the ability of participants to also observe and understand particular behaviour might well assist in the determination of acceptable limits of therapy, but the participants were recognising specific cues and signals and then interpreting these and the strategy *Interpreting signals* became apparent. Another example of the evolving nature of the analysis was evident in the labelling of the categories, which changed throughout the process. For example, the category *Seeking clarification* was originally called “Enhancing patient self-determination”, because it appeared that the participants were adopting strategies that enabled patients to identify therapy options. As the analysis continued it became apparent that participants were really clarifying which procedures or therapy were being refused, for both patients and themselves. It was largely an instructive process designed not only to assist patients but also to guide the subsequent actions of participants, and the initial title of the category was not sufficiently explanatory or accurate. Participant behaviour in this strategy was more preliminary, not necessarily designed to enhance patient autonomy, but rather to discover what patients were, often indirectly, telling them.

#### **4.9 SUMMARY**

This study involved a sensitive topic and the ethical considerations were of particular importance. A strict adherence to ethical principles and processes throughout the study, including the various approaches to the recruitment and involvement of participants, enabled the data to be collected in the absence of any adverse outcomes. The type of methodology used, emphasised the need of the researcher to balance objectivity and subjectivity, and be explicit regarding prior sensitising influences, in order to comprehend and interpret the data. In accordance with the methodology, concurrent data collection and analysis occurred, using interviews, observations and documentary sources. Although these methods were appropriate to the research question and aims of the study, the researcher was mindful of the principles and problems associated with the use of these approaches. Lastly, the need to be flexible was highlighted, as analysis progressed and the dimensions and properties of the categories and theory emerged.

## **PART B: THE STUDY**

**CHAPTER 5**  
**OVERVIEW OF THE STUDY AND THE CORE PROBLEM**  
**COMPETING PERSPECTIVES: ENCOUNTERING REFUSAL OF**  
**TREATMENT**

**5.1 INTRODUCTION**

This chapter begins with an overview of the findings of the study. The study describes the processes nurses and medical practitioners undertake when patients with serious illness refuse medical treatment. The chapter commences by providing a diagrammatic overview of the findings that give rise to the theory. The theory *Endeavouring to Understand Refusal: Agreeing on a Way Forward*, highlights the most common processes of participants throughout this study. A brief synopsis is then presented of the core problem and process, the categories, strategies and contextual determinants are then concisely explicated, in order to provide an outline of the study. The chapter then addresses the basic social problem of this study and the factors contributing to it which are encapsulated in the title: *Competing Perspectives: Encountering Refusal of Treatment*.



## 5.2 OVERVIEW OF THE FINDINGS

**Table 6: Overview of the findings**

<i>Core Problem</i>	Competing Perspectives: Encountering Refusal of Treatment			
<i>Core Category</i>	Endeavouring to Understand Refusal: Agreeing on a Way Forward			
<i>Categories</i>	<b>Seeking Clarification</b>	<b>Responding to Patients &amp; Families</b>	<b>Advocating</b>	<b>Influencing</b>
<i>Strategies</i>				
	Determining patient competence	Providing timely, understandable & complete explanations	Coaching patients & relatives	Managing information selectively
	Ascertaining whether there is a refusal	Reiterating	Encouraging patients to voice their concerns	Using mystifying language
	Interpreting signals	Elucidating	Verbalising patient wishes	Asserting authority
	Enabling reflection	Offering alternatives	Intervening on behalf of patients	Maintaining control
	Considering prior information	Harnessing the patient's life story	Mediating	Persevering to succeed
	Identifying acceptable treatment modalities	Using metaphors or images	Lobbying	Using relatives as leverage
		Adopting the patient's perspective		
	Engaging as a unified group			
	Searching for cues			
<b>Contextual Determinants</b>	<b>Context of work</b>	<b>Beliefs and Behaviours</b>	<b>Legal and Ethical Frameworks</b>	

### 5.2.1 Core problem

The initial analysis focuses on identifying the core problem, which is experienced by participants although it is often not clearly articulated. The problem is conceptualised as *Competing Perspectives: Encountering Refusal of Treatment*, which reflects the five main themes that emerge as patients are admitted to hospital, therapy plans are made, and medical and nursing staff are required to deal with the subsequent decisions. The five competing themes include the existence of legal principles and the sometimes contradictory perspectives of the four key groups of individuals who influence decisions. They comprise the medical and nursing health professionals, and patients and their family members, all with their own perceptions of the situation. Refusal of treatment can manifest as a routine affair or a major challenge in everyday clinical practice. All participants encounter patients to a greater or lesser extent refusing therapy, but they can respond in vastly differing ways, revealing divergent processes and varied clinical practices.

### 5.2.2 Core category

The core category encapsulates a process that explains how the problem of *Competing Perspectives: Encountering Refusal of Treatment* is addressed. The theory centres on the core category, which describes the main phenomenon and to which all other categories are linked. It embraces and explains the range of responses identified in other categories, and accounts for variations in patterns of behaviour that are demonstrated by participants as they respond to the basic social psychological problem. The core process or category, *Endeavouring to Understand Refusal: Agreeing on a Way Forward*, occurs frequently in the data and comprises three discernable transitional phases. The transitions are not linear or successive, and can encompass elements of each phase at any time or concurrently.

The first transition, *Struggling to come to terms with the centrality of patient self-determination*, illustrates a dichotomy for many participants, where the focus is directed to the provision of therapy, assuming it will be accepted, whilst caring for patients whose concerns they have not fully acknowledged or understood. The second transition, *Responding to the dynamics of patient and family*, highlights the

evolution of relationships with patients and family members. It emphasises the efforts and varying degrees of reciprocation with their patients and families, allowing for a more flexible and comprehensive approach to care. The third transition, *Changing the terms of reference: From the disease state to the person*, represents an ability of participants to identify single issues in the amalgam of perspectives, with the realisation that initial treatment plans may not be the most suitable. The emphasis shifts from the disease state to the individual patient as a person, incorporating his or her thoughts and wishes. To do this treatment is customised and follows an agreed plan of therapy.

### **5.2.3 Categories and strategies**

Four categories relate to the core category and indicate the many varied behaviours utilised by nursing and medical participants as they deal with patients and relatives who indicate a refusal of procedures or treatment. The categories embody a wide assortment of processes that are not necessarily complimentary. They are constituted by the numerous strategies contained within each of them. The categories consist of: *Seeking Clarification, Responding to Patients and Families, Advocating, and Influencing.*

#### **5.2.3.1 Seeking Clarification**

*Seeking Clarification* is a category that comes about when patients or relatives raise concerns regarding therapy or aspects of it, and the ability of participants to identify and refine these messages. There are six strategies associated with this category: *Determining patient competence, Ascertaining whether there is a refusal, Interpreting signals, Enabling reflection, Considering prior information, and Identifying acceptable treatment modalities.*

*Determining patient competence* emerges as an early strategy where the reluctance of patients to proceed with treatment can trigger consideration of their cognitive ability to actually refuse treatment. Participants are often surprised that therapy may be refused and should a patient be deemed incompetent, this strategy reveals how relatives are involved and drawn in to the decision-making process. When there is an indication of patient unease, many participants seek to refine their observations. This

is achieved by *Ascertaining whether there is a refusal*, as many verbal and non-verbal messages emanate from patients. Participants do not generally accept an equivocal statement at face value. Patients and their family members provide a range of ways to communicate their desire not to receive treatment and thus *Interpreting signals* requires participants to understand not only verbal signals but also non-verbal forms of communication. Sometimes the severity of the illness and the sheer weight of proposed therapy places heavy emotional burdens on patients, and nursing and medical staff recognise that *Enabling reflection* can assist patients to clarify their thoughts. Apart from direct communication with the patient, participants extend their search to include information gathered from earlier hospital admissions. *Considering prior information* about previous patient requests can shed light on earlier requests or decisions. Refusal of treatment can encompass the rejection of specific elements of treatment or the overall direction of therapy. The importance of *Identifying acceptable treatment modalities* becomes a critical strategy to employ because patients are seriously ill, with a high possibility they will experience physical or mental impairment. The sequelae of treatment become vital as they can produce differing long and short term consequences for patients.

#### **5.2.3.2. Responding to Patients and Families**

The category *Responding to Patients and Families* incorporates behaviour which highlights the level of interaction nursing and medical participants display as patients and families express their concerns and wishes. This category entails strategies aimed to convey information and the ability of participants to enhance reciprocation of viewpoints. When participants demonstrate acknowledgement and address patient and family issues, a sense of equality develops in their relationships. Conversely, when issues or concerns are ignored or neglected, the likelihood of reaching an agreed outcome is considerably reduced. The category contains nine strategies: *Providing timely, understandable and complete explanations; Reiterating; Elucidating; Offering alternatives; Harnessing the patient's life story; Using metaphors or images; Adopting the patient's perspective; Engaging as a unified group; and Searching for cues.*

*Providing timely, understandable and complete explanations* necessitates informing patients and their families of matters relevant to their illness. It entails the provision of suitable opportunities for them to understand and be able to make considered decisions. Providing information relating to illnesses, associated treatments and their consequences requires an ability to tailor plain understandable language and communicate with this throughout the entire relationship. It must also be sufficiently comprehensive to allow patients to make informed choices. The strategies of *Reiterating* and *Elucidating* are more commonly utilised by nursing participants. The former strategy is employed to reinforce information previously provided to anxious patients who may need to hear it more than once. The latter strategy, is employed to expand and shed light on specific procedures, such as providing both procedural and sensory information, in order for patients to more adequately understand and then consider what is being proposed. It also involves an ability to make transparent the possible options of therapy to assist patients in their choices. *Offering alternatives* demonstrates an acknowledgment of patient refusal and the desire of participants to ensure therapy is ongoing, albeit utilising a different delivery, or mode of treatment. Therefore, the ability to be flexible and offer a substituted form of treatment can ensure an acceptable alternative for patients.

The strategies *Harnessing the patient's life story*, *Using metaphors or images*, and *Adopting the patient's perspective* all feature techniques to conceptualise the immediate problem which relates to sensitive aspects of possible treatment outcomes. Participants acknowledge that there is a propensity for patients and families to assume that modern health care will almost always succeed in “curing” or “alleviating” illness states. In many situations discussion inevitably must consider the potential success of various therapies and preferences need to be aired. *Harnessing the patient's life story* encourages a wide contemplation of patients' illness states in relation to their current views, lifestyles and the expected effects of therapy. The aim being to allow patients and relatives to weigh these considerations, before choosing either intensive and aggressive treatments, or comfort measures and palliation. *Using metaphors* illustrates how the judicious choice of language can enable the introduction of delicate subject matter into discussions addressing possible poor outcomes, including the topic of death, in a bid to assist a decision.

Participants also recognise the importance of eliciting the wishes of patients wherever possible and this sometimes requires separating out patients' wishes from those of relatives. This is when *Adopting the patient's perspective* is utilised by participants and can assist in the resolution of conflicting family opinions.

Providing consistent information is more likely to be achieved when participants are *Engaging as a unified group*. This strategy shows how therapeutic teams can provide a suitable environment and team approach to discussions, incorporating patients and relatives. This approach enables an inclusive sharing of information and can be highly successful in attaining decisions that reflect a consensus of opinion. It also serves to demonstrate a genuine interest in the perspectives and thoughts of all involved parties, as decisions commonly reflect wishes expressed by patients or families. *Searching for cues* makes explicit a particular strategy of nursing participants as they attend family meetings looking for signs of confusion or indecision exhibited by those in attendance. The aim is to identify and address a lack of understanding regarding any issues discussed between medical staff, and patients or family members, so as to avoid confusion or frustration and enhance decisions.

### **5.2.3.3 Advocating**

The category *Advocating* necessitates participants drawing to medical or nursing colleagues' attention that patients and relatives do not wish to continue with particular treatment or procedures. This behaviour can include direct and indirect forms of support and is considered necessary by participants as a response to the unnoticed or unheard voices of patients and family members. There are six strategies adopted by participants in this category: *Coaching patients and relatives*; *Encouraging patients' to voice their concerns*, *Verbalising patient wishes*, *Intervening on behalf of patients*, *Mediating*, and *Lobbying*.

The first group of strategies can be considered indirect as participants seek to encourage, educate and validate, for patients and families, how to express their concerns regarding therapy and the most suitable times to do so. *Coaching patients and relatives* relates to efforts to show patients and relatives the various roles they can adopt to enhance their participation in the decision-making process. Building on

this strategy, *Encouraging patients to voice their concerns* reveals the ability of participants to encourage and acknowledge patients and families that they can take some control over treatment decisions and indicate what they do and do not want. This includes participants pointing out to patients and relatives the most appropriate occasions to raise their concerns, identification of key senior staff, to whom they should direct their attention.

The advocacy strategies employed by participants are more direct when intervention occurs openly with colleagues, with the explicit intention of raising patient and family wishes. *Verbalising patient wishes* demonstrates an understanding, usually by nurses, that patient or relatives' expressed wishes have not necessarily been listened to by medical staff. It illustrates the efforts made to ensure this situation is rectified. *Intervening on behalf of patients* acknowledges the perceived absence of involvement on the part of patients or family members. Participants seek to raise issues with senior staff. This is undertaken to attract notice to a specific issue, especially where therapy or the behaviour of colleagues is considered inappropriate. *Mediating* is another form of advocacy, designed to generate agreement between patients and various members of the treating team when there has been insufficient dialogue between them. *Lobbying* illustrates the response of participants to include others external to their unit, when participants believe their expertise will enhance or support the wishes or concerns of patients and families. This behaviour reflects the degree of reticence demonstrated by some senior staff to include others, when they are determined to adhere to their therapy plan. However, the involvement of staff from other units can effect modifications or changes in treatment deemed more acceptable by the patient and family.

#### **5.2.3.4 Influencing**

The category *Influencing* comprises patterns of behaviour where individuals, including patients, relatives and some health professionals, are prevailed upon in order to achieve specific outcomes. For many participants the desire is to implement therapy they consider appropriate when patients or families reject it. This category highlights the divergent beliefs among the parties where the goals of therapy have not been clearly agreed upon and because of this certain behaviour is designed to

shape outcomes. The category unfolds in the context of differing opinions and the failure of health professionals to properly address patient and relatives' concerns. There are six strategies evident in this category: *Managing information selectively*, *Using mystifying language*, *Asserting authority*, *Maintaining control*, *Persevering to succeed*, and *Using relatives as leverage*.

*Managing information selectively* is a common practice where participants selectively and discerningly communicate information to patients or relatives to ensure that a specific outcome is reached. *Using mystifying language* reveals the tendency of participants to use technical words and phrases, without sufficiently ascertaining the patient's level of understanding. Both strategies can limit the ability of patients and families to be informed and thereby reduce their participation in decisions. The professional-patient relationship is frequently perceived as one-sided in terms of knowledge and authority. *Asserting authority* acknowledges that participants sometimes utilise this power imbalance in order to affect certain outcomes. *Maintaining control* is another strategy that demonstrates the exercise of power by participants. It might entail overt or implied threats, or a reticence to oblige patients due to their refusal decision. It demonstrates the ability of participants to effectively dictate the terms of their relationship, to ensure patient conformity with decisions. *Persevering to succeed* illustrates the determination of participants to persist in their endeavours to convince other members of the treating team, or the patient and family, that therapy decisions must be reconsidered. These efforts can continue for days and tend not to conclude until there is a least further discussion between the parties. *Using relatives as leverage* is a strategy commonly utilised by participants to influence patients to continue with therapy. Relatives can be used to lend support to therapy decisions or they can contribute to care by providing additional patient information, all in a bid to ensure treatment is accepted and maintained.

#### **5.2.4 Contextual determinants**

All categories, including the core process *Endeavouring to Understand Refusal: Agreeing on a Way Forward*, are influenced by contextual determinants, factors which moderate the processes adopted by nurses and medical practitioners.



Determinants can either augment or restrict these processes, thereby considerably impacting on participants' appreciation of patient refusal and the likelihood of a consensual outcome. The determinants identified in this study include *The Context of Work, Beliefs and Behaviours*, and *Legal and Ethical Frameworks*.

*The Context of Work* highlights that the manner in which hospital work occurs for nurses and medical practitioners is highly relevant to their contact with patients and relatives. Factors such as the temporal-spatial organisation of the workplace, whether they are permanent or transient workers, how the varying therapeutic units interact and the enforcement of rank hierarchies, all contribute to the way these practitioners relate to each other and to their patients and families. *Beliefs and Behaviours* reflect the educational focus and experiences of each professional group and also impacts on their approach to professional relationships. In addition, the beliefs of patients and relatives serve to further illustrate important factors that influence professional-patient relationships and an understanding of disease processes. There are also *Legal and Ethical Frameworks* in existence, which are intended to guide clinical practice and decisions relating to refusal of therapy. These frameworks inform guidelines and policies and are designed to influence the clinical practice of the two groups of health professionals studied.

### **5.3 THE CORE PROBLEM**

The central concern of this study is to examine the problems associated with the practices of nurses and medical practitioners and how they manage situations when patients with serious medical illnesses refuse treatment. Before a theory can be explicated it is necessary to identify the basic social problem. In order to address the issues of how nurses and medical practitioners deal with patients' refusal of therapy, one must identify the problem and consider the contributing factors, which emerge from the data and the participants' perspectives. These factors promote an understanding of the problem and provide the framework for, and insight into, the eventual actions adopted by nursing and medical staff to resolve it.

When patients are admitted to acute care hospitals, health professionals expect to provide treatment that reflects their expertise and experience of disease processes. As

care is provided, information is offered and reiterated by various health professionals at differing times, as a result of investigations and a whole range of other activities. The majority of patients accept the judgment of staff and acquiesce to proposed treatment. However, situations arise where the behaviour of patients, or relatives acting on behalf of patients, indicate an unwillingness to proceed or accept suggested procedures or therapy. Despite the fact that some information will have been afforded by health professionals, it becomes apparent that there is unfolding, a series of interactions, revealing multiple perspectives from patients, families and involved health professionals. It is important to highlight how nursing and medical professionals deal with these situations and whether current practices are sufficient to address patients' wishes, regarding refusal of treatment and boundaries of acceptable care. This is necessary so that future care and treatment plans will be agreed upon and it is therefore expected by all parties.

### **5.3.1 Contributing factors to the basic social problem**

There are five key factors that influence the manner in which health professionals deal with patients refusing therapy. They include:

- (i) the legal perspective,
- (ii) the medical perspective,
- (iii) the nursing perspective,
- (iv) the family perspective, and
- (v) the patient's perspective.

Each viewpoint emerges from the data and are highlighted in the contextual determinants and the categories.

#### **5.3.1.1 The legal perspective**

The existence of legislation in the form of Victoria's *Medical Treatment Act 1988* enshrines a right for individuals with an existing medical condition to refuse medical

treatment. Apart from the establishment of a right to refuse treatment, the legislation largely focuses on the details and requirements necessary for an individual to evidence a decision to refuse. It is likely that there has been insufficient examination regarding the effectiveness and workability of the legislation. Largely, it appears the legislation has been under utilised. Initially, when first enacted there was some criticism from legal circles that the legislation produced unworkable and confusing definitions.<sup>46</sup> These criticisms were never sufficiently addressed by subsequent state governments.<sup>47</sup> It was not until 2003 that a superior court<sup>48</sup> was required to provide some guidance. Whilst the judicial decision did clarify an area of significant concern regarding interpretation of the meanings of “palliative care” and “medical treatment”, the decision addressed only one specific area of ambiguity.<sup>49</sup> It is contended that if interested members of the legal profession had difficulty with the workability of the legislation then it would be of little surprise that health professionals might be uncertain or unwilling to embrace it, and this appears to be the case.

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<sup>46</sup> For example, the definitions of ‘medical treatment’ and ‘palliative care’ were deemed by some to overlap, creating confusion as to the practical use for patients and health professionals. See Clark, K. (1989). The Medical Treatment Act 1988: Safeguarding patient rights or risking patient welfare? *Law Institute Journal*. 6, 473.

<sup>47</sup> Apart from an initial explanatory memorandum initially issued with the legislation, there are no accompanying regulations or guidelines formulated to provide assistance for those seeking to understand how to use the legislation.

<sup>48</sup> The Supreme Court of Victoria is the most senior court in that State.

<sup>49</sup> *Gardner; Re BWV* [2003] VSC 173 (23<sup>rd</sup> May, 2003).

There is some evidence that health professionals have been largely unaware of the legislation or how it may be used in clinical practice.<sup>50</sup> The data in this study reveal that the majority of participants are unaware or uncertain of the mechanisms of the legislation. The study also reveals the minority of participants, who demonstrated a more thorough awareness of the legal principles, prefer to document patient refusal decisions in the patient file, rather than utilise the documents provided in the schedules of the legislation. Furthermore, the information collected and recorded by health professionals in patient files, usually does not incorporate the salient legal principles outlined in the legislation.<sup>51</sup>

In addition to the apparent lack of understanding expressed by many health professionals, the data highlight an equally uninformed group of patients and relatives. There were several occasions when patients or family members were asked by health professionals whether a power of attorney had been completed.<sup>52</sup> Indeed, the hospital paperwork in many patient files provides a space for this to be documented.<sup>53</sup> The responses from patients and family often highlighted an absence of knowledge or confusion as to the type of power actually held. Of the few patients or relatives who acknowledged the existence of a power of attorney, the majority thought there was only one type. Closer scrutiny of the documentation was more commonly undertaken by the social workers, not the nursing or medical staff, and in

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<sup>50</sup> There has been only one study in Victoria, which asked general medical practitioners to indicate their level of understanding and use of the legislation. The results indicated limited or poor comprehension and utilisation of the requirements of the legislation (Darvall, McMahon, & Piterman, 2001).

<sup>51</sup> For example, there is commonly no notation regarding the patient's wishes as to the particular treatment to be refused, or what the patient would consider as reasonable palliative care, such as the acceptance or rejection of a surgically inserted feeding tube.

<sup>52</sup> During the participant observation phase of data collection the researcher noted these conversations between nursing and medical staff and family members regarding the existence of a power of attorney. It was also noted that on many occasions patients or family were not asked at all.

<sup>53</sup> Interestingly, the legislation provides for more than an attorney to be appointed. It also allows for patients to indicate for themselves whether there is any treatment they do not wish to accept. In a *Schedule One: Refusal of Treatment for a Competent Person*, the hospital admission documentation does not provide for, or invite staff to, include this information.

many cases revealed the power of attorney related to financial affairs, not refusal of treatment issues.<sup>54</sup>

### **5.3.1.2 The medical perspective**

Modern medical research and knowledge has amassed a vast array of cures and therapies for all sorts of illness states. The widespread ability of medical care to utilise science and technology to assist myriads of patients, underpins the educational focus and practice of medicine. While medical programs continue to concentrate on the biological aspects of disease processes, many embrace additional aspects of an individual's response to health care, such as the psychological and social spheres. However, the empirical evidence suggests that while medical practitioners consider death from the biomedical perspective, patients and families think more broadly (Steinhauser, Clipp, McNeilly, Christakis, McIntrye & Tulskey, 2000). Therefore, the medical focus largely continues to concentrate on the disease process and this can lead to less attention paid to decisions based on patient or relatives' values or beliefs.

Standards of ethics and codes of conduct further encapsulate and emphasise the desire for medical practitioners to relieve suffering and provide treatment whenever possible. These themes dominate in principles, such as beneficence and non-maleficence, which underline the codes, despite the inclusion of other principles such as autonomy. The imperative to treat using all available technology and knowledge continues as a prevailing force of the medical profession. The ability to balance and incorporate ethical and legal principles appears to develop with individual practitioners as they gain experience, knowledge and insight into their practice, although the extent to which this occurs does vary.

In acute care hospitals, medical therapies and practice are the greatest influence on the business of health care. The medical practitioners are central to many services

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<sup>54</sup> There are several differing types of powers of attorney designed for specific purposes. For instance, in Victoria a 'power of attorney' and an 'enduring power of attorney', both only relate to financial decisions and transactions. The former usually exists for a specified time, for instance when the donor is geographically distanced and unable to sign contracts. The latter comes into effect when the donor loses mental capacity, for example, in the case of dementia, the attorney is then able to manage the donor's business affairs. These types of powers do not relate to health care decisions.

offered to patients; they are ultimately responsible for management of the disease process. Within each therapeutic unit medical staff direct and order patient therapy. Given this central role of the medical profession there is a need for, and expectation of, control of each patient's therapy and treatment plan. When patients or relatives decide not to accept a given treatment or demonstrate an unwillingness to proceed, this can be contrary to the medical plan, giving rise to potential conflict with medical advice. The medical response is influenced by the individual practitioner's approach and ability to incorporate a broad range of considerations into the decision.

Given medical staff take responsibility for overall patient care in hospitals, patient refusal decisions can also raise medico-legal issues, which may cause some disquiet for practitioners. If medical staff believe they have a responsibility to provide treatment, but have a limited knowledge of the existing legal principles or the extent of their obligation to provide treatment, they can adopt strategies which favour their perception of the situation. There can also be fear of complaints from relatives that might lead to investigation or unwanted litigation if a patient dies prematurely.

### **5.3.1.3 The nursing perspective**

Nursing education and models of care tend to vary from their medical counterparts. While bioscience subject matter forms a fundamental basis of many educational models, the bioscience components are provided in less depth when compared to the medical educational programs. In nursing programs there is a broader approach to patient illness and care. The concept of "health" is viewed as a continuum reflecting an individual's ability to interact with his or her environment (Brink, 1992). A number of facets, including the psychological, social, cultural and spiritual beliefs of patients, are viewed as equally important as the biological issues surrounding a patient's perception and reaction to health care. In addition, there are codes of conduct and ethics, and competency standards, which are tied to practice standards and expected behaviour from the very beginning of clinical practice. These appear to provide nurses with a different perspective of health care and sometimes place them in conflict with others, when patients refuse treatment. However, as with the medical practitioners, individual nurses develop their perspectives based on the types of clinical practice they experience and their personal insights into the delivery of care.

Some nurses focus on the bio-medical approach, while others take an all-encompassing perspective. Moreover, as the nursing role does not include ultimate responsibility for controlling the overall management of patients, often their holistic focus does not dominate or infiltrate the process where key decisions are made. The nursing role is often perceived as less influential and secondary to that of the medical role. This becomes apparent when treatment relating to the disease is ordered and subsequent decisions must be made. Individual nurse's levels of experience, confidence, beliefs and insights into other people's perspectives, largely determine the nursing response.

Nursing work in acute care settings demands that nurses interact and spend more time with patients than other health professionals. Nurses tend to get to know the patient and family better and consequently, are more likely to develop professional relationships with them. Often patient and family requests and thoughts are highlighted as nursing staff members interact with them for many hours each day. This can provide insight into patients' or relatives' perceptions and reactions to the proposed therapy. Thus, nurses are commonly the first to identify patients' intentions or decisions to refuse therapy. Nurses play an important role, as much depends on whether they respond to patients or relatives, how they manage the situation and whom they might involve to discuss the issues or concerns raised. This positions nurses as intermediaries, somewhere between patients and relatives, who are not accepting or wanting the treatment, and medical practitioners, who order and prescribe the therapy.

#### **5.3.1.4 The family perspective**

Family members and significant others bring with them their own beliefs and understanding of health care. They interact with patients and health professionals, expressing their views and perceptions of expected outcomes. The general consensus from participants is that expectations of what modern health care can offer are most frequently high and even unrealistic on many occasions. There is little comprehension or appreciation of different disease states or the impact of existing co-morbidities on the success of the therapy.

In addition, the experience of dealing with a loved one who is suffering from a serious illness and then admitted into an acute care hospital can be quite unexpected. It is a highly emotional time, creating stress and anxiety. Family members can also be included in treatment decisions, particularly when patients are unable to participate. There may have been little preparation or discussion regarding the patient's wishes, or the possibility of a poor outcome for the patient. Family members or significant others can impose their own beliefs or needs of proposed treatment and care onto patients. Conversely, even after family members have discussed possible outcomes for patients, they become frustrated and distressed when they are excluded from treatment decisions and plans, and have no clear understanding of how health professionals are dealing with their loved ones. These scenarios can give rise to disagreement and hostility among those close to patients, and this can and does, affect the direction of care taken.

#### **5.3.1.5 The patient perspective**

As with family members, the beliefs of patients shape the interactions they have with health professionals. Patients, as individuals appear to share similar expectations with family members, regarding the relative success of modern health care delivery. They generally have little knowledge of disease processes and associated therapies and hospitalisation only re-enforces the foreign environment they must confront. This might explain why participants constantly referred to patients relating to medical and nursing staff with deference and respect or uncertainty. This translates to patients commonly adopting passive roles, whereby they are less likely to participate in decisions or acquiesce and fail to become involved, believing the health professionals' as experts would make the "right" decisions on their behalf. This allows treatment plans to be organised and implemented by health professionals and relatives despite underlying patient uncertainty or misgivings. On the other hand, when patients are assertive, articulate and persistent, it appears that their decisions are likely to be given more credence. Whether patients adopt active or passive roles is largely dependent upon individual patients, including the degree of incapacity due to the illness, their beliefs, perceived expectations, and the interactions and relationships assumed by the health professionals.



The difficulty for patients in many cases is their ability to actually participate in discussions, formulating treatment plans and decisions. Many patients believe that they will be in a position to make their own decision when the appropriate time comes. The difficulty for staff is the lack of guidance they are provided if patients have not previously discussed their wishes with family members and are deemed to be too ill to participate in decisions. Patients may have firm ideas but if they are unable to communicate or feel unable to voice their thoughts and wishes, they can be overlooked. This can create anxiety and frustration, and enhance the likelihood of refusing to proceed with therapy.

When patients are ill they become particularly vulnerable, allowing health professionals and families to influence decisions. Sometimes there is an initial acceptance of treatment and then as time passes patients decide they do not wish to continue. The data highlight situations where other parties assert their influence, or disagree with each other, and patients concede to pressure in order to please, or due to an inability to contribute. These situations can create aggravation and disagreement as health professionals' grapple to identify the most appropriate therapy for the patient.

#### **5.4 SUMMARY**

This chapter has presented an overview of the study. The problem, *Competing Perspectives*, and the core category, *Endeavouring to Understand Refusal: Agreeing on a Way Forward*, have been presented. As the main category it is linked to the four categories, *Seeking Clarification*, *Responding to Patients and Families*, *Advocating* and *Influencing* and comprise numerous strategies, briefly outlined in this overview. Changes in one category will highlight alterations in another category, and the conduct of participants reflects a broad continuum of behavioural patterns throughout the categories. The contextual determinants qualify and moderate the processes in which the two professional groups engage as they deal with patient refusal of treatment.

The basic social problem *Competing Perspectives: Encountering Refusal of Treatment*, depicts the matters associated with the practices of nursing and medical

staff in the specific circumstances of patient refusal of therapy. The problem and related factors comprise a number of differing viewpoints arising from individuals with diverse backgrounds. They highlight the contradictory perspectives of the various parties and the complexities with which nursing and medical staff members must contend. It emerges that there are competing perspectives influencing and affecting the behaviour of staff members, all of whom believe they are promoting the health and well being of patients. Nonetheless, the practices and perceptions of staff members contribute to, and inform, the social psychological process.

To assist a comprehensive understanding of this study, the material has been selectively ordered. The contextual determinants are identified in Chapter 6 and the basic social psychological process in Chapter 7. The findings and discussion in each of the four categories are presented in Chapters 8, 9, 10 and 11, and then finally in Chapter 12 an overall discussion of the findings and conclusion are addressed.

## **CHAPTER 6**

### **CONTEXTUAL DETERMINANTS**

#### **6.1 INTRODUCTION**

This chapter presents the key factors that serve to influence the practice of the nurses and medical practitioners when they deal with patients in the context of refusal of treatment. The contextual determinants impact on participants in a number of ways and this characterises and embodies many of the processes adopted by them. Hence, the presentation of the determinants establishes the framework in which the processes employed by participants can be completely understood. An appreciation of the contextual determinants is also necessary in order to comprehend the resultant theory.

#### **6.2 CONTEXTUAL DETERMINANTS ON ENDEAVOURING TO UNDERSTAND REFUSAL: WORKING TOWARD AN AGREED WAY FORWARD**

When health professionals are dealing with seriously ill patients who wish to refuse medical treatment, there are various influences that affect the strategies they subsequently implement. The contextual determinants both restrict and enhance the processes that nurses and medical practitioners employ when patients refuse medical treatment. Moreover, these factors can work consecutively, or concurrently with each other. They serve to shape the interactions of the participants as they deal with each other, with patients and their relatives.

If nurses and medical practitioners desire an expeditious and successful outcome they need to be sentient of the factors that affect their behaviour. These influences, as extrapolated from the data, are located in three contextual determinants:

- (i) *The Context of Work,*
- (ii) *Beliefs and Behaviours, and*

(iii) *Legal and Ethical Frameworks.*

*The Context of Work* reflects the design and manner in which work, including communication, occurs by nursing and medical staff in the hospital setting. This determinant comprises the context of work, namely the locality and accessibility of health professionals, the stability of the workforce and the existence of professional hierarchies. *Beliefs and Behaviours* considers the influences and values that underlie the conduct of staff, patients and family members. *Legal and Ethical Frameworks* consider the legal principles, policies and the ethical codes that establish expected clinical standards. These serve to provide guidance for the practice of nurses and medical practitioners and specifically address issues associated with patient refusal of therapy.

### **6.3 THE CONTEXT OF WORK**

Health professionals working in acute care hospital environments work within a specific organisational framework. Workplace design determines the everyday contact nurses and medical practitioners have with patients and each other and this impacts on the accessibility of professionals, to patients and family members. The factors highlighted in the context of work offer certain revelations, which assist in an understanding of the work practices of each professional group. The factors comprising the context of work include the temporal-spatial organisation of the workplace, the continuity and experience of staff, competing authority amongst therapeutic units, and the effects of professional hierarchies.

#### **6.3.1 Temporal-spatial organisation**

The design of workplace provisions in public hospitals directly influence the manner in which nurses and medical practitioners engage with their patients and each other. Hospitals are required to provide twenty-four hour care, including nursing and medical cover. In this study two distinct workplace locales were considered – the ward environments and the high acuity intensive care unit – both accommodating seriously ill patients.

### 6.3.1.1 The ward setting

In the acute care hospital environment nurses<sup>55</sup> are usually located in a particular ward in which they carry out their professional roles and responsibilities. In practice, this means that nurses arrive at work and are commonly allocated a specific number of patients, for whose care they are responsible for the duration of the shift. In this study, during a twenty-four hour period there are usually three distinct rotations of nursing staff: morning, evening and night shifts. The clinical area determines the number of patients each nurse must care for. In the medical or surgical wards a nurse may be responsible for the care of four or five patients. The nurse is physically situated in the ward for the entire shift, with the exception of meal breaks.

This work arrangement firmly locates nurses in close physical proximity with patients. It is common for the nurses' working day to span eight hours. Their ongoing exposure with individual patients ensures that they have greater hourly contact with patients than any other member of the health care team. This work arrangement provides an opportunity, and is used by patients and family members, to communicate thoughts and concerns to the nurses. They hear conversations between patients, family or friends, and are in a position to observe interaction between these parties. When patients have concerns regarding therapy or specifically refuse treatment, it is most often communicated to the nursing staff.

*The patients tend to open up more to us, that's probably because we are there all of the time. ... The patients tell us what they want; the medicos hear from us what the patient is refusing.* (Nse 8/4)

Compared to the number of nurses, there are fewer medical practitioners per patient. The organisational design of work in the public hospital system studied reveals the medical residents and registrars<sup>56</sup> are assigned to specific therapeutic

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<sup>55</sup> Nurse participants in this study refer to registered nurses (called Division One registered nurses) in Victoria. By comparison, there are also enrolled nurses (Division Two registered nurses) also working in wards, but they are fewer in number and were not participants in this study.

<sup>56</sup> The words or terms used to denote medical staff members, varies in different hospitals. In this study, 'resident' refers to the most junior, often newly graduated medical practitioner. Other words used to describe them include 'intern' or 'resident medical officer' (RMO) or 'house medical officer' (HMO).

units.<sup>57</sup> Each unit comprises one or more consultant, who supervises and directs the work of those more junior. Commonly, medical staff are not located in the same ward environment as their patients. The “medical team” will be required to visit patients admitted into their therapeutic unit and this often involves patients who are located in more than one ward setting. Medical staff are also required to see patients in a number of other localities in the hospital, such as the emergency department when a patient first arrives to the hospital. They constantly move from one area of the hospital to another. This requires the medical practitioners to be highly mobile as they endeavour to treat patients admitted into different ward and unit areas. This is a significant factor in the time they can spend with individual patients or family members.

*We are maybe there with the patients for 5, 10 or 15 minutes. The nurses are more in tune with what's happening and they see the family.*  
(Dr 012/11)

The extent and nature of patient contact for members of the medical team contrasts with nursing colleagues. Unlike the three distinct nursing shifts, medical staff tend to work extended hours. To ensure that there is evening or nighttime medical staff available, they are often rostered “on-call”.<sup>58</sup> Consequently, the number of patients seen by the resident or registrar could amount to several dozen in every ten to twelve hours when they work on-call. Nonetheless, these members of the “medical team” are more likely to have daily consultations with patients within their assigned therapeutic unit.

*That's the problem; it's just so busy for them [residents]. They don't have time to sit with every patient and fully explain everything like I know they should. They are constantly having to move on to the next patient ...* (Nse 11/15)

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<sup>57</sup> The term ‘therapeutic unit’ denotes an arrangement of work according to a speciality area of medical practice, such as orthopaedics, neurology or intensive care.

<sup>58</sup> When residents and registrars are ‘on-call’ they are often responsible for more than one therapeutic unit. This translates to dozens of patients, many they would not have had the opportunity of previously caring for or meeting.

In the public hospital system, consultants leading a therapeutic unit visit fewer patients in a particular hospital than their junior counterparts (residents and registrars), who deal with the hourly needs of patients. This is due, in part, to the fact that the consultants rely on the junior medical staff to communicate information to them. Therefore, they might not actually see every patient every day. In addition, consultants are usually not located full time in the hospital as many are not employees of one specific hospital. They commonly have workloads in other hospitals and many have private consulting suites. However, they direct, and are ultimately responsible for, patient treatment plans.

When queries or concerns regarding patients are raised, the residents or registrars might come to the ward but they do not always see the patient. For all members of the medical team the time actually spent with patients varies, but is considerably limited when compared to the nursing staff. This directly impacts on how patients' treatment decisions are communicated between the patient and health care professionals.

*I think sometimes the nurses have a better gauge of what the patient is experiencing and what they're capable of as a snap shot of time, ... the nurses sometimes have a more realistic idea of what the patient's going to achieve, they look after them each day. (Dr 015/15)*

### **6.3.1.2 Intensive care setting**

If the temporal-spatial design integrates the medical team in the same geographical location as patients on a full-time basis, a different pattern of communication can prevail between nurses, patient and family members. In the intensive care unit the medical team are all situated in the same surroundings as the patients and nurses. The consultants' offices are located adjacent to the main work area, which is shared by all staff. In addition, while the length of their working hours may vary, the timing of their shifts is closer to that of nursing staff working in the environment.

Nurses are responsible for one or two patients depending upon the severity of the patient's condition. As in the ward setting, nurses working in intensive care are situated in the unit for the entire eight or ten-hour shift, excluding meal breaks.

Effectively, the clinical work of both professional groups occurs in the same environment. They can all physically see each other, and be seen. They can all see and often hear many of the patient and family interactions as they work. The medical team's attention is truncated only by visits outside the unit to emergency calls or when requested to see a patient elsewhere in the hospital. Their primary focus remains on patients in the intensive care unit. This contrasts with medical staff in other therapeutic units. The excerpt below highlights the pressures placed on these medical staff, to attend numerous patients and how nurses deal with this.

*There's always admissions, discharges, the outpatients clinic; there's ED [emergency department] and in-patients [patients in wards] to see and there's theatre [operating suites] ... I just think it's public hospitals; you [patients] have to wait; that's part of being in one, where you have to wait and you may not get the proper explanation, but hopefully someone will come in and try ... like I will say, "Any questions, is there anything you need ask me?" (Nse 11/16)*

An important determinant as to which professional group interacts in patients' refusal decisions, relates to the proximity to, and availability of, nursing or medical staff. The context of work denotes that nurses' work places them with fewer patients for longer periods, when compared to the medical teams. In ward settings the medical teams are more mobile, consult with a greater number of patients and therefore spend much less time with each patient. This contrasts with the medical teams working the intensive care setting where they are continuously consulting. The medical practitioners, including the consultants, are actually located in the unit where their offices are physically situated, and their work is largely carried out within the unit. There is a clear advantage in terms of accessibility for patients and family members of both the medical and nursing staff in the intensive care unit.

### **6.3.2 Continuity, experience and education of staff**

Other factors that might impact on how health professionals deal with patient decisions to refuse treatment or procedures relates to the stability and experience of staff working in a specific environment. Less experienced nurses and interns working



in acute hospitals usually rotate through a number of different therapeutic units in their first years post registration.<sup>59</sup> Effectively, junior staff are more transient as they move between therapeutic units every few months. They do not necessarily become acculturated with the particular work, the environment, nor become well known to each other as colleagues. This is despite the fact that the junior medical staff are responsible for informing the consultant of patients' current clinical state and progress.

*I [consultant] assume that anything [concerning the patient] that needs to be brought to my attention, is brought to my attention, but it doesn't always happen because again registrars usually are training and are on three-month rotations and it takes them a couple of months to tune into the speciality [therapeutic unit], and they then move on. (Dr 013/9)*

The data reveal that these factors vary considerably in the different areas studied and become relevant to the interactions between staff, and consequently patients. Staff who have worked in an area for prolonged periods are more likely to have established a rapport with their senior colleagues. They know each other by name and the nurses know the style and therapy preferences of their medical colleagues. When staff know each other there is a greater likelihood that discussion will occur between them. Patient issues and concerns might be raised and suggestions discussed. In the ward settings, partly due to the transience of staff, junior nurses and senior medical staff are less likely to discuss patients' in any detail. The following excerpt from a junior nurse highlights her surprise when she raised an issue with a consultant on behalf of a patient and his family.

*I spoke to the consultant about getting an NFR [not for resuscitation] order only because he [consultant] was the one standing at the desk ... so I just asked him ... and he sort of looked shocked, horror ... [the patient, his wife and daughter had asked me to request the order], they could all explain exactly why they wanted it and that they understood*

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<sup>59</sup> All nurses and medical practitioners are required to register with a suitable regulatory authority at the successful conclusion of their education. In Victoria, these authorities are the Nurses Board of Victoria and the Medical Practitioners Board, respectively.

*[the patient's current condition and the ramifications of the order]. I said, "I'll get someone [from the medical staff] to come and speak to you about it and you can sign the form" ... He [the consultant] just looked horrified and he said, "No". He had a real go at me [was angry] about it and said, "That's not appropriate" [the NFR order]. I think it was because he didn't know me and I had the front to talk to him about it. The family then walked down to the desk and heard what I'd been saying and just said, "No, we want an order done in case he has an arrest [cardiac arrest] ... we don't want anything overly invasive," and he then said, "Oh, oh, fine, here is the NFR order". (Nse 07/7 & 8)*

This contrasts with the intensive care unit where the entire nursing and senior medical workforce are stable and know each other. The accompanying advantage of a permanent workforce is the relative experience gained working continuously in the specialty area. Moreover, there is a tendency for nursing staff to hold specific post-graduate qualifications when they work in intensive care and this aids a comprehensive understanding of their professional obligations. This continuity and experience was considered by some participants a unique benefit, which enhanced the various encounters they had shared and was a contributing factor to a collaborative team effort and management of patient concerns or decisions to refuse treatment.

*I have a very stable workforce. I probably have about 74 EFT [effective full-time positions] and I probably only ever had about 2 EFT vacancies at any one time. That's mostly due to maternity leave. It certainly helps because a lot of these staff have been here ten years plus and so they know the unit [and each other] really well ... most have additional qualifications. They have a lot of input [into treatment plans], but also helped with a lot of change. We've all been through a lot of change together, so it does help. (Nse 18/26)*

The data reveal that staff who know the working environment and each other are more likely to work collaboratively and effect change to various work practices. There is a likelihood of enhanced interdisciplinary communication between both

nursing and medical staff and this assists the development of trustworthy and respectful working relationships. Staff who are familiar with a high level of teamwork express surprise when confronted with a work environment where this is not the norm.

*... the consultants really, really respect the nurses' role within intensive care and that's really important and ... last week ... we were quiet [there were few patients] on the Tuesday and one [nurse] had to go to a ward [to work] and upon her return to the unit, she said, "The doctor, a junior resident, has just spoken to me like I was a piece of dirt and I can't believe it." She said, "Nobody would speak to me like that in intensive care". (Nse 18/6)*

When both professional groups work collaboratively this is recognised as having some impact not only on how they relate to each other, but importantly how they relate to patients and family members.

*Working as a team, nurses and medical staff working together, it carries some weight with the patients and their families. (Nse 05/9)*

The relative permanence of health professionals working in a therapeutic unit provides experience of the specialty area and enhances the probability of collaborative relationships. There can be a greater understanding between them, including how to respond to patient or family requests regarding refusal of treatment. This, in turn, provides a relatively organized team, which is considered a positive attribute as the two professional groups are seen to be working as one.

### **6.3.3 Competing authority**

When patients are admitted to a particular therapeutic unit they will usually remain within the care of that particular medical team for the duration of their hospital stay. Treatment plans and decisions become the domain of the medical team of that particular unit. Medical staff from other therapeutic units only become involved when patients are referred to them. Difficulties can arise when the medical staff

communicate, independently of each other, with the patient. Nursing staff and patients find that diverse messages are exchanged.

*... she [the patient] was [admitted into] both paedics [orthopaedic unit] and plastics [plastic surgery unit] and they were saying different things and that was frustrating as well. ... they [the plastic surgery unit] were going to take her [the patient] back to theatre a few days later and do the split skin graft, but said, "You have to stay in bed and you have to stay there for three days" ... but the orthopaedics guys [medical staff] were like, "Yep, she's fine to get up and moving" ... (Nse 11/11)*

Involving health professionals from other therapeutic units is achieved by a referral system and is considered a medical responsibility. It was observed that there are times when the nursing staff believe that patients admitted into one therapeutic unit should be referred to a different unit, to meet their particular needs. This was observed more than once and in circumstances where the patient, family or staff did not believe an aggressive approach to treatment was appropriate. In these situations nursing staff sometimes approach members of another therapeutic unit in an attempt to get them involved with patients' treatment. The success of this approach is largely moderated by previously established relationships and the ease in which staff from other units are prepared to become involved. Another relevant factor is acceptance of this practice by individual consultants; some do not condone or view this role as acceptable, even when it has been suggested. The patient or family might be sufficiently firm in requesting a referral to another therapeutic unit, but as the excerpt below demonstrates, due to the self-contained nature of therapeutic units, even senior consultants are reluctant to interfere with other therapeutic units.

*... sometimes the nurses will indicate informally they feel that some patients should be referred to us, but unless there is a referral, either informal or otherwise, from the medical team I do not become involved ... if the family, for instance, feel very strongly that it's time to shift the care ... it's a rare event, but I have been rung by medical administration to assess the situation and give my opinion [about referring the patient] and then a decision is made and the consultant*

*[from another therapeutic unit] is asked to refer the patient ... This is very unusual and it takes a very courageous family or patient to do that.*

(Dr 013/5)

The autonomous and disparate nature of the various therapeutic units ensures that they can remain independent of each other, despite the fact that they may have patients admitted into the same ward or unit and may know each other professionally. However, the ease with which the medical staff in each unit communicate and refer patients is largely determined by the senior consultant's approach to care and willingness to involve others.

#### **6.3.4 Rank hierarchies**

The organisation of nursing and medical staff in acute care hospitals is established along specific lines of authority. The traditional character of both nursing and medicine has seen the development of hierarchies within each group, which delineate junior from senior practitioners. In the hospital environment the nature of medicine is to place the consultants at the apex of the hierarchy, the ranking down this social order moves to the registrars and then to the residents. Nursing is less clearly delineated after the unit manager is identified at the peak and the newly graduated nurse at the base. There are associate nurse managers, who might be the most senior clinician working a particular shift, and there are also a number of nurses working at the same time with varied years of experience between them. In both professional groups the hierarchy is established according to the official position of each individual and this commonly corresponds to years of experience and qualifications.

The nature and type of work for each professional group is designated according to where the individual is located on the hierarchical continuum. This workplace arrangement has a direct impact on individual staff members and their relationship with the patient, including how often each individual is likely to confer with patients and how decisions regarding patients' treatment decisions will be managed. The workplace hierarchy also impacts on the way members of the same professional group, and different professional groups, interact. In some work environments the professional groups are well integrated, in others areas this is much less evident.

When less experienced nurses become aware of patients' concerns regarding treatment decisions, they will often communicate this to more senior nurses. This is because they sometimes feel unsure of how to respond or they are unable to change patients' minds. The action taken thereafter, might involve both nurses returning to the patient to discuss the refusal, or senior nurses dealing with the situation.

*Junior nurses go to the senior nurses when there is trouble with [patient] refusals, we don't like arguments. (Nse 06/8)*

The most usual form of action taken by nurses in refusal situations, is to engage in a discussion with the patient. If the patient agrees to the treatment then workplace activities continue unabated. Patients' initial refusals may be communicated to other oncoming nurses or the medical team, although the matter may not be verbally communicated or recorded. When patients continue to refuse treatment the most likely practice for senior nurses is to inform the intern or the registrar. Although, many experienced nurses recognise the limitations of the residents. Residents are the most inexperienced members of the medical team and have the lowest status amongst the medical team members. They tend to work long hours and this, combined with their inexperience, adversely affects how they communicate with others and deal with difficult situations.

*Junior medical staff [residents] are not great at dealing with patient refusals ... (Nse 04/8)*

Residents tend to work closely with registrars and take considerable direction from them regarding patient treatment plans. Residents do not communicate beyond the registrars, to the consultants, they are more likely to attempt to deal with patients' refusals and then defer to the registrar.

*The intern [resident] went and spoke with the patient [about the patient's refusal of the proposed treatment] and they had a big chat and then he got the registrar just to make sure, cause I think the intern wasn't sure how to go about it [the treatment plan thereafter]. (Nse 12/11)*

The level of experience allows registrars a degree of leverage compared with the inexperience of residents. Registrars possess greater knowledge, have more experience and can make a concerted effort to convince patients to continue with proposed treatments.

*The registrar is the key player [regarding refusal decisions] and that depends on their experience and maturity as well. (Nse 10/10)*

The registrars can sometimes accommodate patient requests and change the form of therapy, for instance changing the route by which medications are delivered. When they cannot persuade a patient to continue with the treatment plan they will only involve the consultants as a last resort. There appears to be a reluctance to call upon the consultants, especially if they are not physically present. The desire to continue therapy seems to outweigh the importance of patients' refusal.

*... the registrar will only call the consultant if the HMO [resident] and registrar can't get through to the patient. (Dr 012/9)*

It is rare for registrars to accept patients' refusals without conferring with consultants. It was observed that when patients or relatives continue to refuse treatment registrars will communicate this to the consultants. The timing of such communication to the consultant is influenced by factors such as patient deterioration and the desire to progress therapy, or the refusal occurring when a procedure is about to be carried out. Registrars might wait until the consultants are about to visit the patient to communicate that the patient or relative has refused treatment.

*The intern [resident] started [the discussion with the patient], and then got the registrar, and eventually they went and got the consultant involved. (Nse 08/3)*

The hierarchy can impose boundaries between the varying ranks of authority. This can have an unfavourable impact on how patients are managed, the quality of care provided and the time taken to deal with the patients' refusal of treatment decisions. This was explored in the following example:

*... the junior doctors would rather eat their [own] foot than call someone more senior from the anaesthetic team to come and put an IV in. They'd rather have a go 15 times than ask someone else [more senior] to do it. There are boundaries between roles [of staff] ... (Nse 06/3)*

If it is perceived that a staff member has over-stepped a boundary in relation to a member higher up the hierarchy, significant consequences for both patients and the lower ranked staff members might occur. This can alter the direction of a patients' care and treatment plans. The excerpt below involved an experienced nurse and registrar checking with a patient, who was partially deaf, about whether he understood the procedure proposed by a consultant:

*He was quite a coherent 83 year-old and he had a hearing aid. The doctor, fully masked, was talking into the ear with no hearing aid and the doctor walked outside the cath [catheterisation] lab to get prepared to put the balloon pump in and the nurse just said, "Did you understand what he [consultant] just said?" He [the patient] goes, "Oh, not really", which she then said, "They're going to do this and that, and this is what the catheter does" and he said, "Oh, I don't want that". She went out to the doctor [consultant] and said, "He doesn't want it" ... he [consultant] pinned her up against the wall and told her never to undermine him ever, ever again ... if he wanted to put a balloon pump into a patient, he would. So our registrar [who had been party to the nurse's explanation] went out and said, "Look the patient doesn't want it." He got the same sort of abuse about minding his own business, it wasn't his patient. So they came back and got our consultant and the consultant went back and said, "Look, the patient doesn't want any of this", it was quite clear [he was refusing the procedure]". (Nse 18/7)*

In some wards, work is designed to maximise use of the consultant's time using a traditional "ward round" system. This method of consulting with patients and making treatment decisions reflects the authority and time constraints of the consultant. The ward round comprises the entire medical team, at least one senior nurse, and frequently includes allied health staff, such as occupational therapists, social workers



or physiotherapists. The group is usually large in number and moves through the ward to visit each of the patients in a specific therapeutic unit. The rounds are used to discuss patients' progress and treatment plans and serves to inform patients and all health professionals who are providing care. The round is often the only time patients actually meet a consultant. In the study, several nurse participants criticised this form of patient consultation as it is considered that patients do not always understand or have an opportunity to participate in the decisions being made about them.

*On the doctor's round there is a lot of people walking in and it's very "in your face" [overwhelming] for the patients and sometimes the patients are looking around while everybody's saying things, so they actually aren't listening to what is going to happen. Then [when the team leave] the patient says, "What just happened, what did they say?" and you just try and explain really simply. (Nse11/13)*

The ward round can be used to reinforce rank hierarchies and the authority of the consultant. Observation of the process highlights a particular social order whereby the consultant takes the lead of a large group, moving into patients' rooms, with the most junior staff members filing in at the rear. The group proceeds from one patient to the next at a pace established by the consultant. The consultants rarely wait for other staff; should the bedside nurses be attending other patients, they do not always have a chance to contribute to the discussion.

*I try to listen, but if I'm busy with someone else ... they'll [medical staff] "blow in and blow out" [will arrive and leave] and you're like, "Aarrgh, I didn't get a chance to catch [hear] anything!" (Nse 11/10)*

Conversely, for some medical staff the traditional ward round is preferred because they believe a nurse should be present. Medical staff did express their frustration in not being able to locate nursing staff to discuss specific patients.

*We have lost the communication between senior nurses and consultants because now days the old idea of the ward rounds is more relaxed and*

*you have to look around to find a nurse that knows anything about a patient. (Dr 013/9)*

Analysis of the data highlight that in the intensive care unit, where the medical team is permanently located, traditional hierarchies are not apparent. For instance, traditional ward rounds are not practised. Instead, medical teams appraise patients' conditions throughout each working shift, discussing therapy with each other and then with nursing staff, or as one group, as issues arise. The authority roles of the consultants are utilised, mainly to emphasise to new or incoming medical staff that discussion is more inclusive, utilising the opinions and experience of both nursing and medical staff.

*When the residents and registrars start in the unit, one thing the consultants will make sure is that you [residents and registrars] must listen to the nurses. Most of them [nurses] have been here a long, long time; they know what they are doing; they have considerable expertise and it's made really very clear that it is important to you [residents and registrars] progressing successfully through this unit. (Nse 18/6)*

The organisation of staff from junior to senior is inevitable in teaching hospitals, where junior, less experienced staff must confer with more experienced staff. However, there are clear differences in the way those at the apex of the hierarchies assert their authority and these differences can characterise the relationships between staff members and relationships with patients. Where senior medical staff members embrace and encourage junior staff members to participate, including both nursing and medical staff, there is better communication between staff, generating greater unity within the whole group. In contrast, therapeutic units operating on traditional lines tend to adopt formal or strict lines of communication, where those on the lower levels have limited discussions with those more senior, and there can also be a significant degree of separation between medical and nursing communication as a result.

## **6.4 BELIEFS AND BEHAVIOURS**

The staff members working in acute care hospitals come from diverse backgrounds and a wide range of experiences. They work in groups, interacting with patients and relatives, yet bring with them personal attitudes and viewpoints. These perspectives influence their decisions and how they perceive patients' and families' roles in clinical decision-making. The beliefs and behaviours of health professionals ultimately shape how they deal with patients, therefore, an understanding of their beliefs and behaviours provides insight into the strategies adopted when patient refusal situations arise. Factors found to influence the beliefs and behaviours of nursing and medical staff include their respective educational backgrounds, the level of mentoring they provide or receive and their personal perspectives and concerns. At the same time, patients and families are integral parties with their own distinct views and responses. Their perceptions reveal certain expectations regarding therapy and decisions to refuse; they can exhibit assertive or passive behaviour and their relationships with each other can ultimately influence the processes undertaken by the participants in this study.

### **6.4.1 Nursing and medical staff**

When participants were describing their experiences with patients who had refused treatment, their beliefs and behaviours were frequently highlighted. This was the case, in particular, for many of the nursing staff, who were keen to enlighten the researcher why they believed certain patient decisions were managed in a particular way. The medical staff responded differently when discussing examples of patient treatment decisions. There was a tendency to discuss matters in a clinical context, referring to investigations and results, with little emphasis placed on their personal considerations or opinions.

#### **6.4.1.1 Competing perspectives: medical model versus holism**

The approach taken by staff members when patients refuse treatment is partially influenced by their educational backgrounds and educational experiences. The traditional educational models of nursing and medical courses are founded on the western medical model. One of the features of this model is a rational scientific focus

and the accompanying use of sophisticated technology (Brink, 1992). The aim of the model is to identify a definitive diagnosis and then proceed to cure disease, using the latest diagnostic tests and procedures. This can result in a vigorous approach to treatment, the focus is on the disease process itself and the health professionals' technical skills can take priority over patients' feelings and wishes.

*Yes, the sub-culture within the medical specialty [therapeutic unit], for sure, is relevant and seems to provide different foci and the culture of the [therapeutic] unit, and yes, their [consultants'] personalities; all of these influence the way they [consultants] communicate, ... they're not treating the person but rather they're treating the actual disease. (Dr 015/18)*

Nursing staff frequently articulated that the approach to patient care is generally to provide active treatment, which they believe is sometimes problematic. A number of them believe that this is a driving force for many of their medical colleagues and does not always result in consideration of what the patient and or family actually desire.

*... the western [model of education], yeah, its definitely the model that we're trained on but it is a failure, and because we do have the machines that go "ping", [the belief of many staff is] we can do something, we can extend life ... (Nse 18/17)*

The data demonstrate a pronounced emphasis on medical staff obtaining a definitive diagnosis and treating the disease and associated symptoms. Many nursing staff believe that this is undertaken at the expense of other considerations. Where curative medicine is the primary approach, other more conservative management, such as keeping the patient comfortable or discussing poor patient outcomes, including death, tend to be obscured until it is unavoidable.

*We had a patient that was dying, he was on his death bed and here he [the registrar] was ordering blood tests and x-rays ...; you wondered whether they [medical staff] think that they can make, or do a Lazarus*

*[return from death] with them, the patient actually died that afternoon.*  
(Nse 02/13)

It can be asserted that death is often viewed as a failure in the rational scientific model. This can lead to treatment being perceived as relentless and unending, even when patients or families have indicated that they do not want to keep going with the recommended treatment. The determination of many staff to order and provide numerous procedures might also effect patients who decide to refuse treatment.

*The doctors sometimes provide aggressive treatment even when they [patients and families] don't want it ... and then they [patients and families] finally get it into the doctor's head that, "Bentley" doesn't want this [this can be the case], even with the more senior doctors.* (Nse 12/8)

Despite the educational focus of western medical models, many differences have emerged in nursing and medical undergraduate programs. While many medical programs have recognised this narrow biological approach to patient care is unhelpful, arguably, nursing programs have responded earlier to place more emphasis on the psychological, social, and spiritual factors when attempting to understand why patients refuse treatment.

*I think most nurses do have a grip that death's normal and medical practitioners, being scientists, this doesn't necessarily allow them to see that there is a point where they need to stop pursuing science [and consider the person's alternative needs].* (Nse 03/18)

The educational models of the two groups studied provide diverse foci and this appears to influence their differing approaches to patient care. In adhering to the medical model, medical practitioners can narrow a patient's sources of knowledge and may ignore other considerations such as any value judgment a patient may make based, say, on spiritual beliefs (Briggs, 1995). In contrast, nursing models of health often encompass a more holistic approach; reflecting a patient's ability to interact with their wider environment.

#### **6.4.1.2 Educating colleagues, patients and families**

In the acute care setting, education occurs between the nursing and medical staff, and between staff and their patients and families. To engage in education is to provide information and instruction regarding a precise subject. The process might encapsulate intellectual, moral and social teaching and may be delivered in differing ways (Stein-Parbury, 2005). To be educated regarding an illness or procedure is to be well informed. From the perspective of patients or families this enables them to make their own choices and decisions in relation to treatment. For health professionals, education allows for enhanced clinical knowledge and also influences their future encounters with each other and those to whom they offer care.

The provision of information is exhibited in two distinct ways: the educating of staff and the educating of patients and relatives. In the present study educating in an informal manner is the most common method of exchanging ideas and knowledge. As care and treatment are provided, staff members are interactive, exchanging information, commonly from more experienced staff to the less experienced health professionals. In addition, there is a conspicuous form of educating that occurs when staff members spend time teaching patients and their relatives.

##### **6.4.1.2.1 More experienced staff educating less experienced staff**

The levels of experience of staff working in the hospitals in this study, span a continuum from less experienced, newly graduated nurses and medical staff, to the highly experienced and qualified consultants and nurses, in charge of the wards and units. In everyday clinical practice, informal education occurs regularly among these professionals. As they care for patients they invariably communicate their ideas and intentions to each other. Staff members who endeavour to address patient or relative concerns are, by demonstration, teaching junior staff how to deal with difficult situations, including breaking bad news.

*If I can't get anywhere [educating a patient] then I'll go and get Heather [the unit manager]. That's one thing Heather's good for, she's pretty good with her words. You should see her talking a patient into going to have a procedure that they're refusing and you're just kind of standing*

*there going, “Now why didn’t I think of that?” It helps me for the next time. (Nse 12/16)*

The existence of any barriers between the two professional groups is less evident in the process of educating. Senior nurses educate less experienced nurses almost as often as they teach and inform less experienced medical staff. Senior nurses who take a leadership role assist the junior staff with their ideas and knowledge, but also know when to direct junior staff to others for instruction. Senior nurses can unite the two professional groups by highlighting the importance of respecting what each group has to offer.

*... I had a doctor say to me earlier this week, “Oh we better withdraw that palliative [care] plan, he’s woken up, he’s looking at me!” ... I thought he’s [the patient] is looking at us because he’s uncomfortable ... and if we gave him appropriate medication he would not be uncomfortable ... but he was a relatively inexperienced member of the medical team. We [registrar and nurse manager] talked about it, I explained what was happening and then I was able to direct him to the doctor [palliative care consultant]. There was further detailed discussion then and there and he [registrar] understood after that. It was good. (Nse 03/18)*

Overall, the data highlight that more experienced staff undertake a great deal of informal teaching, and the teaching process transcends professional boundaries.

#### 6.4.1.2.2 The prevailing culture of the unit

The emphasis placed on educating staff varies considerably from unit to unit. While education is usually informal, there was one unit that explicitly identified the value of increasing the “know how” of its staff using a more organised approach. The consultant in the intensive care unit regularly held a series of formal colloquia, open to all hospital medical staff, to teach them how to communicate in situations requiring complex explanations and demanding decisions. The emphasis is to learn how to discuss illness, treatments and poor outcomes, with patients and relatives in ways that can be understood by non-health professionals. Medical staff members

learn to communicate bad news and discuss their approaches. Interestingly, there was an expectation that the registrars and residents attend, as it was stated that the consultants would not attend if they felt obligated to participate.

*... we use actors to play these [patient or relative] roles and to allow the doctors to use a number of techniques to talk about values and goals, rather than medical treatments ... [it is aimed at] all the junior doctors. ... The senior doctors come in and observe the junior doctors doing it, but they don't do it themselves because senior doctors would not come, but if they observe and listen to their junior doctors they may learn something ... it's a program which is a voluntary but they [medical staff] all recommend it to their colleagues. (Dr 014/19)*

The desire to encourage staff to engage beyond their technical skills relies to some extent on the prevailing culture of the particular therapeutic unit. In one hospital the palliative care team readily made themselves available to discuss concerns with ward staff regarding changing treatment and issues relating to patients who were not responding to therapy. This allows for additional perspectives and further discussion to canvas the current treatment plan.

*I use them [palliative care team] for education and insight; the palliative care nurses are really brilliant and often make suggestions we haven't thought of ... (Nse 10/23)*

Therapeutic units led by experienced staff members who openly address all possible patient outcomes, tend to be more readily prepared to discuss a broad range of issues with patients and relatives. For example, the prospect of a patient dying, when the patient or family has indicated a decision to refuse, or withdraw treatment, is not considered as an intractable position. It is viewed as a time to assess and discuss issues and consider the patient's or families vision, rather than a determination to impose a specific therapy.

*I think that [the decision to withdraw active treatment] is driven by two factors; one is the extent of the stroke and likelihood of recovery, and the*



*other is the expectation of the family [and the patient]. You may have two ostensibly similar patients with two different decisions. There is certainly no hard and fast rule ... (Dr 013/4)*

In other units and areas there is much less emphasis placed on encouraging staff to actively learn and share their ideas or thoughts. In these areas it might be assumed that teaching indirectly occurs in the process of providing care to patients. It was observed in these environments that there are fewer questions and less sharing of ideas amongst staff, knowledge appears restricted and consequently staff members are less likely to learn how to deal with patients and relatives.

#### 6.4.1.2.3 Staff educating patients and families

Patients and families require information that will assist their understanding of their illness and the associated therapies that accompany treatment, in order for them to make informed decisions. The provision of treatment for many disease processes requires numerous tests and procedures. It was observed that the medical staff tend to provide a broad explanation of what the disease process and treatment will entail. In contrast, the nursing staff, who have frequent and prolonged contact with patients provide key educative instruction; they make procedures understandable by creating a practical picture, often using examples of what patients or relatives might expect to happen.

*The patient refused then later on [after he] had spoken with another nurse who said to him, “You know, this is all that’s required [regarding the procedure], the jelco [she showed him the intra-venous catheter] and this and that”, to which he [the patient] agreed to continue on ... (Nse 10/2)*

Medical staff tend to provide education at strategic points of the patient’s hospitalisation. This may occur when a decision is required, either with the patient, or when relatives attend an informal meeting to be updated on the patient’s condition.

*I think just taking time out to explain to them [relatives] what's going on, the pathology process involved, which may include educating them that this has been building up over the years, not just in the last couple of days when they've [the patient] been admitted to the unit. I think that kind of education is very important in that situation. (Dr 015/8)*

When staff acknowledge the need and participate in the education of patients and relatives, they often provide a clear picture of what to expect regarding the disease or treatment and address fears, apprehensions or frustrations. Well educated and informed patients and families are better positioned to decide whether to continue to receive treatment, or decline treatment.

#### **6.4.1.3 Personal beliefs of nursing and medical staff**

The personal history and beliefs of staff also guide decisions made about patients. Staff members, particularly nursing staff, frequently refer to the beliefs of colleagues as a feature that impacts on the way patients are managed. If health professionals are uncomfortable with death or the dying process, there is a tendency to continue active treatment. In practice, the medical staff have ultimate responsibility for treatment plans provided for patients. The data illustrate that participants perceive that sometimes the personal beliefs of medical staff influence how long active treatment continues, or when a decision is made to withdraw life sustaining treatment.

*I think it has a lot to do with personality [of the medical practitioner] and particularly if they have issues with themselves, sometimes they don't want to ever withdraw or stop treatment. (Nse 16/10)*

*... refusal of treatment, it can depend on the doctor's viewpoint at a particular time ... (Dr 016/26)*

Some nurse participants raised concerns about the ability of some medical colleagues to step aside from their own beliefs regarding what treatment should be proposed. The need to consider patients' perspectives is identified as a factor not readily addressed in many areas of practice.

*... but they're so busy being doctors that they sort of have no idea what its like to be a patient. ... they're [medical staff] coming at it with their own agendas and their own feelings and their own ideas, but they don't sort of step back a lot of the time and look at it from, you know, the patient's point of view because they're too tired, too busy, they have to go and see the next patient, got to do this, got to do that. They spend their five or ten minutes with the patient and then that's it. (Nse 06/12)*

Moreover, some participants identified the need for staff members to be able to acknowledge personal feelings, which might be adversely impacting on their professional advice and practises.

*We had a cardiac surgeon who was difficult at the best of times ... but he became impossible for a period of months where ... you're faced with a patient who was basically alive only because they were on a ventilator, ... he would actually pre-emptively say to a family, "Now, in ICU if something goes wrong they'll try and give up, but you don't let them do that because its just what they do with everybody". ... he'd lost a parent in the preceding six months and it was probably part of his grieving process, but people don't declare [clarify] themselves ... (Nse 17/25)*

Staff who examine patients' decisions from a range of different perspectives seem more likely to accept a decision to refuse treatment.

*... it just depends on where we [staff] are ... and what the patient wants ... there are some members of staff that say, "If that was me, I wouldn't want this either". (Nse 05/5)*

In contrast, a different reaction occurs when a patient or family member refuses treatment the health professionals believe to be in the patient's best interest. The data highlight that staff attempt to understand a decision to refuse therapy however, their reactions might adversely influence the patient-practitioner relationship.

*I get very frustrated at times especially when I just can't see the logic behind their [patients] thinking and their reasoning behind things, I get very frustrated. I try to reason with them and then I sort of get to a point [and say to myself], "Okay I've got to leave the room now". (Nse 08/7)*

Participants acknowledge that the personal beliefs of individual colleagues can and do shape decisions. Although, it seems that there are few opportunities or processes in the working environments studied, to encourage the personal concerns and feelings of staff to be expressed.

#### 6.4.1.3.1 The 'quality of life' explanation

When staff describe their justification for supporting a decision to refuse treatment or a decision to withdraw treatment, they often make reference to the "quality of life" the patient will retain.

*... if someone refused treatment and I felt it [treatment] was going to be detrimental and they had a low quality of life, I suppose the quality of life is what I always look at when people refuse treatment; but if they've got a full quality of life and they've refused treatment, I suppose I would probably start to talk to them about why I felt the treatment's necessary. (Nse 02/11)*

Consideration of the patient's "quality of life" was a recurring theme. Participants who used the phrase were asked to describe what they understood it to mean. The number and type of physical and mental restrictions patients might have following treatment, and the degree to which patients are willing to accept these limitations, are relevant components of what is understood by "quality of life".

*... they [the patient] will stay in bed all day; they may need to be kept on naso-gastric feeds or peg feeds; they can't walk, they can't talk, they can't eat. For me, that's absolutely no quality of life whatsoever ... I know people that have problems speaking, or probably don't have much vision, they can sort of walk but they are still able to get on with life, like their life is changed, but they still have some quality of life. They're still*

*able to ... see friends and family and go down to the shops ... they're not stuck in bed. (Nse 08/11)*

Participants concede that while there might be broad agreement about the phrase “quality of life”, patients should ultimately, be able to decide. However, the extent to which treatment is pursued largely rests with the consultants who make the decisions, which may be based on their personal beliefs.

*I guess that probably you are not the judge of their quality of life, ... but everybody has a different view of, at what point you stop, and that's based on your background, what you brought to the whole thing, but you know the consultants are the ones making the decisions ... (Nse 17/11)*

While health professionals may believe that it is in the patients' best interest to accept treatment, patients sometimes view the process of undergoing therapy as detrimental to their wellbeing. Some patients prefer to reject therapy and make the decision to live with the illness.

*I mean we thought that she would have a better quality of life by having the treatment, whereas for her the treatment was worse than the disease. (Dr 015/2)*

Overall, even though “quality of life” is a complex issue, in this study it is a concept considered relevant by many health professionals. It can be utilised by some participants to assist their own value judgements regarding patient outcomes, but it also appears to play a role for patients and relatives who make a decision to refuse therapy.

#### 6.4.1.3.2 Fear of legal scrutiny

There is some disquiet that intrusion of the law into clinical practice and concern about possible litigation might influence decisions, when proposed treatment is not pursued, particularly when treatment is withdrawn, even when it is clear that the patient is dying. This is evidenced below, when reference is made to death arising following surgery.

*A surgical patient who was severely ill and really ended up spending six months in ICU [intensive care unit] because the surgeon would not at any time withdraw or even look at withdrawing treatment. I guess we have seen it here too, the surgeons they're very much, "We will go to the end" ... if they die within their [surgeons] care they're often a coroners and that's what they do to make sure that everything is done right. I guess that would be a fear. It does drive a lot of medical decisions in all the things that we do. (Nse 16/10)*

In addition, occasional threat of litigation by patients or relatives galvanise staff into making certain decisions, such as prolonging treatment, and ensuring that all aspects of care are thoroughly addressed. If a patient or family member threatens litigation, staff are inclined to be more cautious. For instance, they take steps to make certain that the explanation is complete and the most senior consultant is included at every stage of the decision making process.

*She [the patient's wife] was saying, "I'm going sue you ... I'm going to do this" ... and so I had tried [to explain to his wife] and I realised that I wasn't going to get very far ... I thought, I need to get the consultant involved because, you know, she sort of had that high level anxiety and I couldn't provide all the answers and that situation couldn't be left [unresolved]. (Dr 012/9)*

Participants expressed concern when situations arise where their conduct might be scrutinised, particularly by external authorities such as the courts. There was a general unease or discomfort demonstrated and acknowledged by some participants that such inquiries did impact on their behaviour and clinical practice.

#### **6.4.2 Patients and families**

Health professionals acknowledge that the underlying beliefs, and the behaviour of patients and families, influence their treatment decisions. It is common for family members to be involved with patient treatment decisions, even when patients are able to decide for themselves. Several topics were described by participants which, they

believed, had some bearing on the conduct of patients and family members when therapy was refused. This, in turn, impacts on how they are subsequently treated.

#### **6.4.2.1 Assertive versus passive behaviour**

Patients, particularly older patients, are considered by staff members to exhibit a number of traits when they are receiving treatment. Staff described patients to be vulnerable, respectful, wanting to avoid conflict and fearful, when they are being treated in the acute hospital system. These qualities render many patients passive contributors to the whole decision making process. They are less likely to ask questions when they are unclear or concerned about a proposed treatment or procedure. This can have the effect of contributing to a decision to refuse therapy, or patients can be swept along, never quite participating in the entire process.

*A ninety-two year old, doctors wanted to do an ileostomy [operation in which the ileum is brought through the abdominal wall] and she says, “Do you think I should have it, do you think they [medical staff] will be mad with me if I don’t have the operation?” They [patients] see the doctors on a hierarchy, they [patients] think the doctors know what’s best ... like this is the right thing to do, forgetting to take into account what they may want. (Nse 13/3)*

If patients are less inclined to ask questions of the medical staff, there is considerable evidence that they might defer to the nursing staff.

*... so they [patients] won’t question a doctor but they are willing to question nursing staff and say, “Well, what about this, this and this?” I think a lot of the time we [nursing staff] act as a liaison between the patient and the medical staff when it comes to refusing different interventions. (Nse 07/7)*

Conversely, assertive behaviour has the effect of ensuring that staff are alerted to patients’ or families’ wishes. Patients and families who insist that treatment take a certain direction or make a specific decision, frequently have their wishes followed.

*We had this lady in who had a massive stroke, but her husband wanted aggressive treatment to continue; the doctors talked to him [to explain her bleak situation] but they complied with his requests anyway. (Nse 12/8)*

However, the data show that it is more commonly relatives who articulate their wishes for therapy to continue, when patients express a decision to the contrary.

*The husband wanted us to treat his wife, even though she didn't want it; he got his way. It was easier to say she wasn't competent. (Nse 08/11, 12)*

The consequential behaviour of the health professionals is to justify the continuation of therapy, despite patients' preferred wishes. This is because relatives can be highly influential, persisting with their personal views, compared to patients who are generally less capable, due to their illness state. Thus, in some circumstances when discharging their responsibility, participants feel obliged to defer to the wishes of relatives.

*I've seen patients who have stayed with us, in the unit for weeks longer than that patient would've liked, because the families haven't come to terms with their [the patient's] condition, but I also keep in mind that we're not just treating a patient, we're actually looking after their family as well ... (Nse 17/5)*

The patients' or family members' behaviours can escalate from assertive statements to making threats, if they become frustrated when they are striving to have their wishes understood. This tends to generate an instantaneous response from staff members as they become rapidly focussed.

*The patient said, "I don't want this; I can leave whenever I want; I know that I can sign myself out," and for us [staff] that was like, "Well, if you do you're not going to get the treatment you need" ... for him [patient], that was a way to get us [nurses] to listen to him and get the doctors to listen to him ... " (Nse 08/3)*



Passive or assertive behaviour can impinge on decisions about therapy. When patients assert their wishes it could be considered a favourable trait, to be exercising their autonomy, although, as the above excerpt illustrates, it can lead to a premature ending of the patient-practitioner relationship. The data suggest that there are more instances of assertive behaviour emanating from health professionals.<sup>60</sup> It appears this behaviour has the effect of ensuring treatment continues for longer, beyond the wishes of the patient.

#### **6.4.2.2 Idealistic views**

For many patients and family members, the thought that therapy might be of limited value can be overwhelming and unacceptable to them. The data suggest that patients' and relatives' expectations are that the outcomes of modern health care will, in most instances, be successful.

*I think the general public still think that everything happens like it does on TV, where success rates of interventions are much, much better ...*

(Dr 013/6)

Many participants acknowledge that the possibility of a patient dying is an everyday clinical reality. For many patients and their families death is considered as a failure in the standards of care provided by the health professionals. This view raises concern for some clinicians as they recognise the need to offer hope but also to be honest about possible outcomes.

*... on the whole, the values and beliefs systems that are out there in the community are, I mean, death is just not seen as natural. The community thinks that death is to be avoided at all costs and they don't accept that death is a normal part of life and that there does reach a point where death will actually occur whether medical science agrees with it, or predicts it or not, and that's normal.* (Nse 03/19)

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<sup>60</sup> See Chapter 11, Influencing.

When patients are critically ill, staff members might suggest that active treatment is unlikely to be successful and families are informed about the alternative of being given palliative care. However, family members are frequently unaware of what the therapeutic units actually do, or what care and treatment entails. The excerpt below, highlights the misconceptions held by some family and friends when the therapy plan is not sufficiently explained.

*Staff members were called “Murderers”[by some of the patient’s visitors] for withdrawing [active] treatment, at the [immediate] family’s request. (Nse 05/3)*

Many participants recognise the unrealistic beliefs held by some patients and relatives. This can create difficulties for staff if these perceptions are not addressed in a sensitive but objective manner. On the one hand, they seem to be supportive, offering hope, conversely, they attempt to identify and dispel unrealistic beliefs.

#### **6.4.2.3 Expectations regarding decisions**

Health professionals must have insight into the varying perceptions of patients and relatives, including religious and cultural beliefs. For example, in some cultures relatives believe that relevant information and subsequent decisions are the realm of the family (Cox et al., 2006). This places participants in the position of having to maintain a sense of balance between patient and family input. Health professionals are primarily responsible to their patients, nevertheless family can assert influence on the patient, which makes the ensuing treatment decision onerous for everyone involved.

*They [family] didn’t want her [patient] to know that she was coming to a palliative care unit; it’s part of their background that they didn’t want her to know exactly what was happening to her. It was a cultural thing, and yet several family members weren’t actually aware of what palliative care was and then they wanted active resuscitation to be given; it was difficult for us [staff members]. (Dr 012/4)*

Family members commonly consult with health professionals in decisions about who can refuse or withdraw treatment for the patient. Some relatives mistakenly believe they have a power of attorney, which enables them to make decisions and take control. The data reveal that few patients or relatives have a clear understanding of the various types of substituted decision making and the scope of these powers. At times this results in conflict in the family.

*... that power [of attorney] was for the money side anyway, but the family thought that they had the medical side as well and they weren't happy about it when they found out. (Nse 12/23)*

When staff members are attempting to identify the next of kin to involve in decisions, they are sometimes confronted with problems and uncertainty among family members. This occurs in circumstances where relatives are unaware of patients' wishes, or family members do not communicate with one another. These situations create further difficulties for staff members, in an already stressful situation.

*We [staff] say "O.K. who is the next of kin, who is down [recorded in the patient file] to actually make these decisions, who are we going to talk to?" Because quite often where you've got four or five different people from one family, we will say "X" was told and they will say "No, I don't talk to them!" (Nse 08/13)*

Difficulties also arise when family members disagree about the way forward with patients' treatment. Some try to influence the patients' decisions, particularly when patients are very ill they can be vulnerable to any pressure. This can impede the decision-making process and subsequent care.

*... you will sometimes get family disagreements; different family members, siblings, having different opinions and a patient who is totally competent fluctuates because of the different influences from the family members. (Dr 013/4)*

When confusion about patients' and relatives' input into decisions is present, there is a possibility that a negative relationship between staff and families, will result. This can impede patient, family and health professional relationships at a time when critical decisions are required. It can also leave long-term pessimistic impressions on the hospital experience for patients and family members, who might later make a complaint to either the hospital or the Health Services Commissioner.<sup>61</sup>

*I think sometimes families feel like, "Oh, every one's against us."*

(Nse 8/10)

For health professionals the focus is primarily on the provision of therapy and care. Consideration as to the roles and responsibilities of others, such as relatives, can be poorly understood and consequently inadequately addressed.<sup>62</sup>

#### **6.4.2.4 Patients communicating their wishes to family**

The data demonstrate that communication from the patient to their family can assist the decision making process. When family members have ascertained the patient's beliefs and perspectives about care and outcomes, it is easier for everyone involved to reach a decision.

*If patients thought about the sorts of treatment they would want it makes it so much easier for staff, than to let the staff make the decisions.*

(Dr 012/12)

Participants identified it was common for many patients to postpone discussions about treatment preferences and possible outcomes until such time a decision was actually required. Nonetheless, the data reveal participants prefer to have some indication into the patient's wishes. When this information is not forthcoming, for

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<sup>61</sup> The Office of the Health Services Commissioner is an independent statutory body specifically established to receive and investigate patient complaints, and make recommendations to improve the delivery of health services in Victoria (Wilson, 1999).

<sup>62</sup> See 6.5 Legal and Ethical Frameworks, the legal and ethical responsibilities placed on health professionals require them to have sufficient knowledge of who can make decisions regarding therapy.

instance, because the patient becomes legally incompetent and the family are upset, or lack insight, then treatment decisions are more difficult to ascertain, and can result in prolonged or unnecessary treatment.

*... the difficulty I think ... is that at a very early point most elderly patients take the view that they'll leave it until the time comes to make a decision because, "I'll know the circumstances and I'll know the context at that time". ... But of course if you decide to leave it until the time comes, ... it may be too late to say anything and perhaps there is a need to make some global comments about scenarios beforehand, so that if it [the illness] catches up with you, we've got some concept [of what is preferred]. (Dr 014/3)*

Decisions are more straightforward when patients have had a prior discussion with a relative or someone close to them. This is helpful to staff in situations where the patient is unable to participate in the decision and one or more family members are aware of the patient's beliefs and wishes. This is shown below, when a young patient had previously discussed his wishes with his de-facto wife and then the family were required to consider whether to withdraw treatment or continue with a severely brain damaged patient following a sudden accident.

*... they [patient and his partner] apparently had a discussion amongst themselves ... they [patient and his partner] didn't ever want [him] to be kept alive if ever something [like this] happened ... so they [the family] discussed this and they all felt that they just couldn't see him be anything other than what he was [before the accident] and he wasn't going to ever be that, so that's the way they made the decision [to withdraw life support]. (Nse 16/6)*

There is a wide range of beliefs held amongst staff, patients and families, and each group has the ability to effect the progress and type of outcome patients may experience. Outcomes are often determined according to the abilities of health professionals to guide, support and dispel improbable myths.

## 6.5 LEGAL AND ETHICAL FRAMEWORKS

The legal and ethical principles that direct the conduct of health professionals are an important determinant of practice. Legislation in Victoria, which addresses refusal of treatment, and codes of conduct for nursing and medical staff, guide practice and impact on professional conduct, including the process of decision-making in the area of refusal of treatment. In addition, hospitals create policies, which staff are expected to abide by in everyday clinical practice. The policies are commonly designed to provide guidance about expected standards of practice in precise circumstances.

### 6.5.1 The legislation

The *Medical Treatment Act 1988* (Vic) (MTA) establishes the principles, which enshrine a legal right to individuals to refuse medical treatment. The legislation allows a competent adult<sup>63</sup> (hereafter referred to as patient), to specify when medical treatment is unwanted (MTA, Preamble, 1), or when an attorney (also called agent) is deciding on behalf of an incompetent patient (MTA, section 5B(2)). Medical treatment the patient can refuse is defined broadly to include: an operation, administration of a drug or any other medical procedure (MTA, section 3). However, a patient cannot refuse palliative care, which is defined in the MTA and includes the reasonable provision of food, fluid and pain relief (MTA, section 3). The MTA is designed for the patient or attorney, to be cognisant of the medical diagnosis of the patient, before providing direction as to unwanted treatment. A medical practitioner must therefore record the patient's diagnosis on the MTA Schedules One and Three. This is an attempt to ensure that sufficient information is provided, regarding the specific illness, before a decision is made as to the direction of care.<sup>64</sup> A further safeguard was built into the recording of such important decisions and that involves the need for the Schedules to be witnessed by a medical practitioner and another person (MTA, sections 5(1) & 5A(2)(a)).

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<sup>63</sup> The MTA section 5(1)(d) states that the patient is of sound mind and has attained the age of 18 year. A sound mind refers to the capacity of the patient to make a decision to refuse therapy and requires the patient to understand the nature and effects of a decision (Collier, Coyne & Sullivan, 2005).

<sup>64</sup> The MTA refers to a 'current condition' referring to a patient's diagnosis (MTA, section 5(1)(a)).

The MTA enables a competent adult or agent to specify refusal of treatment “specifically” or “generally” (MTA, sections 5(1)(a) & 5B(1) (a)). This enables competent patients to identify detailed treatment or procedures, or record in broader terms, the types of treatment or procedures the patient would not accept. The competent adult patient can also specify the limits to palliative care that would be personally unacceptable. This permits the patient to delineate the boundaries of the medical intervention. For example, a patient could refuse the insertion of a nasogastric tube, an intravenous line, or percutaneous endoscopic gastrostomy (PEG) tube, all interventions which provide hydration and nutrition to patients who can no longer take fluids orally.

The MTA also allows for a competent adult (the patient) to appoint another adult, as an attorney,<sup>65</sup> also called an agent (proxy decision maker) by way of a Schedule Two. The agent is meant to consider the patient’s perspective when deciding to reject therapy, in the same manner in which the competent adult can when using the Schedule One.<sup>66</sup> The agent’s power comes into effect when the patient becomes incompetent and the scope of the power allows the agent to decide to refuse treatment, including withdrawing medical treatment, even if death will occur. The agent may only refuse treatment on behalf of the patient when it would cause unreasonable distress to the patient, or there are reasonable grounds for believing the patient would consider the treatment is unwarranted (MTA, section 5B(2)(a) & (b)). Most importantly, the legal authority of the agent’s decision takes priority over any family or next of kin and allows the agent to legally refuse treatment, or make the decision to withdraw treatment.

### **6.5.1.1 Knowledge of policy and law**

Participants mentioned medical powers of attorney however, their answers demonstrated that few of them had sighted the relevant documents (Schedule Two, the appointment of the agent), or were familiar with any of the schedules in the

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<sup>65</sup> Schedule Two is an enduring power of attorney (medical treatment) and is commonly referred to as a medical power of attorney. See Appendix 2.

<sup>66</sup> The proxy decision maker must complete a Schedule Three. See Appendix 3.

MTA. It seems that staff members often take relatives' statements on face value. When relatives state they have a power of attorney participants do not usually ask what type of power it is, or they rely on someone else to check the power. Some nursing participants indicated that it was left to the social workers to "sort out". Only two senior medical staff members demonstrated clear understanding and some experience with the documents. The excerpt below highlights a registrar's experience with a power of attorney.

*I must say I don't, I don't know. I mean, usually I've taken it ... it's been presented as a factual piece of information. Obviously, when it comes to the crunch and you're making possible life and death decisions with treatment you should know. ... On one occasion a power of attorney turned out not to be really a medical power of attorney so, perhaps I should change my practice ... and find out what I need to look for.*  
(Dr 016/9)

Hospitals use written policies to provide guidance to staff about a wide range of procedures. Hospital policies usually reflect existing legal principles. The data reveal that relevant hospital policies exist, but they relate to two very specific situations. The first policy involves circumstances when patients decide to refuse all treatment and want to discharge themselves. This policy is focused on the patient leaving the hospital premises, contrary to the opinion of the treating health professionals. The second policy relates to the narrowly defined circumstances where a decision is made not to actively resuscitate the patient. This latter policy details a not-for-resuscitation (NFR) order and refers to the situation generally, where cardio-pulmonary resuscitation will not be attempted by staff should the patient's heart stop.

The participants discussed examples of situations in which the two policies are relevant. The data did not highlight policies relating to patients refusal of treatment in any other situation. When patients decide to refuse treatment and discharge themselves, staff identified a precise document and process that was to be followed. The emphasis was on the practice of staff to obtain a patient's signature on a form, or document the situation, clearly stating the patient is leaving the hospital against the



advice of the staff. There is no requirement for staff to demonstrate, in writing, how the patient's refusal was actually managed and what discussion ensued.

In relation to situations where a NFR order was made, the medical staff are required to document the order. In the high acuity units the senior consultants take responsibility for this type of order, whereas in the wards this is usually a role for registrars.

*The registrar can do an NFR order here. It would probably be discussed on the [ward] round or in a meeting and it would be up to the registrar to actually document it. (Nse16/15)*

It was observed that the documenting of such order commonly involved writing the phrase "Not for resuscitation" in the patient's file, sometimes on a specific form,<sup>67</sup> together with the signature of the medical practitioner. Observation of numerous patient files revealed that there was very little written on this document or elsewhere in the patient's file about the decision. Despite participants frequently discussing and dealing with not-for-resuscitation orders, the data illustrate experience and knowledge of the relevant hospital policies and existing legal principles is generally deficient and there is minimal documentation to accompany the decision.

*I think because there's no set policy on what is and is not an NFR order ... there is no form for doctors within the hospital, to fill out. It's just written on the alert sheet in front of the history so there's no guidance for them as to what you write or what discussion has taken place with the patient. (Nse16/14 +15)*

*I don't know what's required in this State [Victoria], actually ... (Dr 012/12)*

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<sup>67</sup> A standardised form is pre-printed by the hospital and used specifically to document an NFR order, it might complement clinical notes made in patients' files.

Many participants were unable to confirm knowledge regarding the existence of a policy or legal principle that guides practice. Nevertheless, they were able to describe what actually happens in the clinical setting.

*We document it [the decision] if they [patients] do refuse it [a treatment or procedure]. Sometimes if they [patients or relatives] make the decision themselves, then we document that and ask them to sign that.*

(Dr 011/19)

Practice dilemmas arise when staff members are unable to plainly express the expectations of policy or law and there is an absence of clear guidelines from the hospital. Health professionals devise their own systems, the problem arising is that each therapeutic unit might determine its own practice, and this is likely to change from one unit to another.

*Up until last year the ward staff used to put coloured dots [on the patient list] beside the patient's name if they were not-for-resuscitation. Well that is fine for one ward where they used, say red [dots], but if you went to another ward, that same colour dot actually meant the patient was private [pertaining to insurance]. If you had graduates [junior staff] running between them [the wards] you'd have some that thought that means they're [patients] not-for-resuscitation, when in fact they're just a private patient. (Nse 16/15)*

The data demonstrate that only a few of the most senior nursing and medical staff were able to communicate a clear understanding of the appropriate legal principles that might apply when a patient was refusing treatment. In one hospital the admission documentation required staff members to indicate whether a patient had completed a power of attorney however, the patient files failed to distinguish whether the document was indeed a medical power of attorney.<sup>68</sup> There was merely a tick in a

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<sup>68</sup> In Victoria a legally competent adult can complete three different powers of attorney. Only one, the enduring power of attorney (medical treatment) relates to medical decisions. The remaining two powers relate to the business and financial affairs of the donor and are referred to as power of attorney and enduring power of attorney. There is no reference made to 'medical treatment' in the title of these documents.

designated box labelled “Power of Attorney”, on the patient’s admission document. This is clearly problematic when staff members generally do not recognise the existence of different types of power of attorney and therefore, are unable to distinguish between them. This problem might also exist because in the two hospitals studied, few patients arrived with a medical treatment power of attorney. Therefore, health professionals were not often required to deal with them, as the excerpt below reveals.

*Medical powers of attorney, about 90% of the cases you have nothing, no direction, there’s your dilemma. When you look at it, who has the right to say don’t go ahead? I’m not sure, really. (Nse 10/14)*

The participants with the clearest understanding of powers of attorney and the associated legal principles regarding a patient’s right to refuse treatment, were identified as those members who tend to deal with palliative care or intensive care patients. Staff in these therapeutic units frequently address decisions relating to withdrawal of treatment and managing dying patients however, these decisions are also highly relevant to the decisions made in many other therapeutic units.

*There has been little or no uncertainty in palliative care or palliative medicine as to what the law meant and the fact that artificial nutrition was medical treatment, and as such can be refused, by a competent patient or by the person who has the [medical] power of attorney. (Dr 013/7)*

However, the senior staff with knowledge of policy and legal principles did acknowledge that there are many staff, both senior and junior, who have little understanding of the area.

*Yes, there is a lot of misunderstanding, even in terms of the act [MTA] and palliative care, and the definition of palliative care, which was clarified three years ago in the BWV case. (Dr 013/6)*

In addition to the two hospital policies identified above, the intensive care unit had, after a legal problem arose, discussed the lack of clarity of practice, including the

requisite documentation, in situations where withdrawal of treatment from patients occurred. Senior staff working in this unit explained that they had tried to seek guidance and information from other hospitals and sources however, the information and practices were unclear. The senior nursing and medical staff recognised the need for a well-defined process when treatment was withdrawn from patients. They sought to identify the key legal principles and developed their own policy to guide clinical practice.

*In ICU [intensive care unit] we have a withdrawal of treatment guideline so the doctors actually have to go through a process, through the form basically: has this and that been done and so on, and it has to be worded in a certain way so that there is clarity for everybody. (Nse 17/16) ...*

This issue led staff in the same unit to further consider the area of patient refusal of treatment. The result was the identification of the schedules in the Act which were then posted on the hospital's intranet system.

*We've also made the refusal of treatment document [Schedule Two] a lot more accessible ... for nurses and medical staff ... it's not impossible to locate now ... but there was no policy on how to use it, but that has changed now ... (Nse 18/19)*

Nevertheless, many participants were uncertain as to how the relevant policy was to operate in practice, indeed in many cases staff were unsure of the precise content of the policy. In the absence of policy knowledge, participants were keen to describe what actually occurs in clinical practice. There was even less evidence of knowledge or understanding of the relevant legal principles in situations where refusal or withdrawal of treatment occurred. There is an expectation the senior staff will know and provide direction, although it was observed that many senior nurses and medical practitioners do not raise or discuss legal principles or policies relating to the Act, indeed many were not well versed with this area.

### **6.5.1.2 Recording outcomes**

The patient file provides the means by which health professionals can provide a record of care and treatment to patients. Health professionals have both professional and ethical responsibilities to create and maintain accurate records in relation to treatment and care provided to patients (Forrester & Griffiths, 2005).<sup>69</sup> Therefore,

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<sup>69</sup> The Australian Medical Association Code of Ethics (2004) 1.1 (f) requires that medical practitioners 'maintain accurate contemporaneous clinical records'. For nurses the writing of patient records is an integral part of a nurse's work; they should provide an ongoing account of the patient's healthcare experience and may be used in civil or criminal proceedings as evidence and as such must meet the standard expected of them (Staunton & Chiarella, 2008).

refusal of therapy decisions, because they can alter treatment plans, should be reflected in the file. The current study included examination of patient files in an effort to observe participants' common practice in this area. It was found that the methods used to record a decision vary in relation to therapeutic units. Documentation is dependent on the usual practice of the unit, the individual staff member and the emphasis placed on various conversations between participants and patients or relatives. Since medical staff members ultimately order therapy it is an expectation that the responsibility to record decisions, including refusal of treatment, rests with them. In some units this is visibly evident nonetheless, the amount of information recorded varies considerably. For example, when a decision is made to withdraw treatment in one unit, there is a documentation protocol followed by medical staff.

*... the consultants have to document everything that is said at that family meeting; they outline who was present, what was said and what the plans are, so we're [staff] all very clear. So when we get onto the computer [to read the patient notes] there's a section there that talks about family meetings and we can all be very clear of what the outcome of that family meeting was. (Nse 18/16)*

However, in most units the everyday conversations staff have with patients and relatives are commonly not documented in patients' files. Only requests perceived by staff to be important or relevant are documented. This ensures that staff members' perceptions of what is important determine what information is recorded. Patients may request a change of treatment or clearly refuse a procedure and the outcome might be recorded, sometimes in the absence of the rationale. Nursing staff will commonly verbalise the patient's request to medical staff, but it is only when the patient or relatives make repeated requests that this information is documented. The details of the discussion and reasons for a decision are not usually included; merely a notation is made that there is a change in the treatment plan. In some units more detailed documentation is encouraged, but this varies greatly.

*... if there is a family meeting or discussion around the patient's bed, then I think it's either the social worker, or if they were there [medical staff] they'll put "family meeting, such and such a time, this was discussed and this was what was decided or what the family decided".*

(Nse 08/11)

Hospital protocols exist for "not-for-resuscitation" decisions and when patients discharge themselves against medical advice.<sup>70</sup> Where pro-forma documents exist, which is the case for NFR decisions or premature discharge scenarios, the tendency of staff is to make a brief notation. For instance, medical staff write "not for resuscitation" and then provide a signature and date, demonstrating which staff member had been involved with the decision. There is scant information about the actual decision, which individuals were party to the conversation, and why or how the decision was made.

*They'll [medical staff] usually write it [NFR] in the history; it depends on the medico [medical staff member] how much info is written, usually it's not a whole lot.* (Nse 12/13)

Other situations where patients or relatives refuse treatment are not addressed by protocols. Where patients or relatives have made requests not to proceed with specific therapy, this is not always documented. The recording of information varies and the degree of detail is largely dependent upon the individual staff member's preferences. For instance, repeated requests by patients or relatives might be recorded, but only when staff believe these wishes should be brought to the attention of senior medical staff. When a final decision has been reached, for example, a change from therapeutic interventions to palliative care, a notation will be made in the patient file. This entry in the file will usually be brief and might only note the referral from one therapeutic unit to another.

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<sup>70</sup> Although, one unit had in recent times, also implemented a policy on how to document withdrawal of treatment decisions following an incident which triggered a coronial inquiry. The staff in the unit believed that a written policy might prevent a similar incident from reoccurring.

## **6.5.2 Ethical standards for practice**

Medical practitioners and nurses are professional groups with established codes of ethics. The Australian Medical Association (AMA) and the Australian Nursing and Midwifery Council (ANMC) respectively, are responsible for these codes. Both organisations are nationally based and represent the broader medical and nursing professions in a range of policy and ethical opinions. Codes of Ethics are seen to articulate and promote a body of ethical principles to guide professionals' conduct in their relationships with patients, colleagues and society (Staunton & Chiarella, 2008).

### **6.5.2.1 Medical practitioners**

The AMA Code of Ethics (Code) is a voluntary guide to its members. The AMA Code originates from other similar codes stretching back to the Hippocratic Oath (Australian Medical Association, 2004). There is no legal enforceability to the AMA's Code and medical practitioners do not have to be members of the AMA to practice medicine. However, by becoming members of the AMA, medical practitioners agree to abide by the Code. Nevertheless, the Medical Practitioner Boards in each state and territory, with whom all medical practitioners must be registered, have the power to deal with any breaches of medical misconduct and the Code represent a key testimony of expected behaviour of the profession. The Code also serves to inform the public of what expectations they should have of their medical practitioner and the profession as a whole. Therefore, it is a professional expectation that medical practitioners are well acquainted with the Code.

The AMA Code (2004) establishes four broad sections that are further divided into several statements of principle. There are several statements identifying doctors' responsibilities to their patients regarding the patient's role in decision-making and the requirement for doctors' knowledge to be current. For example, section 1 – The doctor and the patient, includes the following: “Respect your patient's right to choose their doctor freely, to accept or reject advice, and to make their own decisions about treatment or procedures” (AMA, section 1.1(k), 2004). section 1.4(b) of the Code states “Respect the patient's autonomy regarding the management of their



medical condition including the refusal of treatment” (AMA, 2004). Further  
guidance is

provided to the expected level of knowledge of doctors in section 2.1(g) which maintains “Keep yourself up to date on relevant medical knowledge, codes of practice and legal responsibilities” (AMA, 2004).

#### **6.5.2.2 Nurses**

There is abundant guidance relating to practice for the nursing profession. Nurses in Australia, just like their medical counterparts, are regulated and accountable to the community for providing safe and effective work practices. The state and territory nurse regulatory authorities set standards of competence that describe the expected standards of practice in addition to codes of ethics and conduct. The Australian Nursing and Midwifery Council (ANMC) comprises representatives from each state and territory and provides the framework for national standards. This includes the ANMC National Competency Standards, the Code of Ethics, and the Code of Conduct for Nurses in Australia. The ANMC reflects the position of the Australian nursing regulatory authorities and all nurses must be registered with a state or territory regulatory authority.

The Code of Ethics for Nurses (ANMC, 2008) is designed to identify the fundamental moral commitments of the profession and provide a basis for conduct of members of the profession. The Code is used as a guide to ethical practice and indicates to the community the moral values which nurses can be expected to hold (ANMC, 2008). It specifically recognises the rights of individuals to make informed choices in relation to their care (ANMC, 2008, Value Statement 5). This statement requires nurses to recognise and respect the rights of patients to engage in shared decision making when consenting to care and treatment. Nurses should value and facilitate the role of others, including family, when the patient’s ability to contribute is impaired (ANMC, 2008, Value Statement 5, sub-section 2). Moreover, the Code refers to “respecting the individual ethical values people might have in the context of health care” (ANMC, 2008, Value Statement 2). It is very clear that nurses have a moral obligation and a legal responsibility to have knowledge of the existing legal principles and relevant policies, in addition to fulfilling the competency standards and codes of ethics and conduct.

The Code of Conduct for Registered Nurses (ANMC, 2008) contains several statements that might apply to the practice of nurses when patients refuse treatment, where harm may result to the patient. For example, Conduct statement 1 states: A nurse must practise in a safe and competent manner (ANMC, 2008). This includes participation in ongoing professional education to maintain and upgrade knowledge and skills relevant to practice in a clinical setting. The standard also specifies that the nurse's scope of practice is based on each nurse's education, competency and lawful authority. Conduct statement 3 unequivocally states that nurses must practise and conduct themselves in accordance with laws relevant to the profession and practice of nursing (ANMC, 2008). This requires nurses to be familiar with relevant legal principles to ensure that they do not engage in practices prohibited by law, or delegate to others, activities prohibited by law.

Further guidance is provided by the ANMC competency standards, which have been widely accepted and incorporated into Australian undergraduate nursing education programs. The standards are utilized to determine levels of safe clinical practice. The standards for registered nurses also clearly specify that nurses are required to demonstrate knowledge of legislation and common law pertinent to nursing practice, and display a knowledge of policies and procedural guidelines that have legal implications for practice (ANMC, 2006, Competency section 1). Given the existing law in Victoria and the hospital policies, it is a professional expectation that nurses have an understanding of the rights and responsibilities of patients, and the ability to ensure that their professional practice aligns with expected standards.

## **6.6 SUMMARY**

This chapter has identified and explained the three contextual determinants: *The Context of Work, Beliefs and Behaviours*, and *Legal and Ethical Frameworks*. The determinants establish the overriding framework in which the interactions of nurses and medical practitioners occur as they manage patient and family decisions to refuse therapy. They provide insight into the environment in which nurses and medical practitioners work and interrelate. The determinants also provide the setting in which the basic social psychological process and categories develop and these will be discussed respectively, in the following chapters.

**CHAPTER 7**  
**CORE CATEGORY**  
**ENDEAVOURING TO UNDERSTAND REFUSAL:**  
**AGREEING ON A WAY FORWARD**

**7.1 INTRODUCTION**

The basic social psychological process utilised by participants to deal with issues associated with patients with serious illness who refuse treatment, was identified as *Endeavouring to Understand Refusal: Agreeing on a Way Forward*. This process is a response to the basic social problem, *Competing Perspectives: Encountering Refusal of Treatment*, which represent the paradoxical points of view and the interplay between patients, relatives, nurses and medical staff as they grapple with refusal of treatment decisions. In this study the core category overarches the existing processes identified in the four interrelated categories of *Seeking Clarification, Responding to Patients and Families, Advocating, and Influencing*. Moreover, the three themes identified in the contextual determinants *The Context of Work, Beliefs and Behaviours, and Legal and Ethical Frameworks* moderate the way nurses and medical practitioners deal with patients' refusal, and directly and indirectly influence their interaction. Together, these factors underpin the theoretical framework, which seeks to explain the process entailed in the core category of *Endeavouring to Understand Refusal: Agreeing on a Way Forward*.

This chapter will explicate how the core category overarches and embodies each of the categories to a greater or lesser extent, to form a series of transitions. The core process is found to comprise three identifiable transitional themes and these manifest in a variety of contexts. The transitions do not always unfold in a linear progression; rather the identified behaviour can encompass elements of one or more of each transitional phase at any given time. The three transitional themes include:

- (i) *struggling to come to terms with the centrality of patient self-determination,*
- (ii) *responding to the dynamics of patient and family interactions, and*

(iii) *changing the terms of reference: from the illness to the person.*

The following discussion will provide an overview of the core category and then highlight each of the three transitions.

## **7.2 ENDEAVOURING TO UNDERSTAND REFUSAL AND AGREEING ON A WAY FORWARD**

*Endeavouring to Understand Refusal and Agreeing on a Way Forward* is undertaken partly as a consequence, and partly as a solution to the health professionals' concerns when dealing with patients and relatives who have refused therapy. The terms "Endeavouring to understand" and "Agreeing on a way forward" represent processes. They interact with each other in a way in which one augments and maintains the other and together they illustrate the core process identified in this study. It is necessary to distinguish them, to demonstrate this process.

Endeavouring is defined as to "try earnestly", or to "do one's utmost" and understanding is "an individual's perception or judgement of a situation" (Moore, 2004). These terms aptly capture part of the basic social psychological process that health professionals exhibit in response to patients' decisions to refuse treatment. Health professionals must reconcile what they ascertain from patients and family members once they discover the actual intentions of patients to refuse therapy.

*I couldn't quite put myself in her [patient] shoes at first; it takes time to get to know them, but that's what I try to do, especially with patients who want to go home too soon; I try and understand why, why do they feel this way? (Nse 08/7)*

The origin, nature and scope of the refusal must be determined. This entails the ability to recognise that the patient is refusing. Participants must also have a capacity to integrate the likely effects of such a decision, for everyone involved. This knowledge highlights a firm resolve of participants to make the refusal known to others in the treating team. It is also evident from the data that the participants engage in a process of endeavouring to understand, rather than merely accepting a refusal without question.

The second aspect of the core category refers to agreement. It means to “hold the same opinion” and is “an arrangement between parties as to a course of action” (Moore, 2004). “Agreeing on a way forward” reveals a keen preference of participants, that all involved individuals ultimately reach a settled position. However, decisions are not always agreed, or approved of, by all concerned parties. Strauss identified specific symbols embedded in the data as those words or phrases that have been used by the participants themselves to describe the phenomenon (1987). “Agreeing on a way forward” is illustrated in the following comment:

*... so we [staff] will continue discussing it [treatment] until either everybody's [patient, family and staff] happy, or in most cases, the majority agree on how to proceed. (Nse 16/8)*

Participants desire agreement among patients and families regarding proposed treatment; this is integral to all transitions in the core process. It involves the interaction of health professionals with each other, and with patients and their relatives. It involves making an effort to clarify and respond to patient and family wishes and to support and effect particular outcomes, all the while trying to minimise conflict and dissent, and attempting to encourage patients to accept the proposed therapy. Some participants are slower to respond than others, or the situation is resolved prior to agreement by some, or the process moves on without them. This transition has the tendency to minimise the likelihood of dilemmas for participants and reinforces the suitability of the ultimate decision reached.

The three transitions comprising the core category require participants to incorporate new knowledge and to alter their responses. Transition in this study symbolizes a change in role and relationships, including expectations and acceptance of the eventual outcome of decisions. They are situational transitions, requiring participants to challenge their understanding and beliefs in each refusal situation, and essentially, to define and redefine their roles (Meleis, 2007). For the participants, the transitions allow insight into the phenomenon of what they know and this in turn provides ways to effectively use that knowledge to enhance their clinical practice.

*Endeavouring to Understand Refusal: Agreeing on a Way Forward* is identified from the data as the core category or process and meets the criteria espoused by Strauss (1987). The core category integrates the relationships between the categories and their properties. It occurs frequently in the data, relates well to the other categories and accounts for maximum variation in the phenomenon studied (Strauss, 1987). It is a process, which occurs over time, under different conditions in the context of the study and with patients refusing a variety of interventions. Thus, it was identified as a process which explains the variation in the data and links the three conceptual transitions of *Struggling to come to terms with the centrality of patient self-determination*, *Responding to the dynamics of patient and family interactions*, and *Changing the terms of reference: from the disease to the person*. The transitions made by the participants, are relational and not mutually exclusive. They may occur sequentially, although there is a greater propensity for behaviour to oscillate between transitions, as the following excerpt illustrates:

*... the patient was awake and said, "I don't think I can do this anymore, I don't want to continue [with treatment]". But his wife said, "No, no, I will not accept that," that was her words, "I will not accept him dying, it is not going to happen, I'm not going to deal with this, you must keep treating him" ... She became very angry with any staff who suggested that her husband might not be going too well, or that she needed to have respect and listen to what he [patient] was saying ... He [patient] tried to tell her [wife] he didn't want the treatment to continue ... we [staff] came to accept his [patients] decision. It became really clear, but it was a long process and he suffered through that, and with a lot of pain and a lot of fear. .... she [wife] would only talk to the surgeon. And eventually we [unit staff] got the surgeon to come to a meeting and he said, "I can't do anything else." (Nse 17/7)*

This example reveals that during the first transition, participants may recognise that the patient is moving toward refusing treatment and having difficulty, due to the influence of a close relative, who is not accepting the patient's demise. The participants might undertake to draw attention to, and emphasise the patient's perspective in their discussion, placing the patient in a central position, behaviour

evident in the third transition, where the terms of reference are framed to consider the patient as a person. Should this approach prove unsuccessful they may respond, generating a staff or family gathering to utilise the dynamics of the entire group: the formation of an alliance evident in the second transition. This demonstrates the intermediary and relational nature of the three transitions in the core process.

For the participants *Endeavouring to Understand Refusal: Agreeing on a Way Forward* entails the struggle to come to terms with patients' roles. It demonstrates recognition that patients are not always passive participants and will form beliefs and decisions, which do not necessarily coincide with members of the treating team. In the first transition, *Struggling to come to terms with the centrality of patient self-determination*, participants are seeking clarification, to determine whether there is a refusal of therapy, and the nature or scope of that rejection. This process requires participants to acknowledge that patients possess the ability and have the right, to articulate thoughts and wishes in relation to therapy they receive. In the second transition, *Responding to the dynamics of patient and family*, participants react to patients and family members by establishing alliances with individuals, frequently patients, but on other occasions it might be with specific relatives; usually individuals with whom participants have developed an affinity or empathy. The third transition, *Changing the terms of reference – from the disease to the person*, highlights participants' tendencies to move from treating an illness, to recognition of patients as individual people, with thoughts, expectations and values which are personal or exclusive to their situation. This transition emphasizes a change in perspective to one which is more all encompassing and places patients and their individual viewpoints in the centre of the process of deciding.

### **7.2.1 First transition: Struggling to come to terms with the centrality of patient self-determination**

The initial approach identified in this study for many participants when caring for individuals, is the prominence placed on the patient's illness and the goals necessary to affect a responsive treatment plan. Patients are admitted, diagnosed and treatment is commenced. There is usually little discussion with patients to determine their perceptions, wishes and values. A patient's decision to refuse available treatment is



not a common consideration for a great many health professionals, it is not considered a likely outcome of patient consent.

*I think in a way its something about perhaps consenting to treatment, that having treatment is something which [the patient] needs a whole load of protections [to ensure the risks are sufficiently explained etc], but not having treatment [refusing therapy] is something, which it isn't even on our [health professionals] radar. (Dr 014/7)*

Given that patients commonly accept treatment, there is little recognition that the patient is a unique component in the determination of decisions. This assumption might, in part, rely on the very nature of patients' refusal of therapy, as few are unequivocal about treatment from the outset. This is because there may be a range of possible treatments and patients usually have little comprehension of what to expect, or how these will impact on them. It is more common for patients to form a decision to refuse at some stage during the course of therapy. This might occur after experiencing different procedures, or over time when consideration has been given to their illness trajectory, and they have evaluated their response to the treatment. This raises an ambiguous state of affairs for health professionals, who must continually interpret cues from patients or relatives to discern that a decision is made or about to be made, to refuse treatment. This dilemma highlights the dichotomy of foci. On the one hand health professionals concentrate on the illness state and medical options, on the other hand, a number of patients appear to contemplate what the therapy and possible outcomes will mean to them.

*... we [health professionals] think that the thing [treatment] is all about the medical options [as a direct response to the specific illness] ... I don't think it is about medical options. I think it's much more about where you are in your story of your life, which doesn't perhaps matter what the disease is you've got. (Dr 014/18)*

The association formed between health professionals and patients is crucial, as patients appear more likely to embrace proposed therapy or at least articulate their wishes, when they perceive that there is reciprocity in the relationship. Few

participants attest to the importance and acknowledgement of patients' centrality in the therapy cycle and the need to encourage that involvement. Thus, there is a struggle for many health professionals to come to terms with patients' roles in the determination of the health care experience, but it does occur to a greater or lesser extent, especially when patients or relatives do not simply acquiesce to proposed therapy.

### **7.2.2 Second transition: Responding to the dynamics of patient and family interactions**

The realisation that patients are refusing therapy generates varying responses from health professionals, who genuinely believe they are acting in the best interests of their patients. This transition highlights a wide variety of reactions. Initially they may feel frustrated, annoyed or angry with a patient or family members, particularly when participants believe that the decision is not justified.

*Oh, I was furious with her [patient], absolutely furious and it wasn't a lack of understanding because she'd been told and had numerous explanations given, and she would say, "Yes, oh that makes sense, but oh no, don't do it". (Nse 07/3)*

Beyond the initial emotional responses, individual participants will acknowledge their professional obligation to ensure that patients and family members are made aware of the consequences of rejecting specific therapy. When participants have immersed themselves in relationships with patients and relatives, they are more likely to concede acceptance of the patients' points of view. Therefore, when encounters are fleeting, relationships can be more tenuous with less depth and consideration.

When participants believe that they have forged a relationship with patients and family members there is a notable change in their reactions: in a ripple effect they commonly alert colleagues to changes in circumstance. At this time alliances can be formed with patients and families as well as with colleagues, to explore the changed situation. These coalitions serve to address a number of possibilities as the following

excerpt illustrates: a staff meeting to discuss a decision regarding withdrawal of treatment from an unconscious patient who has not responded to care.

*Oh, we're always encouraged as a team to make a decision together ... if they've [patient] had an enormous family dynamic [such as disagreeing relatives or difficulty in accepting the patient's demise] or there's been other issues going on ... It would often be a group discussion, initially just amongst the nursing and medical staff, and we look at where we are [the patient's condition] and where we think we should be going, and ask, "Does anyone have any issue with that?" (Nse 16/12)*

The patients' or families' views are promoted to others in the treating team in search of respective changes in care. Once discussion is initiated among participants, patients and relatives are usually included and the subject matter will be expanded to canvass the reasons underlying the refusal, or to offer encouragement to continue with recommended therapy. If this proves unsuccessful, consideration is given to alternative treatment or possible options of care. This highlights a comprehensive approach, which provides for a range of thought and opinion to be considered throughout. Senior health professionals are inevitably involved and required to participate in broad communication with their colleagues and patients or relatives, to clarify and validate professional decisions.

### **7.2.3 Third transition: Changing the terms of reference – from the disease to the person**

The third transition recognises the influence of the patient and family members in the entire process. When good relationships are formed with various health professionals, the patients' or families' wishes are articulated and communicated throughout the treating team, participants are compelled to consider other perspectives. Insight is gleaned into the patient as a person with particular interests and expectations, rather than merely a patient with a specific illness.

*Yes, the sub culture within the medical specialty [therapeutic unit], for sure, is relevant and seems to provide different foci and the culture of the [therapeutic] unit, and their [health professionals] personalities. All of*

*these influence the way they communicate and some of them like, I mean, they're not treating the person, but like they're treating the actual disease. It's different in this unit, the whole team seem to work with and for the person [patient] ... (Dr 015/18)*

When patients are viewed as people with individual needs, the predominantly treatment focused imperative progressively transforms into one of holism. The emphasis is to treat individuals as whole beings, including their social, spiritual and physical components, rather than just concentrating on the symptoms of the illness. This enables health professionals to accept that reaching their treatment goals might not be the most appropriate outcome in every instance.

*... I think what we've got to do ... is to try and focus on their [patients] feelings and goals and aspirations. (Dr 014/18)*

In the process of making key decisions there is a general preference by participants for all parties to be in agreement regarding overall decisions relating to the direction of care. When patients, relatives and health professionals are in agreement therapy can proceed in the absence of hindrance or doubt.

*... we've had family meetings where they [relatives] don't agree or some will not accept that that's the way to go [regarding therapy] and often what that does is just prolong what we're doing but we [staff] will continue until either everybody's happy, or most people agree ... (Nse 17/8)*

When there is some understanding and agreement as to the therapy plan the likelihood of dilemmas for most participants is minimised. The potential for conflict is reduced and the appropriateness of the decision is reinforced when the majority of parties can agree on proposed treatment. Health professionals favour collective agreement. This is illustrated in their strategies, which go beyond the achievement of mere understanding, to a position where the majority of concerned participants aim for a consensus, particularly of patients' and relatives' views. To achieve this,

typically requires some modifications or compromises to be made by participants and this occurs to varying degrees.

### **7.3 SUMMARY**

This chapter describes the core category or basic social psychological process employed by the participants when patients refuse treatment or procedures. It reveals a process comprising the modifying influences and embodiment of the categories and contextual determinants. For the health professionals this means that concerns and resolves of patients and relatives, strategies used for clarifying, advocating, influencing and responding to patient and family concerns, must be drawn together. In addition, the organisational structures, beliefs and behaviours of all parties, and the legal and ethical considerations of participants, also shape their behaviour and ultimately, this central process.

These factors comprise the core category, which encompass three situational transitions. Each scenario of patient refusal obliges participants to delineate and characterize their own roles. There is a change in relationships and subsequent behaviour. This is achieved to a greater or lesser extent, as individual participants with enormous degrees of variation and success, embrace the transitions. This occurs in an environment where the perspectives and opinions of all parties can be disparate, as participants strive to accept and maintain the centrality of patients' wishes. Health professionals respond and form alliances with each other, patients and family members, in order to progress an understanding from the various perspectives. Ideally, the parties reach an understanding, opinions harmonise when the individuality of patients as unique people are recognised. In these circumstances agreement is more likely to be achieved for a decision to be reached about the way forward: whether to proceed with all available treatments, or proceed with a limited range of therapies of varying invasiveness, or to abandon all attempts to treat, and instead provide comfort. The process may also address withdrawing treatment altogether. Nonetheless, this drawing together of perceptions, opinions and facts, and moving to an understanding and definitive agreement create the core category: *Endeavouring to Understand Refusal: Agreeing on a Way Forward.*

## CHAPTER 8

### SEEKING CLARIFICATION

#### 8.1 INTRODUCTION

The first category, *Seeking Clarification*, involves health professionals identifying and exploring important information and behavioural traits displayed by patients and their families throughout the delivery of care. Health professionals normally acquire information from their patients in order to plan therapy. In turn, patients or their families usually oblige, but there can be certain verbal or non-verbal communications, which alert professionals to explore and clarify further. These are critical disclosures in the sense that once they are recognised and clarified, participants are well positioned to determine individual responses. Health professionals commonly approach the delivery of acute care therapy on a taken-for-granted approach, assuming that patients want to receive treatment. However, as the experience of illness and treatment unfold there are occasions where the thoughts and preferences of patients and their relatives diverge from the intentions of those providing care. Such views are not always clearly communicated to the treating team who might be proceeding in a contrary direction. Attentive health professionals appreciate the value of elucidating specific information so as to avoid alienating patients, or expending considerable resources providing therapy that is not wanted. Nevertheless, the ability to differentiate between a range of emotions from patients who are exhausted or traumatised by illness, and a definitive refusal of treatment, requires considerable discernment.

The communication and interactions between health professional and patient, ideally, should allow for sufficient dialogue and appreciation of the situation. Health professionals must determine whether patients understand the disease process and proposed treatment and whether they are, in fact, refusing therapy. When patients are reluctant to agree to proposed treatment, the skilfulness of staff to enquire and deal directly with these issues impact on the extent and type of treatment subsequently provided. In this chapter, the context in which *Seeking Clarification* occurs is

identified and the individual strategies are presented. This is followed by analysis and discussion of the concepts in this category.

## **8.2 THE CONTEXT OF SEEKING CLARIFICATION**

Once patients are admitted to the acute care hospital, health professionals work on the premise that treatment and care will be promptly initiated and continue each day. There is an assumption that patients and families will be co-operative, in that they will accept the recommendations and treatment offered. Thus, nursing and medical staff members convey their proposed plans to patients and family members and at times seek information from them, as they formulate treatment plans. As therapy is implemented much is dependent upon information, which passes between staff, patients and families. The various strategies are underpinned by two recurring themes: the insight staff possess, and the capacity and scope of individual staff to clarify.

### **8.2.1 Insight of staff**

Patients' refusal of treatment frequently presents as a concern communicated in the form of apprehension, hesitancy or unease, or patients can clearly indicate a resolute decision to refuse a procedure or treatment. Patients and relatives refuse treatment for a variety of reasons. Sometimes they hold to particular beliefs; other factors include fear, a misunderstanding of the therapy or expected outcome, frustration or anger. There are also occasions where patients and families actually understand what is proposed but still do not want it. The ability of staff to recognise and clarify a refusal decision is crucial, and this is largely determined by the insight staff possess in relation to the patient's circumstances. There must be some initial recognition that the patient is indicating a desire other than acceptance of the therapy. This is when the process of seeking to clarify becomes critical.

*As soon as I think the patient isn't too sure about the treatment I tend to go to whoever's in charge but then if they are really busy I find out from them [nurse in charge] where I should go with it. Quite often they'll [senior nurse] say ... "I'll go and talk to the medical team, or get on the phone and let them [medical staff] know". ... Doctors, they will come up*

*and talk to the family themselves and see if they can find out, you know, anything else that's outside [external factors] that's relevant [to the patient's decision]. (Nse 08/4)*

### **8.2.2 The capacity and scope of staff to clarify**

The level of experience of staff members largely determines their capacity and the scope of their individual responses. When less experienced nursing staff members believe that a patient is refusing therapy, they usually seek advice from more experienced colleagues. Most commonly they inform the senior nurse in the unit or ward. The situation is then addressed either by the senior nurses talking to the patient, or the matter might be referred to the medical team to explore further.

*We knew that she didn't want it [the naso-gastric tube] but they [the medical staff] were persistent and we kept putting it [the tube] back in. In the end the decision was made, finally, because they [medical staff] thought that she'd [the patient] made it quite clear she didn't want the naso-gastric tube in ... so she was made palliative, finally, which is what she wanted all along. (Nse 01/5)*

The fact that patients' wishes or concerns have been brought to the attention of medical staff does not necessarily mean these concerns will be accepted automatically. Medical staff require more than a suggestion that treatment is being refused; they insist on an unwavering effort from a patient before they accept this claim, particularly if the patient cannot verbally express that decision. Thus, the capacity and scope of individual staff members to clarify patients' or relatives' wishes will largely determine the strategies they adopt.

### **8.3 STRATEGIES FOR SEEKING CLARIFICATION**

Concerns can be raised by either patients or family members at any time, while patients reside in the acute care hospital. Many health professionals are keenly aware that patients' wishes are not always made clear or that as care progresses, patients or relatives might change their perspectives. Nursing staff play a vital role in exploring and clarifying patients' wishes and communicating these to each other and to the



medical team. This situation highlights the interdependence of nursing and medical staff. When additional information is detected by the nurses and communicated to medical staff, the latter group have an opportunity to return for further discussion with patients. However, the researcher found that there are instances where nursing and medical staff fail to communicate relevant information to their senior counterparts, assuming that patients or relatives will inform appropriate individuals. There are also occasions where senior members of the team might have received information that could be explored, but fail to engage in further discussion. Five strategies were identified that illustrate a desire to seek clarification: *Determining patient competence, Ascertaining whether there is a refusal, Enabling reflection, Considering prior information, and Identifying acceptable treatment modalities.*

### **8.3.1 Determining patient competence**

From the very first interactions and throughout patients' stay, health professionals usually recognise whether patients are able to participate in the decision making process. Clinical practice proceeds on the assumption that patients are competent to provide consent and this is consistent with the current law.<sup>71</sup> When patients demonstrate a reluctance to progress or clearly refuse therapy, some staff members will consider the possibility that the patient is mentally incompetent. This is the case particularly if a patient has been unable to express a clear rationale for the refusal.

Health professionals, armed with knowledge of the various illness states, are generally aware of the potential for patients to be cognitively impaired. If a patient demonstrates certain behaviour, such as inappropriate or inconsistent answers to questions, memory problems or difficulty with reasoning, these usually become apparent to staff and are clear behavioural traits which might indicate a patient is incompetent to make decisions (McIllwraith & Madden, 2006). Indeed, dealing with patients who are not mentally capable of making decisions is perhaps the most

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<sup>71</sup> At law, the adult patient is presumed to be competent to make decisions unless there is knowledge or evidence to the contrary. An adult who is competent is capable of understanding the nature, consequences and risks of a proposed procedure, together with the consequences of refusing treatment (McIllwraith & Madden, 2006).

common expectation identified by staff members, as a reason for patients not wishing to continue with treatment.

*... the first thing, I guess, in all refusal of treatment situations; are they [patients] capable of making a decision? You make sure they're not influenced by, you know, delirium, dementia and so forth. (Dr 012/3)*

When health professionals believe that the patient is not mentally competent, there are usually two outcomes. First, senior staff members are informed and they determine whether any further examination of the patient is required to determine mental competence.<sup>72</sup> This is generally the case when there is a possible psychiatric condition. More commonly, the treating registrar or consultant tends to determine competence. The second outcome, once a patient is deemed incompetent, is the involvement of relatives, to make treatment decisions, on behalf of the patient. Both nursing and medical staff members routinely ask relatives and inspect the patient's file to identify the nominated nearest next of kin. Following observing a medical practitioner she was asked why she was searching through a patient's file and she stated:

*When the patient can't make a decision, you have to locate who can from the family ... (Dr 012/6)*

With very ill patients there can be considerable difficulty in assessing their levels of understanding, particularly where they cannot easily verbalise thoughts and wishes. Some experienced health professionals recognise the need to select appropriate periods when patients' conscious states are optimal, to discuss therapy issues and plans.

*What our doctors will then do is look at that person's care; well, actually often our long-term patients have tracheotomies; it doesn't mean they*

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<sup>72</sup> In clinical practice medical practitioners have the authority to deem that a patient is mentally incompetent (McIlwraith & Madden, 2006). In the present study, it was observed that specialist psychiatric staff did not independently assess the majority of patients who were deemed incompetent. In practice the decision largely rests with senior medical staff from the therapeutic unit the patient is admitted into.

*can't communicate. It just means it has to be done sensitively and sensibly when that person's awake as they can be, so it's a matter of maximising their conscious state, you know are they really aware, are they really oriented to what's going on ... and then talking through all the issues ... (Nse 17/3,4)*

For many staff members, patients indicating a refusal of therapy are often viewed in the context of particular patients' progress and disease states. An indication not to continue with treatment can be interpreted as a sign that patients are just too ill to make decisions. Patients who indicate a refusal of therapy in that situation are given little credence.

*We [staff] took the refusal with a grain of salt because the patient was so sick; she [patient] was unable to really understand [what we were proposing]. (Dr 011/10)*

However, if the patient or family members do not verbally communicate a clear refusal of therapy, other signs indicating that the patient is uncertain or unwilling to continue, may well be overlooked. A great deal of sensitivity and insight into the various reactions of patients and their relatives is required in order to identify a refusal of treatment that is not clearly articulated. Staff members are generally not expecting patients to refuse treatment, and might retreat to the proposition that the patient is incompetent or too ill to understand. Nonetheless, once staff members have addressed the issue of patient competence, there is still a need to establish whether there is a refusal of therapy.

### **8.3.2 Ascertaining whether there is a refusal**

If patients communicate concern regarding a proposed procedure or treatment this is addressed in various ways. Patients will sometimes directly raise concerns or demonstrate an unwillingness to proceed and question staff, or staff might learn by other means. In the present study, it was observed that patients sometimes inform their relatives who, in turn, notify staff members of the patients' concerns or intentions to refuse. On other occasions it was observed that conversations regarding an unrelated issue between patients and staff members would result in staff members

clarifying the patients' true feelings and intentions. Given that most nursing staff spend longer periods of time in the unit area, compared with medical staff, they are generally more accessible to patients and relatives. It was frequently observed that nurses identified the patients' concerns or refusals at first instance. However, health professionals will not generally accept an unclear message, without enquiring further.

*You do need to know why people are refusing things and not just accept, "Oh, I'm not having that," and you [the nurse] go, "Oh, all right then." You don't just accept it at face value. (Nse 01/ 4)*

There is significant recognition by health professionals that seriously ill patients experience a range of emotions and thoughts as they try to come to terms with their illness state. Thus, off-hand or spontaneous comments or actions, which might be construed as a refusal of treatment, are often ignored or not taken seriously. Astute and sensitive health professionals are usually capable of deciphering patient behaviour. They consider the context in which it occurs and then determine whether further exploration and interpretation is required.

### **8.3.3 Interpreting signals**

When health professionals are interacting with patients they interpret signals provided in everyday conversation to identify patients' real wishes and thoughts. This was specifically observed in the daily practice of many nursing staff and some senior medical staff, who also demonstrated insight into particular cues. If nurses explore these cues and behaviours, and it was observed that experienced nurses do, they often then discover patients' true wishes. This is attended to in extended conversations and further questioning of patients and relatives.

*Often we have to "suss" [find] out for ourselves what the patient's actually thinking even though they have articulated something; you know what they said isn't what they're thinking. We [staff] have to figure it out, often it's a fear or they don't understand something and if we ask the right questions then we get clearer answers. (Nse 09/7)*

There are instances where patients are non-compliant regarding treatment, such as physically removing tubing equipment. This sometimes occurs when patients are unable to verbally converse. The manner of seeking additional information then extends to observation of the patient's behaviour. Staff members note non-verbal signs and other forms of communication, such as facial expressions, to determine a patient's wishes.

*... [A patient] was having naso-gastric feeds and she was quite livid [about the procedure] but not able to express herself verbally, but she did understand what was happening and she kept taking that tube out. We could clearly see what she was telling us. (Nse 01/5)*

There are considerable qualities required by staff to interpret signals and determine whether there is a refusal or potential refusal of care. Patients do not always clearly articulate their ideas and it appears that staff members, with insight and consideration of patients' situations, tend to recognise the various signals exhibited by patients and then endeavour to address them.

#### **8.3.4 Enabling reflection**

Some staff members adopt specific strategies to encourage patients to reflect and think about their decision. There is evidence that these staff members share a certain empathy with the patient's plight. They try to create an atmosphere where the patient can reflect for a brief period, in order to consider the consequences of a decision to refuse therapy. Certain staff members, often those with more experience, or maturity evidenced by a degree of compassion, take patients' statements seriously and strive to deal with them. Nurses were observed taking time to assist patients to move an outside garden area.

*Sometimes it's simply taking someone ... down to the podium [garden area] and giving them some "sunshine" in a sense of still belonging to the world, you know, or giving them the things that they might need to still feel connected and letting them express what it is they're really feeling [and why] ... you know if we [staff] can't take them with us [to*

*accept therapy], no amount of coaxing or motivating will make a difference. (Nse 17/4)*

Continuous treatment and confinement in a bed or room in a hospital can greatly affect a patient's physical and emotional wellbeing. Participants describe patients expressing a sense of loss with their previous lifestyle and this can impact on patients' frames of mind and consequent decisions. The removal to a different environment enables a degree of separation from the hospital routine and can provide connection with the wider world. Simple changes, such as the introduction of sunlight or moving outside to a garden area, can encourage patients to contemplate their situation and may permit more measured considerations. This can and does then lead to critical disclosures as to what is really wanted, often stated in terms of expectations of future lifestyle, from which therapy plans can then be made.

### **8.3.5 Considering prior information**

A further method of clarifying patients' wishes involves examination of the patient file, if one exists.<sup>73</sup> When a patient has been previously admitted to the hospital, health professionals will have recorded notes and this sometimes highlights prior patient requests or relevant information. If a patient has informed staff of a particular desire regarding treatment, for example, not to be resuscitated, staff will revisit the patient's file to look for evidence of a previous notation. Conversely, if a staff member reads a notation from a previous admission in a file, and this was observed many times, this usually triggers further conversation in order to ascertain the patient's current wishes.

*It's [the NFR order] looked at again or reviewed by medical staff here as to whether that [particular resuscitation] order is wanting to be implemented during this stay at the hospital. If so, the documents are then signed again. A brief discussion usually takes place between the medical staff and the patient and its [the NFR order] still in place if they [patients] want it. (Nse 14/3)*

Clearly written medical files provide valuable information for health professionals and are commonly scanned for prior information which might be useful. The pattern of record keeping is also important. Where there is a prior NFR order made, hospitals use a specific coloured page and customarily locate it in the front of patients' medical files. This is easily identified when the medical file is utilised again and enables health professionals to re-examine the notations made by previous staff. This documentation allows for ample information to be included, such as who was involved in the decision and a brief description as to what was discussed. However, in the medical files examined during data collection, while there was often a notation stating the patient was NFR, there was usually no more than a medical practitioner's signature accompanying the statement. Commonly, there was minimal or no associated information provided, only the previous decision, and this would be explored by staff.

### **8.3.6 Identifying acceptable treatment modalities**

When staff members have actually identified that patients want to refuse treatment, in whole or in part, there is often further purposeful conversation to illuminate the extent and scope of treatment modality they actually want. The discussion can uncover that a specific area of treatment is deemed unacceptable, or the concern might be more expansive and entail a rejection of the overall therapy direction.

*I would sort of just say to them [the patient], "Well, do you want to stop it, you know; is that what you're telling me? You don't want to have any more tests or any medical treatment?" (Nse 08/5)*

The patient might have provided prior instructions regarding care, or might arrive at the unit unable to communicate, and staff are faced with the need to make decisions without knowing the patient's wishes. In the absence of prior communication from the patient, experienced staff members attempt to refine information provided from family members regarding the patient's beliefs. This information assists the health

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<sup>73</sup> A file will exist when a patient has been previously admitted to the hospital and that file is usually recalled.

professionals' understanding and enables them to make suggestions regarding the ultimate direction of care. This strategy requires versatile staff members who can move comfortably beyond discussing medical facts, to include additional information which allow connection and resonance with the patient and relatives' everyday perceptions and expectations of life.

*I often add in extra bits of information where the family are hesitating; I will usually ask, for example, "Do you know what X [patient] would have wanted in regard to tube feeding; had there ever been any discussion about that?" ... very often older people do have views about that because quite often they know somebody who has had that experience and they've talked about it and they will know that, "I wouldn't have wanted that to have happened to me." (Nse 03/3)*

Health professionals may be able to keep the patient alive, but they usually discuss what that means in practical terms and their expectations of the patient's outcome. This approach draws attention to the anticipated result of therapy, particularly if it is expected the patient will suffer significant physical or mental impairment. This aids discussion with relatives to elucidate if there has been any conversation with the patient before the admission, which may prove insightful.

*... [the consultant] sat down with the two adult children [of the patient] and said, "This is the situation; I feel confident your mother would never get back to her unit [home] and be able to live in the way she was. The best outcome would probably be a nursing home, and we now have to talk about whether or not we're going to put her on dialysis and continue treatment," ... and they [relatives] just said, "Well, we talked to mum before she came into hospital and she said, "You know this isn't what I would ever want. I wouldn't want to go on a breathing machine, ... I certainly wouldn't want a nursing home." (Nse 15/9)*

Nevertheless, the knowledge gleaned from relatives can lack clarity of the extent to which the patient would accept treatment and where relatives are equivocal their views are not always relied upon. Should a health professional consider that the



information provided by family members conflicts with the treatment plan proposed, or is actually detrimental to the patient, the enquiry process continues in order to seek further information. There is often additional discussion amongst nursing and medical staff.

*I sometimes worry about a daughter or son who comes in and says, “Well, I don’t think that you should progress any further [with therapy]”. You have to think, is there an ulterior motive, that does cross your mind, because I think this [idea of withdrawing treatment] got mentioned a bit too early. I’d discuss this with the medicos [medical team] and ... they would sit down [with the relatives] and ask them why ... (Nse 10/13)*

Staff do seek information regarding acceptable treatment modalities from patients or relatives however, this frequently does not occur. Health professionals largely work on the assumption that all care, curative or otherwise, is usually accepted. There is little emphasis placed on the extent and consequences of treatment and the limits acceptable to patients. Therefore, the success of the enquiry as to treatment boundaries relies to some extent on the relationships between staff and how skilfully they communicate and listen to patients or relatives.

*Unfortunately, in this hospital I’ve noticed over the last two years or so that there isn’t a culture of discussion [to determine what a patient would want] by the residents if things don’t go well, [for example] prior to people going to theatre or when they [patients] first come into hospital. (Nse 15/9)*

If staff members have failed to clarify the beliefs or feelings a patient has raised, then they may well be overlooked. Treatment and investigations will continue, as planned by staff. This was observed in situations where the patient’s condition deteriorated or failed to respond to the treatment plan. The outcome for the patient is then dependant on the actions and determination of various staff to “champion” the patient’s cause, and continue to implore other members of the health care team to clarify, wherever possible, what the patient might desire. Participants use their techniques of *Seeking*

*Clarification* regarding therapy with patients or relatives, depending upon their insight into, and commitment to, fulfilling patient wishes.

#### **8.4 DISCUSSION**

When health professionals are *Seeking Clarification* they are making the initial discovery that the patient or family are reluctant to accept or continue with proposed treatment. These are critical disclosures as they can effectively circumvent serious communication breaches, ensure therapy is agreed upon by all parties, and save valuable time and resources for health professionals. The focus in acute care is to provide treatment, and the majority of patients accept care, there appears to be a taken-for-granted approach by many health professionals. The possibility that the patient might not actually want therapy can be simply overlooked. Part of the dilemma is that refusal of treatment decisions do not usually present to health professionals as clear, decisive and well-articulated considerations. Rather, the data reveal they tend to manifest in more subtle ways, over time, such as a change in language, which depicts hesitancy or discontent, or a behavioural pattern, for example, repeatedly removing tubing. Sometimes patients will inform their closest relatives or the relatives will interpret the patients feelings and communicate these to health professionals (Engstrom & Soderberg, 2007). Even when a decision to refuse is clearly communicated, if health professionals fail to clarify and ascertain what is occurring, patients can prematurely terminate the relationship and all associated care.<sup>74</sup> Thus, seeking clarification at the earliest sign of patient reticence is important as it provides a window of opportunity for staff members to address the patient's concerns and discover the underlying reasons for the refusal. Once there is clarification, the emphasis of care can change altogether; a modification might be made to current therapy, or active treatment might be ceased altogether.

Patients' refusals are often understated and seldom become evident when key decision makers, the medical consultants, are present. The health professionals most likely to notice a change of mind are nursing staff. Nurses often clarify information provided by medical staff and other health professionals and they become the

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<sup>74</sup> See Chapter 11, Section 11.3.4.

primary source of information exchange from patients (Crisp & Taylor, 2002). Frequently it is the bedside nurses who notice a change in patient behaviour, although the meaning may initially be obscure. While formal communication and appraisals of patients are crucial and occur when medical staff visit the patient, they do not always lead to critical disclosures. Much of what health professionals, particularly nurses, learn about patients occurs because they are in an immediate and professional relationship with them. One explanation for this relationship is because nurses provide personal “bodily” care (Aranda & Brown, 2006). This is when the ability of health professionals to recognise a potential change in patients’ wishes and their willingness to venture further, reveal key characteristics of patient centred and attentive staff. Sometimes relatives will inform senior members of staff, the nurse in charge, or the registrar, and that might generate further investigation. Bedside nurses often address patients’ concerns, nonetheless other health professionals are usually incorporated as the matter is addressed. Much however, is dependent upon the sensitivity of health professionals to be attuned to the possibility of patient refusal. It is quite common that patients and family members must expend considerable effort before their wishes are acknowledged.

Patients refusal of therapy is rarely accepted at first instance, particularly when it is not openly communicated with associated rationales. This is not surprising as patients are often very ill, with altered emotional and conscious states and thorough patient assessment is required (Engstrom & Soderberg, 2007). The most common concern raised by participants is the possibility that the patient refusing therapy might be mentally incompetent. When patients are demonstrating difficulty with memory or reasoning, or provide inappropriate answers or questions, participants are usually alerted to the possibility of incompetence. In this context it is assumed that health professionals are reasonably well acquainted with the notion that competency functions as a “gatekeeper” in clinical practice (Deverux, 1999). Health professionals are taught that competent patients should exercise their autonomy, and thus their decisions be respected, because patients are exercising self-determination. Incompetent patients on the other hand, might have treatment imposed upon them, if it is considered to be in their best interests, because they are unable to interpret or evaluate their current circumstances (Deverux, 1999). This explains why

considerable emphasis is placed on patients' mental state when refusing therapy. However, the practice of assessment in everyday acute care appears somewhat more casual and is often dependent upon the individual preferences of those health professionals involved with the patient. The reality of clinical practice does not necessarily comply with the rhetoric of authors in legal or health fields.

For patients to be deemed competent, Australian law has adopted the understanding test. That is, patients in possession of relevant information, must understand in broad terms the nature and effects of a decision (Rogers v Whitaker, 1992). Competence, however, requires more than mere cognitive function of patients, rather there is a range of capacities required. These include the ability of patients to receive, comprehend, integrate and evaluate the information presented (Kerridge, Lowe & McPhee 1998). Some authors believe that the task of conducting competency assessments is not well defined and there is some concern regarding who should conduct such assessments, and what level of impairment is considered necessary to constitute incompetence (Sullivan, 2005; Searight & Hubbard, 1998). There is concern that physicians and other health professionals currently appear to differ widely in their conceptual understanding, their clinical approach and the standards they apply when deciding competency (Marson & Harrell, 1998).

In acute care settings the medical staff commonly determine competence. In this study it occurs during patient interaction or when nursing staff members raise concerns as to patients' mental states. These assessments are often informal in both the manner of assessment, often a brief conversation with patients, and in the recording of the decision. The outcome may be documented in patients' files, or there may simply be a conversation between staff as to the outcome, particularly if patients are considered competent. Specialised professionals, such as psychiatrists or psychologists, are only requested to undertake more formal assessments of competency in circumstances where there is uncertainty or considerable dispute over patients' ability to make decisions.

The data reveal that patient competence is a primary consideration of many health professionals when patients refuse therapy. This assists an understanding of why many health professionals look to interpret signals the patient provides. A patient

may converse with health professionals however, it is often during quieter moments a comment is made or thought expressed. Insightful participants recognise the significance of this information. Skilled health professionals encourage further interaction and conversation in an attempt to determine or explore the underlying motives or wishes of the patient. For this to transpire, some participants demonstrated skills as active listeners. They pay attention to conversational themes, to acknowledge and focus on the patient's total communication, including the content, intent and feelings expressed (Stein-Parbury, 2005).

When patients are unable to verbalise their wishes many health professionals rely on non-verbal communication, where a message is transmitted through body language. Facial expressions, gestures and sounds, such as groans, sighs or sobs, all communicate feelings and thoughts (Crisp & Taylor, 2002), but physical actions, such as continuously removing a specific tube, can also indicate the patient is refusing therapy. In these circumstances, health professionals who are attuned to patients' needs, examine carefully the overall behaviour of their patients and consider the context in which it occurs. They may select appropriate times, for example, as ventilated patients are often heavily sedated, participants in one unit waited until the patient's level of consciousness had sufficiently returned before they attempted to communicate important information and sought to obtain the patient's response. Those in another ward identified a patient constantly removing a nasogastric tubing as one indicator that required further examination, to determine whether the patient was indicating a rejection of that treatment. As participants interpret patient signals they also are ascertaining whether there is an actual refusal of treatment.

When health professionals believe that patients are reticent to accept therapy they adopt specific approaches to allow patients time to consider their decision. This, in turn, assists clarification of patient wishes. Temporarily ceasing therapy, which is causing pain or distress, enables time to rest or interact with family members (Engstrom & Soderberg, 2007). Changing the environment is also recognised as an effective strategy to allow the patient time to think and reflect. This entails moving the patient from the ward area into a garden or different space. This practice

demonstrates staff empathy, to perceive and understand the patient's feelings and current reality. It requires health professionals to be sensitive and imaginative, to be capable of perceptive responses and it offers patients a chance to consider and sometimes determine their precise needs (Stein-Parbury, 2005). These practices can significantly influence patients, sometimes to affirm their original decision not to accept therapy, or to change their mind to accept treatment.

When patients have previously been admitted to the hospital, their medical file is obtained and information associated with the new admission is incorporated. This allows health professionals to scrutinise prior information collected and can alert them to earlier decisions to refuse specific therapy. If a patient has previously refused resuscitation, for example, there is usually a notation in the patient's file and this automatically generates a wider discussion with the patient and amongst staff. It is common for health professionals to revisit information gained from an earlier admission, to confirm whether patients' wishes have changed. This reflects current clinical practice, but is also commonly determined by written hospital policies, directing staff members not to rely upon earlier patient requests without first verifying the current status of that information. This reinforces the need for entries in the medical file to be accurate and complete, ensuring sufficient information is recorded, including who was involved in the decision (Forrester & Griffiths, 2005). Where previous entries are too brief, those examining the file have little insight into the reasons for the decision and who, indeed, was involved. This is important information as it allows health professionals and those relying on the medical record to differentiate that the request or decision was a patient's request, or that of family or staff members. The legislation intends for patients or their agents to record the patient's wishes, clearly identifying who was party to the decision to refuse.<sup>75</sup> The current practice of a scant entry by a medical practitioner does not satisfy these requirements. Furthermore, the legislation requires the patient or agent's refusal

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<sup>75</sup> In the *Medical Treatment Act 1988* (Vic) Schedule One requires the competent patient to indicate his or her wishes as to medical treatment refused and Schedule Three clearly indicates that it is the agent or guardian of the incompetent patient who is indicating the refusal. Moreover, if a patient is unable to indicate a decision in writing it may be expressed orally or in any other way the person can communicate: section 5(3). This ideally should be recorded in the medical file, but commonly is not.

decisions to be included in the medical record (section 5E(a) Medical Treatment Act 1988). Arguably data from the current study suggest that the usual practice of most health professionals does not comply with this requirement because the documented information fails to identify whether the patient or agent was involved.

One important strategy utilised by some participants when they are seeking to clarify, is to determine acceptable treatment modalities. This aspect is often explored, but not always, in the context of a patient's refusal of therapy. Once a patient has indicated a negative response to treatment, further elucidation can uncover the precise area or procedure the patient finds unacceptable. This aspect can then be discussed in more detail, a decision made and communicated to others in the treating team. There are times when relatives provide relevant signals or information and health professionals who investigate further, will frequently discover aspects of care that patients consider unacceptable. This requires an ability on the part of participants to converse in a practical, yet sensitive style to explain the impact or expectations of treatment. It also requires certain skills to appeal to family members to consider whether the patient had ever indicated, prior to admission, any treatment preferences. Successful methods employed by participants are often in the form of suggestions, where statements are tentatively posed and they operate from an understanding of the families situation and knowledge. They are not based on health professionals' personal opinions or values (Crisp & Taylor, 2002), rather they are specifically designed to engage and clarify for staff, important information with which they can proceed to formulate an acceptable treatment plan.

The practice of identifying acceptable treatment modalities is in keeping with the Victorian legislation, which obliges patients or their agents to specify either "generally" or "specifically" the treatment the patient does not want.<sup>76</sup> This allows competent patients (or agent when the patient is incompetent), to either identify detailed treatment or procedures to be refused, or record in broader terms, the types of treatment the patient wishes to reject. So too, the patient can specify the

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<sup>76</sup> The Medical Treatment Act 1988 (Vic), see section 5(1)(a) that a patient has clearly expressed or indicated a decision: (i) to refuse medical treatment generally; or (ii) to refuse medical treatment of a particular kind, for a current condition.

acceptable limits of palliative care. This requires the patient to clearly delineate the boundaries of the medical intervention. Hence, there is a legal requirement for health professionals to identify acceptable treatment modalities once it is apparent the patient is refusing therapy. This is one strategy utilised by some health professionals but it is generally not a routine enquiry made throughout the patient's stay.

The data show that participants do consider a refusal of treatment in the context of the patient's illness. Issues, such as mental competence, patient signals or reflection, prior information and the identification of acceptable treatment modalities are, ideally, all weighed and considered with the disease state and its possible effects in mind. Some health professionals deem all patient behaviour as relevant and worthy of interpretation and exploration, others appear less enthusiastic to interpret and follow-up. Where these strategies are not routinely employed, health professionals fail to identify important data that may be used to formulate treatment plans. In the extreme, patients may make decisions but can be caught up in the processes of therapy and not given the opportunity to reconsider, unless they strongly assert their wishes. Patients are frequently vulnerable and too ill to protest; they might well be overwhelmed. This allows health professionals to make assessments and subsequent decisions about patients based on their own perceptions, rather than from the patient's perspective. This may well be the case particularly when patients or relatives have initially agreed to treatment, but then later have reservations. Given that patients do not commonly refuse treatment at first instance, clarification needs to be an ongoing process.

When health professionals actively seek to clarify, they customarily show a sensitivity and empathy to the patient or relatives' situation, allowing early detection of potential issues that will impact on the direction of care. Detecting additional information when issues are clarified, allows health professionals to determine a considered response. In many ways skilled and responsive health professionals are akin to detectives in this category. They must have the aptitude and capacity to explore and interpret behaviour and everyday communication; their insight is critical in "finding out" this information. The information obtained by *Seeking Clarification* enhances the chances of accommodating patient desires within patients' physical and



cognitive abilities, and making appropriate adjustments (Luftey, 2005). The ability to clarify does not necessarily equate with experience or seniority, participants who regularly engage in these strategies have finely developed qualities. Attributes, such as sensitivity, thoughtfulness and empathy, are traits that reveal a respect for patient and relatives' experience. Some less experienced participants displayed exemplary communication skills, sometimes acquired in previous roles or life experiences. However, once the refusal situation is identified much is reliant upon the actions of those more senior health professionals to acknowledge and follow up.

The ability and willingness of health professionals to clarify, demonstrates recognition of shared decision-making and the adoption of patient centred care. This approach impacts on patient perceptions and behaviour (Gwyn & Elwyn, 1999). The ability of health professionals to take a patient centred approach, allowing patient preferences to be elicited and discussed, contributes significantly to their satisfaction of care and adherence to overall treatment (Charles, Gafni & Whelan, 1999).

## **8.5 SUMMARY**

The importance of exploring and acknowledging patient and family wishes requires particular personal attributes of both nursing and medical staff. The data show that nurses play an important role in identifying and refining relevant information. They are commonly the professionals who, by the nature of their work, have the opportunity to identify changes in patients' or families' views and opinions. Many, but not all nurses, tend to act on this information. They play a crucial role in devising strategies to clarify and then raise this "new" information with medical staff as therapy plans are formulated. The key emphasis for a majority of medical staff when *Seeking Clarification* is in the area of illuminating patient competence. In practice, medical staff make these assessments as they interact with patients. The need for a more formal assessment usually becomes evident when there are major concerns raised, otherwise therapy tends to continue as planned, if deemed incompetent. Nonetheless, the success of the various strategies utilised in the process of *Seeking Clarification* remain dependent on the relationship between the two professional groups and the desire to include patients and relatives. Outcomes for patients and relatives are largely dependent upon the individual or group responses of the treating

team. This is explored in the next category, *Responding to Patient and Family Concerns*.

## **CHAPTER 9**

### **RESPONDING TO PATIENTS AND FAMILIES**

#### **9.1 INTRODUCTION**

When staff members assume the process of *Responding to Patients and Families*, they are embracing behaviour and subsequent techniques that enable and demonstrate a degree of connection and insight into the desires of patients or relatives. When there are responses requiring interaction there is a greater likelihood that thoughts and concerns are shared; there is a two-way flow of information. Staff members who listen and allow patients and family time to express their concerns and wishes and then respond accordingly, establish a degree of equality in the professional-patient relationship. Health professionals might exhibit particular expertise and knowledge however, in the absence of contemplation and acknowledgement of patients' or families' perspectives, relationships can very quickly deteriorate. Moreover, when there is minimal interaction, due to an absence of response on the part of health professionals, an unequal relationship is likely in the sense that outcomes are largely directed and controlled by the health care team. Health professionals are well positioned to interact, to encourage understanding and participation; however if they are ineffective communicators or unwilling to include others they can appear uncaring or aloof, limiting their responsiveness.

This chapter identifies the context and the strategies of the category *Responding to Patients and Families* and then analyses and discusses the emergent themes.

#### **9.2 THE CONTEXT OF RESPONDING**

Responding means “to answer or reply” and to “behave in a corresponding manner” (Oxford Dictionary, 2004), in this category it generally relates to confirmatory behaviour. The quality of the interactions health professionals display is important as they confirm recognition of the need to make all aspects of illness and treatment options intelligible. When this is achieved successfully, staff members promote patient and family knowledge and enhance the likelihood of their participation in

treatment decisions. However, when health professionals fail to respond well, situations can develop where patients and relatives become increasingly anxious and frustrated. The refusal decision can become entrenched or patients and family can become resentful of the process of care and this can contribute to poor relationships between the parties. This is evidenced in the manner in which information is conveyed and can be identified by the varying strategies adopted. Favourable responses are demonstrated by a number of staff who recognise that it is important to make the specific language of illness and the technicalities of the acute care environment meaningful for patients and relatives. This requires taking time to involve patients and relatives at various levels of discussion and providing comprehensive information, which in turn, makes sense of the overall situation, enabling difficult but more appropriate decisions to be made.

Individual therapeutic units take varied approaches to drawing in and encouraging patients and families to participate. During the delivery of acute care there is usually significant activity as investigations and procedures are organised. The practice of health care requires ongoing monitoring and re-assessment of patients' condition. During this time patients and relatives are confronted with uncertainty, and part of this relates to a lack of understanding of disease processes and the manner in which modern health care responds. Patients and families are almost always interested in the progression of care and the associated decisions made. Thus, health professionals are in the unique position of being able to promote a shared experience with patients and families.

The context in which responding occurs can be divided into two themes: first, the ability to successfully convey information relating to treatment and outcomes; and second, the capacity to enhance convergence of viewpoints, or exchange of wide-ranging information from relevant parties, and this includes appropriate timing in a suitable environment.

### **9.2.1 Conveying information**

The work of responding, assumed by staff members, includes the ability to express what is currently happening and what is proposed, regarding therapy. Information

can take varying forms. It can relate to procedural matters, which involves the nature and sequence of events and the reasons for various tests, or it can be sensory, which entails discussion describing aspects of therapy, such as feelings and sensations the patient might feel during and after specific procedures or treatment (Johnson, 1984). In the present study, it was observed that at some stage all nurses and medical practitioners provide information, although the most effective communicators regularly provide both procedural and sensory information. While health professionals appear to acknowledge the need for information to be conveyed, there are considerable individual differences in how successfully this is accomplished.

The data reveal that many nursing participants believe that the ability to adequately convey the necessary detail is influenced by the time spent with patients or family members. Generally, medical staff spend far less time with patients and relatives, and this is, in part, highlighted by the brevity of information provided. These circumstances have a major effect on the level of understanding of patients and relatives, and may play a part in a decision to refuse treatment due to confusion or a misunderstanding. Precious time can also be lost as staff members deal with bewildered patients and relatives.

*Doctors need to spend more time explaining things but don't, and they need to be interactive, seeing [recognising] when a patient's actually understood it. It's not like that, its sort of, "Yes doctor, yes doctor", and the doctor walks out and they've [the patient] said, "What did they [medical practitioner] just say, what did I say, what's happening?"*  
(Nse 06/9)

Inadequate timing, and the provision of minimal information, is deemed by some participants to be a contributing factor to patients' increased levels of anxiety and frustration, which can increase the likelihood that patients will refuse treatment. This situation often requires the subsequent involvement of other staff members to reassure apprehensive patients.

*... more of an explanation at the start of his [the patient's] admission could have subdued a lot of his [patient's] anxiety or fears in relation to*

*his decision and could have provided more information for him to be able to determine what he [patient] wanted. It would have also saved a lot of time for both us [staff] and him [patient]. (Nse 14/19)*

The inability of some staff to communicate clearly was an issue raised by several nursing participants. A number of staff, particularly junior medical staff in one hospital, were born overseas and English was not their first language. Their unfamiliar accents were difficult for some staff and many patients to understand, and they either lacked confidence in their oral expression, or insight into the effects of their communication styles. The outcomes largely impacted on nursing staff, where additional time was spent recalling them in an attempt to clarify or repeat what had been said. This resulted in varying degrees of dissatisfaction for both staff members and patients.

*... one of the registrars, we have many actually, who speak very, very fast and it's very hard to understand them and the patients just say, "Oh" and they [medical staff] will walk away and then they'll [patients] say to you "What does that mean?" Nine times out of ten I will have to get them to come back and explain to patients again and they speak in difficult English, so you've got to sort of half translate to the patient again, and often I think patients are unwilling to question them. (Nse 07/7)*

The extent and manner with which information is communicated to patients and relatives contribute to their knowledge and expectations of what will occur during hospitalisation. While both medical and nursing staff interact and communicate information, there are significant variations as to the quality and quantity of the exchanges.

### **9.2.2 Enhancing reciprocation of viewpoints**

The most common mechanism utilised by health professionals to ensure that information is sufficiently shared, is the use of meetings. Meetings are designed to allow those involved to address issues, including decisions the patient has expressed not to undergo a specific procedure, or decisions relating to the provision of invasive

measures, such as the insertion of a gastrostomy tube in order to provide nutrition, or more final decisions such as withdrawal of treatment altogether.<sup>77</sup> The meeting serves as an ideal opportunity for the two-way flow of information between staff members, patients and relatives. For staff members it provides a forum in which to inform and seek thoughts and for patients and relatives the meeting allows them to hear the “same story” including reasons for proposed therapy. They can ask questions and express their views. Meetings are also particularly useful when parties disagree with each other.

*Yeah, as I said, communication is the main thing, I think; getting everyone involved, and at the same time, so they can talk to the person they're conflicting with, whether that be the other family member or whatever [staff], and it can all be resolved rather than hearing, you know, a story being spread by word of mouth, because it does get changed. People hear things so differently, so if everybody's in the same spot having a conversation, then basically we make sure everyone's on the same page [similar level of understanding]. (Dr 012/4)*

Meetings are often arranged on an ad hoc basis, by senior nursing or medical staff. They are arranged when experienced staff members perceive the need for them. The relative success of a meeting is largely dependent upon the particular staff members who attend and the attributes they bring to the meeting. The frequency and purpose of meetings varies according to the perceptions of senior staff in each unit and their availability to attend. When senior staff have an favourable attitude to meetings, they tend to be held more frequently and with greater success in determining an agreed

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<sup>77</sup> Decisions to withdraw life-sustaining care fall into two possible situations. Firstly, when the patient has previously communicated a decision not to continue with therapy in specified circumstances, or when the patient's prognosis is poor and major interventions are required to keep the patient alive and there is no clear indication as to the patient's wishes. These situations require consideration of the patient's wishes and whether the patient would refuse further endeavours of treatment. These circumstances correspond with the scope of this study, that is, the processes used by staff when patients would refuse treatment. Secondly, when the patient's condition is assessed as being unlikely to recover, for example the patient is deemed brain dead, a medical decision is made to withdraw treatment. This is not a refusal of treatment decision in the same sense, but rather recognition that any therapy will be futile and is considered a legitimate legal and ethical course for health professionals to pursue, regardless of what the patient or relatives would request. These situations and subsequent decisions are not disclosed in this study.

treatment pathway. Moreover, a resolute determination of senior staff to be inclusive of junior colleagues in decisions, reveals a less rigid adherence to hierarchical structures. It provides an opportunity for professional development of less experienced staff as they can observe how senior members of the team interact and lead therapy discussions. The value of recognising and including staff in the process tends to produce a more cohesive treating team and allows for varying perspectives to be voiced and discussed. This, in turn, presents a united group to patients and families and ensures that staff involved with the specific patient are abreast of all of the issues, an approach which creates a more constructive encounter with patients and relatives.

Establishing a suitable environment in which to promote good communication and interaction of the parties emerges as a significant factor. Meetings can vary, from a gathering at the patient's bedside, to more formal meetings held in other areas of the therapeutic unit. It was observed that many units did not have a designated space for meetings, rather common areas, such as the patient lounge are used. This does not always allow for privacy or uninterrupted conversations, as other relatives or patients sometimes wander in. Often, equipment is stored in these areas, with insufficient seating or a noisy television, which provide distractions and reduce the sense of privacy. By contrast, some units have an allocated room or space where meetings can take place in complete privacy and without interruption. Staff members in these units continually identified the importance of a separate, quiet environment where communication can be maximised. It was observed that a number of staff members, working in units with a dedicated space, hold firm beliefs that a suitable environment greatly enhances a positive response from all parties.

*... we [staff] try ... in a family meeting [to be] away from the bedside in that there's just something indecent, something wrong about the context of sitting around the bed with the person who is not able [to participate] in the whole conversation ... it just doesn't feel right around the bedside. It sounds right to be to be away ... perhaps the noise and the other things that within the unit make it an inappropriate place to do that ... and there's a lot of activity [in the unit] and it's [the discussion] not really*



*focused or quiet and the sitting down and the taking time and not being called off to other things, it's all important I think. (Dr 014/5)*

When patients are unable to participate in decisions, in many circumstances they are very ill with limited or no ability to communicate, the family become substitute or proxy decision makers. They are entrusted with the same information the patient would otherwise receive. Patients' next of kin are usually listed in the hospital record, which commonly identifies one or two individuals. However, immediate relatives or significant others who frequently visit are often included.<sup>78</sup> Moreover, even when patients remain capable of communicating, relatives, particularly those individuals closest to the patient, are generally included.

Recognising the circumstances and the need for collective participation is the single most important role staff members adopt when there is disagreement or uncertainty regarding future therapy. The skill of ensuring that all parties arrive at similar levels of comprehension, paves the way to achieving agreement. The practice of using meetings and sensitivity about the location of the discussion, demonstrate a genuine desire to interact successfully with the patient and relatives and serves to promote a sense of collective participation. This compares with the usual form of communication, which is commonly delivered in brief episodes at the patient's bedside, as the senior staff pass through the unit, or in busy hospital corridors, where complete explanation and associated questions are less likely to occur.

### **9.3 STRATEGIES FOR RESPONDING**

When staff members are responding, they assume a major role in determining and shaping the choice of treatment plan. Both nursing and medical staff members provide information to patients and relatives; they also control when and how that information is communicated. An exchange of information can be brief or detailed, and the context and environment in which it is provided can vary considerably. Where staff members express an interest in patients' and families' contributions and

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<sup>78</sup> Immediate family include the spouse, de facto or adult siblings or children, but are not strictly limited to these individuals.

actively seek to encourage and promote their input, they tend to draw in and allow the experience to be shared by patients and relatives. This can also enhance the overall appreciation of each group's perceptions and expectations. When there is mutual understanding between all parties, there is a greater likelihood that treatment will progress in a timely and positive way, even when the patient's health outcome is unfavourable. When health professionals seem haphazard in their approach, or expend little effort responding to patients and family members, they can appear unhelpful or perfunctory.

There are nine key strategies utilised by health professionals as they interact with patients and families. They include: *Providing timely, understandable and complete explanations, Reiterating, Elucidating, Offering alternatives, Harnessing the patient's life story, Using metaphors or images, Adopting the patient's perspective, Engaging as a unified group, and Searching for cues.*

### **9.3.1 Providing timely, understandable and complete explanations**

Manner and approach in the provision of information can create an ideal progression of communication throughout the patient's stay in hospital. If explanations are presented in a timely and comprehensive manner, patients and relatives have greater opportunity to consider their position and make informed decisions. When senior medical staff communicate well it was observed that the entire team of health professionals tend to also be clear regarding therapy, which makes it easier for them to provide unequivocal and consistent information. Some staff recognise that complete explanations are those presented in a form that the patient and relatives can easily understand. Nonetheless, explanations from health professionals vary significantly.

*... they [patients and families] do seem to be well informed in this [therapeutic] unit. They're happy with what's going on; they don't seem so stressed by things ... I think that shows a good level of communication with the explanations and information that is shared between the doctors, nurses, patients and families. (Dr 015/15)*

Alternatively, the failure of senior staff to sufficiently address the options of therapy was an issue raised by some participants. There was some trepidation expressed that it is not uncommon for health professionals to limit their discussion to the specific therapy they propose, without mentioning alternative treatment, or fully explaining what will happen if therapy is not delivered. The capacity of staff to fully explain might be influenced by their lack of experience in another area of expertise, or merely a narrow perspective, whereby the professionals only provide the treatment option they prefer. This demonstrates insufficient information, which restricts the patient's possible choices.

*I was not present in the explanations that were given. I don't know exactly what the patient was told. I do know that the patient came out feeling that he didn't have any choices and he actually said that he didn't have any choice. He said quite clearly, "If I don't have that operation I will die". My feeling was if you do have that operation you will die and I'm not sure that anyone has explained that to you and I still don't know whether anyone explained that to him or not ... (Nse 03/13)*

Ensuring that information is comprehensive requires clear details of all aspects of proposed treatment. An illness can have more than one effect on patients and when the treatment team fails to provide complete information at appropriate times, patients can easily be bewildered and overwhelmed. It was observed that many elderly patients meet one senior consultant and believe that is the person who makes all of the decisions regarding their care. They are frequently unclear about the precise roles of different therapeutic units and the personnel involved. In these situations patients tend to ask few questions, assuming they will be able to discuss this with their original treating consultant. Thus, when different staff members approach the patient or relatives and provide differing strategies to therapy, without adequate communication, confusion can arise.

*Medicos should make the treatment options clearer ... Sometimes patients get here [hospital] ... they may come here for a medical reason [such as pneumonia] and then suddenly the surgeons come in and tell them they want to amputate a limb and the patient says, "You're not*

*taking my foot off". The patient doesn't get the differences [of possible treatments] made clear to them. It's not an easy process, it takes a few days and a couple of interviews to explain the issues and who is responsible for what. (Nse 05/9)*

The roles and functions of health professionals and therapeutic units are commonly assumed by staff members to be evident to patients. There is often less than clear dialogue when one medical practitioner refers a patient to another practitioner with completely different expertise and their connection is not made explicit. For understandable and complete communication, the varying aspects of therapy and who offers them need to be made clear to patients and families. This includes the need for health professionals to take time to explain precisely what it is they actually do.

### **9.3.2 Reiterating**

Tension can arise between nursing and medical staff when communication is insufficient. The nursing staff often expressed concern when the explanations provided by medical staff were insufficient, too brief, too technical and jargonistic, or too little interaction occurred to determine patient or family comprehension of explanations. The nurses are required to either ask the medical practitioner to return to reiterate the explanation to the patient, or on many occasions it was observed that the nurses repeat the detail themselves.

*Well, I've seen people cringe by what the doctor's just said. It can be said quite clearly as an explanation, really, and it's not always explained fully ... I think nurses often have to go back to patients and families and reiterate ... (Nse 01/9)*

Many health related investigations and procedures are unfamiliar to patients and relatives and insufficient time is taken to ascertain whether the purpose and relevance of these have been properly comprehended. It was observed on several occasions that information is explained only once, often briefly, and questions are not encouraged. There is evidence that even when nursing staff request medical team members to provide fuller accounts or restate the information, medical practitioners

do not always understand or demonstrate insight, that the patient or family had not appreciated what was proposed.

*... you ask them [medical staff] to go in and speak to them [patients], but I think a lot of them [medical staff] don't have a grasp on why they're speaking to them ... and you say, "Oh, they just wanted this explained, and this and this", and they'll [medical staff] sort of go in and they'll explain one thing that's really got nothing much to do with it, rather than listening to the patient and getting to what has not been understood.*  
(Nse 07/11)

Reiteration is a strategy more widely utilised by nursing members of staff in response to the actions of medical colleagues. The replication of information serves to reinforce specific details previously given but not necessarily comprehended, and this facilitates its incorporation in a decision.

### **9.3.3 Elucidating**

In many situations the nursing staff play a major role in the process of clarifying information. Explanations of why certain therapy is required, what it actually does or how it will impact on patients, are often not provided in sufficient detail. Medical staff tend to provide procedural information, commonly using the medical term for the procedure or therapy. Information needs to be actually defined and explained, yet complete in the sense that patients and family members can comprehend what is entailed in order to make decisions about it. Nurses provide a range of explanations, using both procedural and sensory information, and this serves to make actual procedures more meaningful for patients. It allows them to formulate realistic expectations. Many nurses believed information was not always explicated suitably by medical colleagues and that they were often required to provide suitable elucidation to enable patients to make decisions.

*... if more time is spent clarifying the benefits of treatment [by medical staff], it's the biggest thing and I think people feel empowered when they've got an understanding and knowledge of things.* (Nse 07/12)

*We [nursing staff] spend a lot of time explaining and describing info so they [patients] fully understand the consequences of their actions or decisions ... (Nse 11/8)*

Conversely, a minority of senior medical staff understood the significance of making proposed therapy clear and the effects that this had on resultant decisions. A few medical staff demonstrated the extent to which they believed coherent information was important. This included discussing the various options of therapy, but also providing a professional opinion relating to each aspect of treatment they had raised. It was acknowledged that merely listing a range of therapies was insufficient to allow patients and relatives to seriously consider what they might want and when this occurs it tends to only confuse them further.

*I mean, some people [medical staff] may only give one option, like the surgical option ... at the other end of the spectrum is giving all the options but never, never giving your own professional opinion, and expecting patients and families who haven't any medical experience to choose between a "Chinese menu" [a long list] of options, that's equally difficult. I think we [medical practitioners] do both, and I think both things are bad. (Dr 014/8)*

The approach to communicating with patients and relatives for many health professionals, particularly medical staff, reveals a lack of insight into the importance of clarity. Nursing staff frequently step in and contribute to elucidation, with the provision of both sensory and procedural information, a strategy which appears to be widely underrated by many medical staff.

#### **9.3.4 Offering alternatives**

One reason for patients refusing treatment is due to the problems or impediment the treatment causes them. In order for staff to reach an agreement with patients, they sometimes offer an alternative form or mode of treatment. This might include a different method of administering medication, from intra-venous to an oral intake. Once staff have identified the reason for the refusal of therapy, they will offer alternative methods, which effectively allow a similar outcome, if this is possible.

This encourages acceptance of therapy and ensures that patients largely adhere to it because it is more tolerable for patients.

*Also, you can offer alternatives ... why we try something like a local anaesthetic, why we do this, if the [patient's] reason was, "Look, I just hate needles, they're painful," or things along those lines. So offering alternatives is another approach as well and usually, as I said, you come to a compromise. (Dr 012/3)*

Arranging a change in the way treatment is delivered, due to a patient's refusal, can occur when one staff member confers and negotiates with another. This was observed on numerous occasions in all wards and units. When treatment continues basically in accordance with the therapeutic unit's plan, then health professionals more readily agree with the alternative approach.

*So we [nursing staff] explain that the patient is refusing the medication and tell the doctors and negotiate with them to have it delivered in a different way and they [the patient] might then agree ... it happens quite often ... (Nse 04/4)*

Offering alternatives, either in the method of delivery, or the mode of treatment altogether, makes certain that whatever form treatment takes, it will be acceptable to patients. This is particularly evident when health professionals hold firm beliefs the therapy will benefit patients. Staff members negotiate with patients and with each other to ensure the continuation of therapy and this often proves successful and constructive.

### **9.3.5 Harnessing the patient's life story**

The practice of using concepts, such as the patient's life story, is an effective strategy used by a very skilled group of consultants in one unit, who recognise that often therapy offers limited success and indeed might well cause more pain and angst, with only partial success. The use of a technique, such as obtaining a "life story", encourages an expansive contemplation of the patient's life.

*I don't think it is about medical options. I think it's much more about where you are in your story of your life, which doesn't perhaps matter what the disease is you've got. A number of families take the view that everyone is the same, so it doesn't matter whether you're twenty or you're eighty-eight [age can make a difference to treatment], if you're alive, you're alive. Whereas, if you're doing the story thing ... you get them [relatives] to tell a story of the person's life and you talk about what they [patient] did when they were young, as parents, what they did as a job, ... and then as they retired ... and then when they moved to the unit and then when they moved to a nursing home, and by telling the story you can actually take people through a life ... so now lets talk about what's next, how much suffering, or whatever, is worth it at this point in their [the patient's] life ... (Dr 014/10)*

Consideration of a person's life journey permits a degree of reflection for relatives and assists a weighing of treatment and outcomes, particularly when potential outcomes may be poor. This approach enables a form of evaluation to be made and then discussion of what might be considered in the best interests of the patient at this particular time.

### **9.3.6 Using metaphors or images**

Where difficult subject matter, such as the possibility of death, must be discussed, the use of a descriptive phrase or figure of speech, which can be easily understood, allow patients or relatives to assimilate and take in distressing information. Some staff use specific metaphors to create images and this can more readily convey information, particularly when decisions relate to major life-changing outcomes. To successfully practice this strategy the professional must demonstrate the capacity to step outside the everyday scientific terms so frequently used by health professionals, and include words and descriptive phrases any person can relate to.

*I [nurse manager] use the word "nature" and I often say, "Nature caused this illness for your family member. The only decision you're making here is in regard to will we interfere with what "nature" has*



*begun by taking action, or will we not interfere with what “nature” has begun and allow “nature” to take its course?” (Nse 03/4)*

This approach can enable a clearer picture for patients or relatives and avoids the use of confusing technical jargon or language considered too harsh. It can be a highly successful method of introducing the idea of life and death outcomes. A few experienced health professionals adopt strategies which allow them to introduce information, using carefully chosen representations that tend to reduce negative or ominous connotations associated with poor patient outcomes. This approach provides clarity for families yet allows bad news to be discussed in a more sensitive manner.

*I talk to them in terms of “benefits” and “burdens”. You know, the “benefits” [are] this person may survive, but the “burden” may be that he will have a long trajectory of illness, and if he does survive this is what the likely outcome of that will be. (Nse 05/2)*

The use of metaphors provides an alternative, more acceptable way of addressing difficult issues in discussions. It allows health professionals to deal with discussions of death or unlikely recovery. It is a strategy that also assists in ascertaining the perspectives of the patient or relatives, that is, the pros and cons of the therapy and then their wishes can be addressed.

### **9.3.7 Adopting the patient’s perspective**

Senior staff adopt the patient’s perspective to assist them to differentiate the relative’s from the patient’s viewpoint. Practitioners bring family members together and subtly direct the discussion to consider the patient’s perspective. The practitioner then asks relatives to think hypothetically; if the patient were asked about the proposed plan, what would be his or her response in this situation? This persuades relatives to consider the issues and assists contemplation of the illness from the patient’s perspective. The strategy assists the discussion by highlighting what the patient might want regarding therapy, rather than what the relatives think should happen. This method of considering the situation from the patient’s perspective also assists in bringing disagreeing relatives to a common agreement.

*... I try to focus it [the discussion] on the patient and in that situation one of the tactics is to talk about what would he [patient] say, "If he was sitting here in the chair next to us, what would he say?" and that's quite a useful way of expressing things because they [family] often would say, "Well, he'd [patient] say this is bloody silly" ... and then that introduces some input from the person [disagreeing relative] and then that can drive the conversation about what's to happen. (Dr 014/4)*

Participants believe that many family members, when confronted with a very ill patient, will commonly transpose their beliefs and feelings into the formulation of a decision and this does not allow for the patient's perspective to be contemplated. The strategy of considering the patient's perspective ensures this aspect is included when difficult decisions are made.

### **9.3.8 Engaging as a unified group**

In addition to nursing staff, a range of other staff members provide information to patients and relatives. This can lead to a fragmented approach in the exchange and sharing of information and can influence perceptions, especially negatives ones, which, in turn, impact on subsequent decisions. The plan to bring staff members together with patients and families is considered by some health professionals as a useful and time efficient approach to ensure information is communicated to all involved parties, instead of individual one-off conversations. For some health professionals, the selection of suitable colleagues to be simultaneously involved in the exchange of information is considered an efficient way of ensuring that sufficient understanding is obtained by all parties. The approach enables input from varying staff members and provides a unified approach to relatives. The preference for including specific staff varies however, some view the senior medical staff, namely the consultant and nurse manager, as integral to the group, while other units also utilise relevant allied health professionals, or view the nurse actually caring for the patient at the bedside, as important group participants. When arranging a family meeting the nurse manager stated:

*Usually, in the case of the neurology team, it is most often the consultant, his medical team or some of them, myself [nurse manager] and whichever members of the allied health team feel that they are relevant. Often the speech pathologist will come where there is a swallowing difficulty, for example. (Nse 03/4)*

Unless the senior nurse or consultant specifically include junior staff members they appear less certain of their contribution to this strategy. A few senior health professionals recognise the value of including less experienced staff, as they have valuable contributions to make and can learn from the experience. However, not all units encourage this.

*We [palliative care team visiting another unit] encourage them [bedside nurses] to come to a family conference, but you get the feeling that they are on edge; it's not something they do regularly, but they have current information to offer [about the patient's condition] and it's important that they are involved. (Dr 013/9)*

This contrasts with other units where there is a manifest plan for the bedside nurse to participate. There is a belief that the inclusion of specific staff is imperative, as each member serves a purpose, and the bedside nurse is the one who will often be asked questions from the patient or relatives which are not aired elsewhere.

*... our consultants wouldn't go into a family meeting without one of the senior nursing staff ... and our registrar tries to go as well and if we can, ... but we always try to get the clinical bedside nurse to go also cause they're the one that the family go back to at the bedside and they [bedside nurses] often get their [relatives'] little questions. (Nse 18/15)*

Not only is the composition of the group considered an important strategy, one unit even considers the ratio of staff to family members is also crucial. Staff members expressed and practised, a firm belief that there should, ideally, be fewer health professionals participating in a meeting if there are small numbers of relatives. There is recognition that a shift to patient and family is necessary, in order to encourage a

reciprocal dialogue, otherwise the presence of too many health professionals has the potential to intimidate relatives.

*It's difficult to involve a lot more [staff] there's often registrars, residents and others who are interested but the balance depends on the number of family members. You can never have more hospital members than family members because if the balance is wrong, ... it feels like bullying ... if you're dealing with a very large family, ... where everyone is in, then you can introduce more hospital people ... (Dr 014/5)*

The overriding intent when staff are engaging as a group is to ensure patients and relatives receive consistent information from health professionals, but they are also encouraged to contribute as a group. This encourages all perspectives to be considered with the aim to address concerns and arrive at an agreement about therapy. Insight is gained into the importance of establishing consensual opinion regarding therapy when staff members have to deal with state authorities. A consultant participant highlighted a difficult case where a patient with an intellectual disability living under the care of the state, was admitted. Treatment was provided but the patient's condition deteriorated and major surgery was proposed. The health professionals in the unit were aware of the patient's limited ability to communicate and his intense distress when receiving minor medical interventions. There was discussion as to whether the major surgery should proceed as the patient was incapable of understanding the treatment and there were important concerns raised that he would be unable to deal with the complex care required. The patient's brother lived interstate and was not in close contact with the patient. The consultant contacted the Guardianship Board in order to ask for assistance on how to proceed. As the patient's brother did not believe major surgery should ensue, he effectively refused on behalf of the patient. However, the Guardianship Board drew attention to the legal position that, in fact, the brother could not refuse treatment and directed staff to consider what was in the "best interest" of the patient. The Board accepted the consensual opinion of unit staff, who had consulted widely as a satisfactory way to formulate the treatment plan.

*... there was a consensus from all the staff at the home [where the patient lived], from us [medical staff in the unit], the nursing staff and the surgeons, that the surgical intervention was not appropriate and from the [patient's] brother, and they [Guardianship Board] then accepted the fact that if we all agreed, then there wasn't an issue. (Dr 014/6)*

Given the patient was unable to provide guidance as to care, and his brother was not legally able to refuse the surgery, the focus shifted to weighing what was in the patient's best interests. Therefore, rather than the issue being viewed as a refusal of treatment, the process utilised the formulation of a decision as to what was best for the patient in the circumstances. Numerous opinions were drawn upon in order to reach a decision.

In many situations the difficulty in reaching a particular decision can be in deciding the degree or extent to which the active, interventionist therapy will be acceptable to the patient. Health professionals usually do not share identical values, nor do patients and their families. If a prior discussion about the patient's beliefs and desires regarding health care has occurred, then staff members have something to guide them. However, this is often not the case and some senior staff recognise the need to shift the emphasis of the discussion, to include the treatment process and the limits of acceptable treatment boundaries.

*But the much more important thing, I think, is about the degree to which patients and their relatives wish to go, in order to achieve an outcome [other than death], and that's a whole discussion that we're [health professionals] not into. So if the only discussion is ... "Is there any chance doctor" and what they want you to say is "No" because that resolves it, but if you say "Yes" there is a bit of a chance, but the journey to get there is absolutely foul ... I think I can put it together, but how do families put it together ... they're [families] coming from a completely naive position. (Dr 014/10)*

The extract above recognises the difficulties for all parties when discussing and weighing the extent to which therapy should continue. Making a decision about

whether to continue with invasive therapy is complex and largely dependent on staff insight and how they approach the entire process. Much is dependent on whether staff can assist the patient and relatives along the journey with the ultimate aim of reaching some consensus about how to proceed. In some situations where health professionals find these issues difficult to address, treatment will in all likelihood continue.

### **9.3.9 Searching for cues**

Responding to patients and relatives requires proficiency in listening and identifying whether the discussion is actually comprehended. Cues may be verbal utterances expressing emotions, worries or concerns, or changes in the tone of voice. Alternatively, cues might come from non-verbal signals, such as frequently changing position in a chair, or avoiding eye contact when specific issues are discussed. A few participants demonstrated this ability. One highly experienced nurse described a tactic used by senior colleagues in her unit. They observed the relatives in attendance and watched for signals indicating a lack of understanding or confusion when therapy plans were discussed. Then when most of the practitioners had left, the senior nurse invited further questions and encouraged relatives to offer their interpretation of the situation.

*... we're [nursing staff] there to pick up if something's said and you can pick the verbal and the visual cues when people aren't really listening to what's happening or didn't understand it. When I go to a family meeting I don't say very much at all. I just listen and watch everybody in the room and I just say, "You didn't look like you understood what was happening just then. If you've got new questions I can now clarify or explain them for you". Inviting questions, picking out the really distressed person that might really be an issue or a problem to that family member, and then staying after the meeting to get them [relatives] to talk back to you. (Nse 18/15)*

This strategy provides multiple advantages in the accomplishment of assisting people to understand the circumstances. It ensures the health professional hears the initial

discussion and input offered from colleagues, individual relatives who may be unsure or confused, can then be identified and further discussion can occur. The strategy also alters the tone of the meeting, as fewer people are present and appears less formal and encourages further dialogue.

#### **9.4 DISCUSSION**

Responding in this category encompasses how health professionals communicate, their willingness to do so, and the techniques they employ. While health professionals are clinically competent to provide therapy, their ability to respond to patient or family concerns is variable. The skills required to successfully clarify and convey information and interact with patients and relatives, necessitates more than mere clinical expertise. Specific interpersonal qualities are crucial. The strategies for responding convey a range of behaviours in which health professionals relate to patients and family members when they indicate a disapproving response to treatment. It involves the manner in which information is provided, shared and documented, as certain behaviours are more likely to influence a change of decision to refuse, or conversely, further entrench the refusal. Other facets of this behaviour include techniques developed to assist and respect decisions, and the determination of participants to ensure that therapy is not just offered, but appreciably considered from all perspectives. The category highlights the individual and group characteristics of health professionals and their desire to work with and value, the decisions of patients and relatives.

The data reveal that a minority of health professionals exhibit highly developed responding strategies most of the time, the remainder some of the time. There are also differences between the strategies utilised by medical and nursing staff. Participants who demonstrate highly developed techniques of responding are capable of innovative methods, such as harnessing patients' life stories, using metaphors or images, searching for cues, emphasising patient perspectives, or engaging as a unified team, all attempts to ascertain and personalise the information gained. This compares with strategies more commonly embraced, such as providing comprehensible explanations, reiterating, elucidating, and offering alternative modes of therapy, which are more commonly utilised by participants. The processes and

strategies adapted are dependent on individual characteristics and the established practices of a specific therapeutic unit.

In the categories *Seeking Clarification, Advocating and Influencing*, many strategies are learned from senior more experienced health professionals. This category highlights the importance of individual and professional life experiences and interpersonal skills, rather than relying solely on experience or seniority. It is the medical staff members in acute care hospitals who assume responsibility for treatment plans and therapy ordered, and there is an expectation, both legally and professionally, that they will provide adequate information regarding therapy to patients or relatives. Thus, the commitment of senior medical staff to the process, largely denotes how well the process of responding unfolds and helps to explain the responses of other health professionals in this process. Despite this important role, the senior medical staff observed demonstrate considerably diverse abilities to interact and respond to others. Some demonstrate empathy and purposeful engagement with patients and families throughout all aspects of therapy, others are more distant, keeping dialogue to a bare minimum.

Some authors believe that few medical practitioners receive adequate guidance and help to respond and communicate effectively, during their initial formative experiences (Orlander et al., 2002; Firth-Cozens, 1987). Many medical staff themselves, have reported difficulty handling their own emotions when discussing sensitive or difficult news<sup>79</sup> with patients or relatives: sorrow, guilt, identification and feeling a failure are some of the emotions described (Fallowfield & Jenkins, 2004). Indeed, consultants often miss cues and concerns and adopt behaviours that discourage disclosure (Zimmerman, Del Piccolo & Arnstein, 2007). Some senior practitioners have not developed suitable skills, which can then be used as a model for others (Farrell, Ryan & Langrick, 2001), and generally, communication skills do not improve with experience alone (Cantwell & Ramirez, 1997). Often the task of discussing treatment and the associated difficult conversations is delegated to junior

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<sup>79</sup> Where patients have serious illnesses difficult news and conversations include any information that relates to a negative alteration to a person's expectations about present or future wellbeing that causes a level of distress (Fallowfield & Jenkins, 2004).



medical staff, who must “learn on the job” in the absence of direct support or guidance from colleagues (Stewart et al., 1999). This is evident in the present study where, in some therapeutic units, senior practitioners have minimal contact with patients and relatives and assume additional involvement only when a major decision is required.

The expectation is that the registrar will work with the resident to communicate with, and respond to, patients and families. The junior medical and nursing staff provide the “front line” for much of the information and only when a change in therapy is considered will the senior medical practitioners spend time in any form of exchange. Even then it may be relatively brief, and constructed to deliver specific information, usually procedural in nature, and little time or energy is directed to encouraging questions or ensuring relevant family members are included. This form of responding, arguably, provides an example for junior staff members, who in turn, are likely to replicate this form of behaviour when they become senior staff. This was noted in the current study as many residents appeared guarded and engaged in limited dialogue with patients. The responses of registrars varied widely; some displayed impressive skills of providing information and interacting, and when this occurred, patients and relatives would often acquiesce to the suggested therapy. Conversely, other registrars mirrored the behaviour of some senior consultants and maintained a distant approach, keeping their interactions to a minimum.

The limited approach to responding to patients by some medical staff provides insight into the significant role nurses play. While it is recognised that medical practitioners have an important role in discussing life changing diagnoses and serious illness, other professionals, most frequently nurses, can be equally involved in this encounter (Farrell, Ryan & Langrick, 2001). Nurses are important because they are often in closer contact with patients on a day-to-day basis and may be more aware of how the therapy and associated decisions affect patients (Farrell, Ryan & Langrick, 2001). They also have an opportunity to provide support during the ongoing process of adapting to the illness. They are the key players who alert and then suggest alternatives to therapy, in the event of refusal.

Many nursing participants appreciate the need for flexibility, as patients describe problems with current modes of therapy. Where an alternative method of treatment is available and considered effective, nearly all of the medical staff are agreeable to the change, but the request usually comes from nursing staff. Where residents or registrars are less than clear or forthcoming with their explanations, it is the nursing staff who recognise this shortfall and respond by calling them back, asking them to elucidate and clarify important information. The absence of clear and understandable explanations are common. This is exacerbated when the registrars and residents have some difficulty communicating in English. Without suitable responses of nursing staff, who seek to ensure that reiteration and elucidation occur, it is possible that more decisions to refuse treatment might occur. On the occasions where nursing staff display limited abilities with these techniques, the concerns of patients escalate more dramatically and sometimes result in angry patients and relatives and heated exchanges with staff.<sup>80</sup>

Health professionals have reported unhelpful encounters with patients and relatives due to inadequate communication and this can increase stress levels, provide a lack of job satisfaction and impact on emotional burnout (Fallowfeild, 1995; Ramirez et al., 1995). The skills of providing timely, understandable information, reiteration and elucidation are strategies that can make a difference when patients raise concerns. They demonstrate expertise in effective communication and, as this study illustrates, are viewed by some participants, particularly nursing staff, as necessary behaviours to ensure appropriate information is conveyed. These strategies are often a response to inadequate interaction by medical staff, but they can also be utilised to re-enforce information previously supplied. From the patient's perspective, a willingness to listen and explain is considered to be one of the essential attributes of a health professional (Fellowes, Wilkinson & Moore, 2004).

The literature provides insight into the effects of health professionals' deficient communication proficiency on both themselves and their patients. Fallowfield (1993) states that despite the fact every area of clinical practice requires medical

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<sup>80</sup> See Chapter 11, section 11.3.4 Maintaining control.

practitioners at some stage to discuss difficult or bad news, a lack of training exists. This gap is considered damaging for patients and their relatives, and for the practitioners themselves. An insensitive approach when communicating, particularly difficult information, increases the distress of the recipients and can exert a lasting impact on their ability to adapt and adjust and can lead to anger and an increased risk of complaint or litigation (Fallowfield & Jenkins, 2004). From the data in the present study, an insensitive approach can further entrench a decision to refuse therapy. Many medical practitioners also find situations stressful and in the absence of effective education, they often adopt inappropriate ways of responding and coping with the emotional fall-out (Fallowfield & Jenkins, 2004). Palmer (1998, p.23) describes “the normal approach of academic education as one in which professionals are taught about the world as if it were a world they do not themselves inhabit”. This is ironic when applied to health professionals who are meant to be helping patients and relatives deal with life changing illness, because these are universal life experiences that many human beings will be required to endure (Browning, Meyer, Truog & Solomon, 2007).

Ingelfinger (1980) states that inadequate communication might be related to a number of factors, including the truth of the information which may be masked by euphemisms or language too technical for the patient to understand. The health professional may think they have informed the patient, whereas the message may not have been received or retained by the patient (Ley, 1982). Moreover, a single interaction may be insufficient for a listener who is distressed by shock, pain or anxiety (Goldberg, 1984). Some practitioners might suffer feelings of inadequacy and respond by restricting their relationships with patients to topics with which they feel comfortable, believing professional detachment is important, or deciding that psychosocial care is not part of a medical practitioner’s role (Ray, Fisher & Wisniewski, 1986).

Health professionals often find it difficult to step back and take into account the spectrum of physical, social, occupational and emotional issues that may affect how the illness and associated information is classified by patients and their relatives (Fallowfield & Jenkins, 2004). This, in part, may be explained by the sociological

and historical accounts of medicine, and arguably, to a lesser extent nursing, that have placed emphasis on a longstanding trend, which objectifies patients (May et al., 2004). In this view patients are passive things upon which the practice of medicine is applied (Turner, 1995). Medical knowledge and practice serve to objectify the patient, denying the experiential and subjective aspects of ill health, focusing on the patient as a specific pathology; patients are reduced to organs, lesions or diseases (Jewson, 1976). While the central focus is relevant knowledge of science, the discussion needs to take into account a far wider set of conditions and problems, at the centre of which are patients' own subjective experiences of illness (May et al., 2004), and its effect on their lifestyle. In recent decades there has been a shift away from practitioner-centred discussions, to negotiations which are more patient focussed. This is supported by the literature where numerous studies consider practitioner-patient communication and the desire for patient centred approaches (May et al., 2004; Fellowes, Wilkinson & Moore, 2004; Fallowfield & Jenkins, 2004; Girgis, Sanson-Fisher & Schofield, 1999).

The views of patients and their families have become important as one indicator of quality of care however, the methods of consultation between the various parties throughout the delivery of treatment, is now more complex (Gothill & Armstrong, 1999). There remains considerable variation in the ability of health professionals to extract and incorporate wider considerations into the practitioner-patient relationship. From the data the strategies that demonstrate this trend, include the use of metaphors, harnessing patients' life stories and considering patient perspectives of the illness. These serve to elicit specific information from patients and their families. The use of metaphors assists a relatively clear conceptualisation of the effects of a severe illness. They enhance understanding of the types of therapy required to maintain life and the possible effects on the quality of that life. This enables participants to identify the extent of invasive treatment expected by family members.

The technique of harnessing a patient's life story was utilised when it was difficult to include patients or obtain information from them. Relatives were asked to consider what treatment the patient might prefer, given the circumstances. This approach can help to uncover valuable information, and sometimes, patient perspectives are

remembered or highlighted by relatives. When there are differences of opinion regarding therapy, or participants seek to differentiate family and patient perspectives, they construct a hypothetical discussion, in order for consideration of the patient's perspective. They ask the family to consider what the patient would say, if it were possible, about the current illness and proposed treatment options. This requires health professionals to spend time with relatives, actually drawing out this information. These strategies were consistently utilised by the staff in one therapeutic unit. They believed these strategies helped to guide therapy and minimised the likelihood of conflict and refusal, which take even more time to address. The participants reported that these strategies assisted a consensual approach, which made very difficult conversations and subsequent decisions, in the main, less stressful for everyone. This behaviour highlights more than the reduction of stress, in order to successfully complete these practices, health professionals need to convey a sincerity and commitment to act on the information they obtain. Each of these techniques shows innovation and a conscientiousness to honour the patient as an individual.

Units where staff, particularly consultants, placed great emphasis on a group approach minimised refusals due to frustration or uncertainty, as the strategy, when practised competently, proved to inform all involved parties. Carefully structuring meetings to incorporate interdisciplinary colleagues and seeking cues, provided a unique exemplar for staff in two ways. Firstly, the strategy endorses the importance of involving patients and their families in wide ranging discussion. It allows colleagues to interpret cues, observe difficult conversations, and learn how to deal with questions or disagreement, as they observe the more skilled practitioners. When the perspectives and expertise of patients and families are accorded appropriate status, it conveys a powerful message for training practitioners as to who should be considered important in the decision making process (Browning et al., 2007). Secondly, in a health care culture where medicine is highly prioritised, exploration of other perspectives provides a chance for health professionals to discover where to position themselves. They do not have to control or solve all problems, but rather can explore and address the limits of what they can offer and be enlightened as to the desires of patients and relatives. Becoming competent in dealing with others requires

health professionals to be genuine and honest, to “leave their status at the door”, to invite colleagues into the conversation and to ensure the emotional aspects are discussed along with the physical (Browning et al., 2007, p.910).

This study has identified a number of strategies considered effective as a means of responding. Several of the features have also been identified by Girgis, Sanson-Fisher and Schofield (1999), who examined nurses’ and medical practitioners’ ratings of the most essential features clinicians should adopt when discussing difficult news with breast cancer patients. The features include the use of simple language, the need for a quiet and private setting, assessment of the patient’s level of understanding of the situation, and allowing uninterrupted time during meetings to encourage questions. Other aspects deemed important by the nurse and medical practitioner respondents in that study included the need to discuss possible treatment options, documenting what the patient had been told, noting family members included, the patient’s reaction to the information and arranging a time in the immediate future to review the situation. Some health care organisations use specifically formulated guidelines to assist practitioners when engaging in conversations with difficult subject matter (New South Wales Cancer Council & Postgraduate Medical Council of New South Wales, 1994). In this study there were no references made to guidelines; it appears participants largely relied on their own methods or the approach of the unit, when interacting with patients and relatives.

When responding strategies are widely embraced by staff members they can enhance communication between all involved parties. Research has suggested that effective communication influences the psychological functioning of the patient and adherence to treatment regimes (Razavi et al., 2000; Stewart, 1996; Fallowfield, Hall, Maguire & Baum, 1990). Conversely, ineffective communication and responses has been linked to adverse effects on patient compliance with recommended treatment regimes (Turnberg, 1997). This study supports the contention that effective responding strategies are more likely to minimise refusals from patients and relatives when they are caused or exacerbated by confusion or frustration. Moreover, these strategies can assist the identification of patients’

wishes, even when they are unable to interact, and this includes the degree to which patients wish to receive treatment.

Health professionals are compelled to interact with a wide range of individuals; however, it is their ability to do so purposefully, with skill and expertise, that distinguishes simple contact from a more determined and purposeful approach. Communicating with patients and their relatives about serious illness has been acknowledged to differ from communicating about less serious conditions (Korsch, Putman, Frankel & Roter, 1995). When patients suffer serious illness, information exchange can be more detailed and complex and necessitates health professionals to draw upon a broad range of strategies in order to inform, support and to realise the thoughts and wishes of patients and their families.

## **9.5 SUMMARY**

Responding processes in this study were practised to varying extents, and were largely dependent upon the aptitude and insight of the individual health professionals involved, and their capacity to fully convey information and arrange suitable settings in which to do so. Health professionals demonstrated various strategies at differing times. Factors that impact on the ability of many staff members to engage in these strategies include the approach and philosophy of the individual therapeutic units, the availability of suitable quiet spaces, the leadership roles taken by the consultants and nurse unit managers, and their respective experiential preparedness. Interestingly, of the responding strategies highlighted in this study there appears to be little current research that investigates or identifies original approaches that have been formulated and practised by the practitioners themselves.

Staff members require considerable commitment, including insight, and a real desire to relate to the position in which patients and relatives might find themselves. When these skills are poorly practised, the knowledge and participation of patients and their families can be largely overlooked or constrained. The lack of opportunity to contribute to treatment decisions may significantly reduce patients' choices and this can actually enhance the likelihood of refusal of therapy. Conversely, when responding strategies are widely embraced it appears that patients or relatives who

raise concerns or doubts, are more likely to continue with therapy, or therapy plans are changed to reflect their wishes. Furthermore, there is an offshoot for associated staff members, as a deficiency or limited ability to respond, exhibited from senior health professionals, serves to thwart or restrict the ability of less senior staff members to provide support and encouragement for patients and relatives.

The ability and desire to relate well to patients and relatives in multifaceted and highly complex situations require unique staff. These individuals are usually interested in their relationships and the way they interact with others, therefore experience alone is not a determining factor. Such professionals are at ease with their own skills and demonstrate an insight into other people's lives. Moreover, they possess a genuine desire to ensure that patients and relatives truly understand what is happening without being judgemental or authoritarian. Their aptitude to communicate well and recognise that the technologies of modern health care practice do not necessarily suit everyone, appears to earn the respect of patients, relatives and colleagues alike.



## **CHAPTER 10**

### **ADVOCATING**

#### **10.1 INTRODUCTION**

The category *Advocating* highlights that the activities of many staff members involve constructive skills relating to the differing styles patient wishes are promoted. These skills provide some degree of support and endorsement to patients, relatives and other staff for the care provided and ultimately, the decisions made. In the context of this study, advocating is to support or speak on behalf of another. An individual speaks in favour of the person for whom they are advocating to effect change or draw attention to an important issue or interest (Hussein, 2005). It can include guiding individuals who make certain decisions, to consider another perspective. Observation and interview data reveal that many staff members promote patient interests in their everyday clinical practice. Many identify this as an attempt to meet the needs of their patients and families and they concede that it is a necessary behaviour, as the health system in which they work ensure that it is not always sufficiently responsive to the patient's perspective.

This chapter identifies the context in which *Advocating* occurs and explores the varying strategies that are adopted by the participants. This is followed by a discussion of these findings.

#### **10.2 THE CONTEXT OF ADVOCATING**

The data reveal that staff members, largely nurses, play a role in speaking on behalf of patients or relatives. They also support and assist patients and relatives to communicate their thoughts and wishes to those who ultimately order treatment, namely senior medical staff. The significant involvement of nurses and the role of decision-making by senior medical staff creates two themes that underpin the context in which advocating occurs. These themes include acceptance of who should advocate, and overstepping professional boundaries.

### **10.2.1 Acceptance of who should advocate**

In the acute care environment it is the medical staff, in particular the consultant, who will determine and direct the treatment plan. Some senior medical staff members do not acknowledge advocating as a role undertaken by colleagues. Rather, they tend to perceive patient advocacy in the light of independent advocates intervening, only when problems arise.

*... I don't believe that in health services there is a strong enough patient advocacy. Patient advocacy is only visible, I believe, or mainly visible, when a stroppy relative is jumping up and down talking about patient care. (Dr 013/7)*

However, advocacy can be a role adopted by various individuals and it can take differing forms. In this study, it is the efforts of staff as they interacted with patients, relatives and each other that are highlighted. Staff will advocate patients' or relatives' perspectives when they have identified that they have not been adequately communicated or considered, by senior colleagues in the treating team. The purpose of this approach is to ensure that senior members of nursing and medical staff are made aware of patients' or families' points of view. Participants view advocating both directly and indirectly, as part of their roles, adapted to suit the demanding environment in which they work. Staff recognise that information, particularly the thoughts of patients or relatives, can be lost or subsumed, as health professionals move to progress therapy. The role of advocating is an automatic reaction of many staff members who realise that without their input, the voices of patients or relatives may go unnoticed.

### **10.2.2 Overstepping professional boundaries**

Given the existence of rank hierarchies among staff in the acute care hospitals, a recurring consideration for many junior health professionals is the perception that when they advocate they might be considered to have overstepped their professional boundary. Participants provide ample examples, where advocates involved in the provision of care, meet treatment decisions with antagonism and the associated implication that they have transgressed their professional role or expertise. Despite

the best efforts of staff members, as they try to promote the patient's wishes to colleagues, or during attempts to understand a patient's decision to refuse treatment, hostility between individuals or groups of health professionals can easily arise. This can seriously impede further discussion and deny patients their treatment preferences.

The following excerpt describes the typical form of disagreement, where some nurses and a social worker, believed it was important to ascertain what an elderly patient wanted regarding therapy. The nurses had voiced their concerns to the registrar and resident regarding the patient's ability to decide, as he had wavered considerably when a brief discussion took place with him. The social worker also thought that someone should try and clarify with the patient, what it was he really wanted. The surgical registrar believed that this behaviour overstepped a professional boundary. He believed that this type of discussion was the sole domain of the medical staff.

*... a patient didn't really want to have major surgery and wasn't too forthcoming to express this to the registrar, so the social worker tried to talk to the patient about his treatment [to ascertain what he actually wanted]. I believe that the registrar got hopping mad about our role [nurses] and that of the social worker's [he thought we were talking the patient out of the operation]. I believe we just wanted to discover what he [patient] truly wanted, and the resident and registrar hadn't talked with him to consider alternatives, yet the operation went ahead and the patient died ... the social worker and nursing staff were really upset [with the death and the lack of discussion with the patient]. (Nse 05/9)*

The ramifications might impact on the advocate, such as demonstrating annoyance with the advocating staff member. In the example above, the registrar reacted negatively, believing his role had been usurped. This highlights another dimension of advocacy where the individual or group in authority, usually the medical staff, also risk a certain loss of face (Teasdale, 1998). The registrar had already interviewed the patient and it could be construed that he had not performed his role with sufficient care or attention if it became evident to the consultant that the patient decided to

refuse the surgery. Thus, the registrar in the study, labelled the advocates as troublemakers who overstepped their professional boundaries. In acute care settings where rank hierarchies are evident, the role of advocating is, of necessity, circumspect.

### **10.3 STRATEGIES FOR ADVOCATING**

There are two distinct approaches adopted by staff. The first approach is indirect as it deals with staff purposefully raising the awareness of patients and relatives, encouraging and assisting them to actively participate in the delivery of care and treatment decisions. This largely involves nursing staff instructing patients or relatives when and how to speak out, and to whom to address their wishes and concerns. The second approach is more direct and deals with staff advocating amongst each other in relation to patient or family requests that have not been appropriately responded to or acknowledged.

There are six strategies developed by health professionals when they are advocating for patients and families: the indirect approach includes *Coaching patients and relatives*, and *Encouraging patients to voice their concerns*: the direct approach involves *Verbalising patient wishes*, *Intervening on behalf of patients*, *Mediating*, and *Lobbying*.

#### **10.3.1 Coaching patients and relatives**

A number of health professionals commented that many patients appear not to comprehend that therapy can be refused, or feel obligated to continue once they have commenced treatment so as not to disappoint others, including health professionals and relatives.

*I think that very often patients who are going to have chemotherapy or radiotherapy may not necessarily understand that it's okay for them to say, "No, I don't want to do that". Patients don't necessarily understand that they can say no. (Nse 03/14)*

In many hospitals patients are given brochures containing statements of their rights and responsibilities when they are admitted<sup>81</sup>. The aim is to provide some information and insight into the expectations and roles of the hospital staff. Contained within the brochures is usually a statement to encourage patients and relatives to participate in the care and treatment decisions, including the right to refuse treatment. Many staff recognise the limitations of such information, as patients do not always read the literature or necessarily understand how to participate, and indeed whether they should take an active role in treatment decisions. When a patient was given the printed material and then proceeded to neatly file it away in the bedside cabinet, a nurse stated:

*... they [patients] get their rights and responsibilities paper [brochure], that they never read ... that's what they get on admission. That is a waste of money printing out those patients rights and responsibilities [brochures] .... I try to teach them [patients] to ask others whenever they aren't sure and I say, "If you're not happy [with the answer] tell them, hang on, I don't understand". (Nse 11/15, 16)*

The effort to advocate for relatives is evident in the everyday practice of many nursing staff. In situations when patients are critically ill, unable to communicate their wishes, the family members often want to actively participate in treatment decisions. Relatives commonly communicate with nurses at patients' bedsides, assuming that their wishes will be conveyed and automatically addressed. While nursing staff frequently forward this information to medical staff, they also recognise the importance for it to be heard and preferably discussed directly between relatives and medical staff. Nursing staff will often instruct relatives as to the most expedient ways to become involved. The following excerpt demonstrates this approach, taken by a nurse to instruct relatives who had made a decision, which had not successfully been addressed by senior medical staff.

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<sup>81</sup> There is no formal Bill of Rights on which to rely in Victoria. However, all public hospitals publish patient information brochures and within the printed information there is material relating to the 'Rights' of the patient, including a right to refuse unwanted therapy.

*This went on for weeks ... the [patient's] wife was getting very distressed so on the Tuesday she said that they [the medical team] weren't going to make a decision [about palliation] until Friday and I told her to come in on the Wednesday, specifically for the [ward] round. Her daughter was there ... they [family members] weren't going to come in, and I said, "No, I think it's really important that you come in", and then they did, ... [the patient was then referred to the palliative care team]. (Nse 04/7)*

A number of staff members recognise that patients and relatives often fail to understand their own role in the therapeutic relationship. The strategy of coaching patients and relatives demonstrates the insight of many staff, who realise that those entering hospital often lack understanding of, or confidence in, the culture and processes of health care.

### **10.3.2 Encouraging patients to voice their concerns**

In an attempt to support patients, nurses play a key role alerting them to their possible options. There are numerous examples where nursing staff, having assessed and understood the wishes of patients, then move to provide them with direction and support to speak out or assert their wishes to others in the treating team. While staff members often inform their colleagues of patients' concerns regarding therapy, they also recognise the authority of patients' voices to articulate those concerns directly to the key decision makers, that is, senior medical staff.

*I always encourage patients to voice their concerns, if they tell me. I always say, "Voice them to the registrars when they come round, tell them". I always ... encourage all my patients ... that if they have any concerns to make sure that they voice them to the doctors when they do the [ward] round cause that seems to be the time that they're [the medical staff] able to address it. (Nse 14/9)*

Staff recognise that if patients are too ill to voice their wishes and do not have someone speaking on their behalf regarding available therapies, active and invasive treatment is likely to proceed for longer than the patient might wish. This provides

some insight into why patients or family members are encouraged by many staff members to participate and voice their requests regarding treatment.

*Well, it really depends on whether the patient has an advocate and if they've got a strong family support and the family actually respect that their [the patient's] decision's made or the patient has been constantly telling the family what they would want in this situation. ... If a family have no idea or there hasn't been discussion, or it's all too hard, or you just can't really get their [family members] minds around it, then often it will be they [the patient] get on the medical treatment treadmill and then treatment will continue and we'll do lots of investigations ... until we get to a crisis situation or a patient either deteriorates or complications occur, which is maybe not always the outcome that we [staff and family] would like to see, but sometimes that happens. (Nse 05/2)*

Encouraging patients and relatives to articulate their concerns is an indirect form of advocacy, which many staff believe has a significant effect on key decision-makers. Staff utilising this strategy acknowledged that the voices of patients and relatives can be powerful when requests emanate directly from them.

### **10.3.3 Verbalising patient wishes**

There are times when staff will intervene and speak to their colleagues on behalf of a patient or relative. Direct promotion of the patient or relatives' wishes most commonly occurs as a verbal dialogue between staff members. Nursing staff do not always record informal discussions held during the course of patient care, or they may not fully explore what is being said to them. When patients or relatives repeat treatment requests there is a greater likelihood nursing staff members will record this information. A notation in the patient's file may have been recorded by nursing staff however, they recognise that their medical colleagues do not always read their written entries. Consequently, important issues or concerns communicated from patients or relatives, to staff members fail to be considered or addressed if they are not directly verbalised.

*... if we [nursing staff] think that this is the patient's wishes [not to continue with active treatment] and it hasn't been addressed ... we actually talk to them [medical staff] ... and say to them, "Have you thought about the fact that the patient doesn't want this anymore you know?" (Nse 08/4)*

Verbalising patients' wishes is a common form of communication and advocacy utilised by participants. It reinforces statements already made by patients or family and it draws attention and focus to information that has previously been ignored or not taken seriously. When health professionals repeat patients' wishes they are clearly identifying the source of the information. This provides additional influence and reduces the likelihood of antagonism from senior colleagues who cannot dispute the origins of the information.

#### **10.3.4 Intervening on behalf of patients**

There are also situations where staff members perceive that the most appropriate person, the patient or a relative, is not sufficiently participating, or is overlooked when decisions are made. Sometimes less experienced, junior staff members raise their concerns to senior staff after an incident or decision has been made, in order to draw attention to this issue. In so doing, they are advocating to promote and give effect to the rights of a patient or relative. The following excerpt describes a situation where a resident was directed by a registrar to obtain a patient's written consent for an invasive procedure. The patient was deemed to be legally incompetent, supported by a very long and coherent entry in her medical file from the assessing psychiatrist, yet the resident was determined the patient should sign the consent form. The patient's relative had not been contacted in an attempt to consider if the patient had expressed any specific wishes. The inexperienced nurse did not intervene on the patient's behalf at the time but went to the senior nurse to express her concerns regarding the inappropriateness of the resident's action.

*We [nursing staff] were waiting for the son [relative] to give the consent or let us know whether it was going to happen [with the invasive procedure] because she [the patient] really couldn't give us consent, but*



*Julie [the resident] didn't want to wait. She wanted that consent form signed from anybody really. She had other stuff to do on other wards, she wanted to go ... I've never seen anything so bad in my life that I actually called Claire [senior nurse] aside and said, "Look that was shocking," and Claire actually did challenge her [the resident] on it and then Julie did ring the son and did get a consent properly. That poor lady [patient], she would've signed anything. She could've been signing a shopping list! ... I wasn't ready to take on the doctor just yet ... when you're not confident enough, but when it came from Claire, it had much more impact because she told her [the resident] "This is not on" ... (Nse 06/6)*

Intervening can occur at any time, but tends to relate to situations where participants hold a firm belief that action is absolutely necessary. They intervene to prevent overtly inappropriate behaviour or decisions occurring. When junior staff lack the confidence to intervene they summon the assistance of the senior members to act. Experienced staff are less likely to intervene if they consider the behaviour or decisions fitting in the circumstances.

### **10.3.5 Mediating**

Patients or family members do not always engage in treatment decisions in a timely fashion. Often the relationship between staff, patients and relatives takes time to develop and be defined. There are many health professionals delivering care and the thoughts and wishes of the patient sometimes fail to be adequately communicated to the appropriate senior staff.

*... over the course of the week and a half, to two weeks, I guess there was ongoing assessment and re assessment of his [patient] situation and to-ing and fro-ing from nursing staff to patient and then medical staff ... His mother developed a close rapport with a lot of nursing staff and her input into how her son has was best managed, was really beneficial ... and a lot of her concerns were voiced to us [nursing staff], and then we reiterated those to medical staff. ... They [registrars] were made to have further input and discussion with him [the patient] at the bedside,*

*because he was getting so frustrated that he felt like he wasn't being listened to, you know, a lot of the time. (Nse 14/6)*

The nurses play an active role conveying information and promoting patients' and relatives' point of view to other staff. At times they are mediating, in so much as they form a connecting link between patients and relatives and other members of the care team with the aim of producing agreement regarding care. When this is accomplished successfully, key staff are obliged to take time with individual patients and incorporate their wishes into treatment plans.

### **10.3.6 Lobbying**

Acute care hospitals are comprised of many individual, segmented therapeutic units, each with their own staff. The ability to utilise the expertise of staff from a different unit can reveal the extent of their interconnectedness. It was observed that the staff from the palliative care or medical emergency teams,<sup>82</sup> are utilised to varying extents by the different wards in acute care hospitals. The senior clinicians from these specialised units can be well placed to offer their expertise, providing additional insight into therapy, aside from those of the current treating team. Their opinions can be used to promote a particular treatment issue. They might confirm a strategy the unit staff have been trying to promote and their involvement can provide the impetus for the issue to be "heard" by the senior staff in a particular therapeutic unit. The use and success of these health professionals is partly dependent on how well integrated they are into the wards or units and everyday work of the less experienced clinicians throughout the hospital. The decision to involve specialist clinicians from other teams is sometimes perceived as a decision made by the consultant leading the therapeutic unit into which patients are admitted.<sup>83</sup>

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<sup>82</sup> Palliative care teams comprise senior medical and nursing staff with specific expertise in pain management and care of dying patients. The medical emergency teams (MET) are similarly comprised with senior staff, however their focus is to provide support, often for less experienced staff members in the ward environment, regarding concerns they may have for a patient. For example, when a patient has unexpectedly or quickly deteriorated the MET will be called to assist ward staff in the acute phase and then the medical staff of the therapeutic unit will be informed.

<sup>83</sup> Although, the involvement of the medical emergency teams in a particular patient's care can be a matter of hospital guidelines.

The process of how specialist staff members actually become involved with patients can raise some interesting insights into the extent of collaboration between health professionals from different units and how they can be utilised to lend support for those staff members attempting to advocate a specific issue. Nursing staff members sometimes informally approach members of the outside team, sometimes for advice, or if staff members believe the specialist team can offer assistance, for example, where there are questions from patients or relatives regarding comfort measures, involvement of the palliative care team might be considered relevant. This is their way of attempting to support the patient or relatives and to make them aware of other available treatment. However, decisions to consult outside staff members can depend on the opinions and views of senior nursing and medical staff in any given unit. It was observed that some staff members welcome the expertise from clinicians outside the therapeutic unit.

*... the palliative care nurses visit here [this unit] all the time, so when asked by us [nursing staff], they'll come and assess the patient according to what they think ... and they liaise with the medical team and they all then decide whether the patient will be put under the palliative care unit ... (Nse 09/5)*

Conversely, if it is perceived that only the senior consultant can or should make the decision to include others, then staff might be discouraged from involving individuals from outside units.

*... we [nursing staff] wanted to get the palliative care [team] involved ... but we can't step on toes and I was going to do a palliative care referral for this person and I was advised [by the senior nurse] actually not to [we had to wait to see if the consultant would consider it first] ... (Nse 04/8)*

There is evidence that despite the difficulties of delineating which staff members can or should involve those from other teams, once firm relationships are established between groups then they can work well together, to ensure that the patient or relatives are given another perspective. It was observed that nurses in some ward

areas had very positive working relationships with the nurses from the palliative care team. When nursing staff from the ward environment feel the patient or family would benefit from contact with the palliative care team, the ward nurses make direct requests to the palliative care nurses. The palliative care nurses, in turn, involve themselves in dialogue with medical staff from the ward unit, thereby ensuring that the issues of palliation are raised with the patient or family.

*Some medical teams believe that they are in control of the patient ... the doctor was telling them [ward staff], well actually, his patient is saying that he doesn't want to have the procedure, [but the consultant still wanted to go ahead with it], ... But they [the ward staff] are saying to me [nurse from the palliative team], "Can you tell the medical staff to talk to the patient about less active treatment, because that's what he [patient] wants?" So I might be able to say [to the senior medical staff in the unit], "Please can you go in with a balanced argument and sit down and discuss this with the patient and listen to what he says." Some medical staff take that well, some medical staff not so well, but it's better than it was ... (Nse 05/5)*

The roles of mediating and lobbying to support the patient or relatives' wishes are strategies some nursing and junior medical staff members use within the confines of the acute care hospital. They reflect the organisational restrictions and fundamental work practices of the varying hospital units and health professionals, and become essential activities, to ensure additional and highly relevant information is transferred either from patients or families, or staff members, to the key decision makers, that is, senior medical staff.

#### **10.4 DISCUSSION**

Advocacy is a term and practice, which reflects broad and differing perspectives and behaviours. In relation to health care it has been described in diverse ways (Hellwig, Yam & DiGiulo, 2003; Teasdale, 1998; Mallik, 1997; Kohnke, 1982). Hellwig et al. (2003) describe two forms: a traditional paternalistic approach, and a more empowering approach. The paternalistic approach is guided by the principles of

beneficence (duty to do good) and non-maleficence (to do no harm), because the health professional is considered the “expert” and must make the best medical decisions on behalf of the patient, while avoiding harm. Decisions that are not made by the patient may be considered less than optimal as the ability of the patient to exercise autonomy is severely curtailed (Taylor, Pickens & Geden, 1989). This approach also reflects a traditional model of patient-physician relationship, which characterises the physician as a “guardian”, providing information the physician considers most favourable to the patient’s well being (Emanuel & Emanuel, 1992). The observational data in this study highlights that this form of advocacy is considered a valid and acceptable position when the patient-professional relationship begins. There is an assumption that the health professional has far greater knowledge regarding the complexities of care and treatment and is in a better position to decide what is in the patient’s best interests. Many senior medical staff members practise this form of advocacy, commonly working with the assumption that the patient will accept the treatment proposed.

However, this study reveals that as the professional-patient relationship develops and it becomes evident that a patient or relative is refusing treatment, the empowering approach of advocacy comes to the fore. Participants use advocacy in a bid to draw attention to patients’ and relatives’ desires, not to proceed with current or proposed therapy, with the aim of enhancing further discussion and possibilities, including changing the direction of care. This role of advocacy is apparent when there is a belief by those advocating, that the patient and families wishes are not being included or sufficiently considered and there is a determined intervention to highlight this situation. Participants actively support patients and relatives and make a special effort to defend patient participation in decisions affecting them (Johnstone, 1989).

This is a more recent perception of advocacy, largely practised in this study by nurses, and to a less obvious extent, some of the medical staff members. This approach to advocacy encourages patients to make informed choices based on information and understanding of their illness and in this study it includes facilitating or promoting the voice or perspective of the patient or relatives.

The manner in which the participants practise advocacy in this study can be further explicated using Teasdale's (1998) findings. He offers three different types of advocacy: self-advocacy, independent advocacy and collective advocacy (Teasdale 1998). In self-advocacy patients are encouraged to speak up for themselves, rather than health professionals doing things for patients. There is a shift to help them present and take responsibility for their own concerns. Independent advocacy in general health care entails the advocate representing the patient's views. Mallik (1997) describes this as the most common form of advocacy, which is "triadic", meaning that it involves three parties, the patient (or relative in this study), the advocate and another person, whom the patient and advocate wish to influence. This occurs when the patient or relative demonstrate difficulty communicating to the third party, such as senior medical staff. Curtain (1979) describes these patients as "silent" in the sense that they had difficulty speaking up for themselves or knowing how to actively participate. The level of independence of the advocate varies considerably, from general members of staff to specifically designated patient advocates who may or may not be employed by the health service. Collective advocacy refers to an organised group of people campaigning for a particular cause. These are usually independent organisations working for specific groups of vulnerable people (Teasdale, 1998).

Participant behaviour in this study demonstrated episodes of self-advocacy and independent advocacy, with a variation of collective advocacy at times. In self-advocacy participants instruct, support and encourage patients and relatives to speak out and share their wishes with senior members of the treating team. Interestingly, this largely unfolds as an indirect behaviour, in so much as the participants when they are with the patient and relatives, inculcate them, when and where to speak out. Independent advocacy is more direct as participants actively intervene with senior nursing and medical staff, with the express intention of highlighting the patient or relatives' wishes. Less experienced nursing staff, largely practise self-advocacy, and independent advocacy is more commonly evident among more experienced nursing staff and some junior medical staff. Participants commonly assume therapy will be automatically accepted. They only take up advocacy as a response to the patients' or relatives' signals. Thus, it is generally only practised once participants become aware

or informed that the patient or relatives have indicated a desire to refuse treatment, or their express wishes have been overlooked.

Given that the purpose of self-advocacy and independent advocacy are to reveal the patient or families perspective, they have been described as forms of empowerment, where knowledge is considered a commodity that enables patients and families to become informed and effectual participants in the delivery of health care (Bramlett, Gueldner, & Sowell, 1998). However, patients must be provided with information before they can gain knowledge or actively participate. At the very least this applies to an understanding of their role in the health care system. The rise in consumer movements has seen an increase in the dissemination of information to patients in respect of their “rights” and the “obligations” of the health service. In many western countries, including the United Kingdom, patient charters have been widely promoted (Mallik, 1998, p.1007) to encourage patient participation in the delivery of care. However, Mallik found that the impact of patient charters and patient advocacy essentially focussed on client groups rather than the individual professional-patient relationships. The current study highlights that participants recognise that there are significant shortcomings of patients’ understanding of their ability to actively participate in decisions and the care provided. Despite attempts by many health services to include and empower patients, using brochures and patient charters, participants recognise that many patients and family members do not actually read, understand, or act on that information.

In self-advocacy participants appreciate that if patients and relatives are made aware that they can refuse treatment, then they are likely to voice their wishes more freely and unreservedly. Furthermore, the activities of coaching and encouraging patients and relatives, inform them of the most appropriate individuals with whom to discuss their concerns and the most opportune time to do so. Hence, the actions of participants when they are directing patients or relatives to speak with specific registrars and consultants and the precise timing as to when those staff members will physically visit the ward areas, are important roles to inform, and empower patients and family. Instructing patients and relatives to self-advocate highlights acceptable roles for patients and relatives to adopt in the therapeutic relationship.

Effectively, self-advocating compels senior medical staff to hear what patients and relatives are saying. Taylor (2000) argues that health professionals often deny patients a real say in their care and are skilled in disempowering patients. This occurs due to poor communication, patients are not always listened to, or taken seriously and not all health professionals are able or willing to take account of the patient's view (Taylor, 2000). When patients or relatives express a decision to refuse treatment in the optimum context, that is, to the senior medical staff when they are physically present, there is a greater chance that the concerns or wishes of the patient will be discussed with them. Indeed, when patients or relatives are articulate and assertive there is a much greater likelihood that their wishes will be heard and addressed. When patients voice their concerns it does not always ensure that treatment will change, but it greatly increases the likelihood that some direct discussion will occur with the patient or family, rather than being filtered through various staff members. It is also acknowledged by participants, that if patients' refusals are not sufficiently communicated to senior medical staff, active and invasive treatment is more likely to continue.

Independent advocacy, where participants verbalise patient wishes, intervene or mediate on behalf of patients and family members to senior staff members, most commonly occurs when therapy persists, despite statements indicating a contrary position. Nursing staff sometimes record in the patient file the patient's or relatives' requests or concerns regarding therapy. These entries are not always addressed by senior members of the medical staff, who might not read the patient file, but rely on their junior medical colleagues to inform them of such matters. When this is perceived to occur, nursing participants will usually make a concerted effort to speak directly with the medical staff. When communication from nurses or junior medical staff to senior medical staff is successful, often discussion will ensue between them and then junior medical staff or nurses return to the patient or family, sometimes with further suggestions or explanations. These staff members become mediators or links conveying information between senior staff, patients and family. Treatment might change, or the patient might continue on with therapy. At the very least there is some attention given to the desires of the patient and the opportunity to further discuss therapy.



Of the different types of advocacy the tendency for a number of staff members to lobby others to be involved could be considered a loose form of collective advocacy. It is a strategy aimed at incorporating others with expertise, to support a particular position, such as the patient not wanting to continue with invasive treatment. Staff members from external teams are experienced and specialised nurses and medical practitioners. The majority of the treating team from the wards usually consider their views as highly credible. Successful involvement of external staff creates a group or collective which is able to promote a particular perspective, that can and does, reflect the patient or families' wishes. Therefore, interventions by staff members from the specialised teams are effectively utilised by many ward staff. The most common situation identified is the ongoing delivery of treatment the patient does not necessarily desire. The involvement of specialised staff might legitimate the views of the ward staff who, in turn, believe that their views and those of patients, are being ignored by senior staff of the existing treating team. The involvement of external staff members has the effect of generating further discussion with senior staff in the treating unit, thereby reinforcing a particular perspective. Patients' refusals or concerns are more widely publicised and therefore, possibilities considered, as there are additional opportunities to discuss the care plan.

The success of direct forms of advocacy, such as independent and collective advocacy, depends on the cultural environment in which the advocacy occurs. Where all contributions are equally valued and where patients, rather than staff members, are located at the centre of care, there is greater likelihood patients' view will be addressed (Snowball, 1996). In these circumstances the advocacy role is not considered an opportunity to gain power, but rather part of a collegiate endeavour, within the bureaucratic constraints of the health care system, providing an opportunity to proactively influence patient outcomes, according to the patient's needs and wants. For example, in ward or unit areas where the external teams frequently attend, they forge positive relationships with all members of staff, who become more attuned and accepting of their involvement. This provides an effective adjunct to ensure that patients' perspectives are aired and this contrasts with ward environments where the specialist teams are less frequently utilised because ward staff members are less likely to incorporate them. Factors influencing effective use of

these teams are dependent upon the general openness and ease with which senior nursing and medical staff accept external involvement, and the success to which the team have been instilled into the bureaucratic structures of the hospital.

It has been argued that it is not easy to act as a patient advocate, as it can be considered a direct challenge to the senior registrar or consultant's authority (Wywiałowski, 1997; Holly, 1993; Winslow, 1984). However, it is evident from the data that staff members with knowledge of patients as individuals are well placed, in the sense that their participation in determining treatment is necessary, if senior medical staff are to gain access to specific patient information, including a desire not to continue with treatment. In this study nurses act as collectors of information and carriers of social knowledge and so have the potential to increase their participation in the decision-making role (Winslow, 1984). The extent and frequency of any direct form of advocacy is dependent upon the culture and personalities of the senior staff members in any given ward or unit.

In the areas studied, the frequency with which independent or collective advocacy was practised, varied considerably. Often, less experienced nursing and medical staff members would promote patients' concerns to senior members of staff, assuming the information would be considered or addressed. Success of further advocating patients' or families' views was then largely dependent upon individual senior nurses or registrars' approaches to the consultant. This revealed reliance upon individual senior staff rather than a general culture of the ward or unit enabling staff members to speak on behalf of patients. However, in one particular unit, all staff members are encouraged to approach patient care by voicing patients' or relatives' wishes and concerns. It is viewed as an accepted method of evaluating and re-evaluating ongoing therapy. The culture of the unit clearly recognises that advocates require the time, energy and empathy to listen to patients and family members. It is important to obtain the whole story, optimally achieved by the involvement of any member of staff, once they become aware of patients' or families' concerns. This information is then directly conveyed to senior medical staff.

Given that nurses largely undertake the role of speaking on behalf of patients, some authors (e.g. Erlen & Frost, 1991; Holly, 1993; Borawski, 1995) describe difficult

ethical situations where staff members describe feelings of “being caught in the middle, helpless and frustrated” (Erlen & Frost, 1991, p.401). Oldaker believes that some nurses experience conflict over whether their allegiance is to the patient or the institution (1996). The data suggests that the effectiveness and frequency of the advocacy is tempered by the culture and the experience of participants in any given ward or unit. Where the ward or unit culture encourages and is responsive to advocacy, especially direct advocacy, it occurs more frequently across a broad collection of staff members, regardless of experience or professional discipline.

The data in this study show that participants recognise that information is not always successfully communicated to senior staff and they consider it as part of their professional role to redress the situation. It was commonly observed that many nursing staff encouraged self-advocacy and participated in independent advocacy, often to resolve a communication issue. Teasdale (1998) argues that the risks or conflict associated with advocacy are relatively low when advocates are trying to settle a communication problem. However, the likelihood of conflict or risk to the advocate increases when those in positions of authority fully understand patients’ positions but are not prepared to agree or respond to it. Health professionals in this study described such occasions.<sup>84</sup> Given that the nature of advocacy is to affect those who have power on behalf of those who do not, there is always a potential for dissent and conflict. When this occurs the issue can be perceived not as a failure of communication but a disagreement over substance (Teasdale, 1998). In this study the registrar’s assertion that an advocate had stepped beyond professional boundaries demonstrated more than dissent; the response was designed to deter further efforts to advocate on behalf of the patient.

There are also possibilities the individual advocate might be reported to a senior manager, or as the data reveal, one group of staff, in this case nurses working on one shift, experiencing considerable dissension with those working on another shift when there was insufficient action after they had communicated precise patient requests. A further consideration for the participant advocate is how far the advocate is prepared

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<sup>84</sup> See Chapter 11, Sections 11.2.1 & 11.2.2.

to pursue the case. Advocacy that involves directing concerns through formal channels within an organisation is less risky than jumping levels in the decision-making hierarchy to appeal to someone over the head of the third party, with whom participants disagree. Teasdale (1998) argues that assertive approaches are less likely to cause long-term relationship problems than either aggressive or manipulative techniques. Those wards and units where mechanisms are in place to consider the varying perspectives and allow for the exchange of patient and family information to be incorporated into decisions, were much less likely to face problems when advocacy roles were pursued. Snelgrove (2000) contends that the role of advocating can de-emphasise any rivalry between the professional groups, particularly when it occurs to advance information and ensure effective communication. The degree of influence advocates could marshal largely depends on the ability of the ward or unit to respond quickly to changing ideas or concerns that patients or relatives raise. It was noted that in many areas there was some difficulty in gathering relevant staff together to discuss changed circumstances or opinions. Moreover, those settings where rank hierarchies were firmly entrenched were less likely to witness direct approaches from junior staff to the consultant.

## **10.5 SUMMARY**

There are many examples of different approaches to advocacy assumed by participants and they clearly believe that the role is warranted. When patients refuse treatment, participants appear to have adopted a wide range of advocacy techniques: from instructing patients and relatives to voice their concerns, to speaking on behalf of patients or relatives to communicate their wishes to others. In addition, it is evident that participants actively involve others, external to the unit, to form a collective group to convey information and opinions that support the patient or families perspective, in order to change the therapy provided. The data indicate that on many occasions the various forms of advocacy prove successful and do not result in major conflict or risk to the health professionals involved. It could be argued that advocacy as largely practised in this study, provides a paradigm for framing challenges by allowing nurses and junior medical staff members to communicate

concerns and thoughts, which usually stops short of disputing the authority of senior medical staff.

## CHAPTER 11

### INFLUENCING

#### 11.1 INTRODUCTION

The category *Influencing* highlights the way individuals exert pressure or use their authority in order to affect specific outcomes. This conduct is located on a continuum, from behaviour that effectively dominates circumstances, arguably due to a lack of insight or inclusion. This occurs in an environment where some participants seek to ensure that the wishes of patients and relatives are considered, to activities that demonstrate an overt use of authority or power. Conversely, others concentrate on the achievement of the goals of therapy, in terms of what individual participants believe is in the best interests of the patient. These two ideals might not necessarily correspond, as beliefs become divergent, behaviour can be polarised and designed to shape different outcomes.

Individuals, from health professionals to patients or relatives, maintain wide-ranging opinions and amidst these approaches tensions can arise when their beliefs are incompatible. Due to the number of individuals involved in, or aware of, decisions relating to treatment, and the difficult climate in which therapy unfolds, there is fertile ground for differences of opinion to emerge. This category reveals the conduct exhibited by health professionals as they strive to compel outcomes which reflect their particular viewpoint, and in so doing, seek compliance and conformity from those around them. When individual beliefs or opinions collide there is a strong likelihood that antagonism or conflict will result. Conflict among staff, patients or relatives can have a profoundly negative effect on their experience of health care and influence choices about future therapy.

This chapter highlights the context in which *Influencing* occurs and then identifies the individual strategies of this category. The chapter concludes with a discussion and analysis of these processes.

## 11.2 THE CONTEXT OF INFLUENCING

Influencing is the ability to affect a particular outcome, to prevail upon another individual (Moore, 2004). It can be associated with the skill to gain leverage in a given situation, or use of authority where an individual has exclusive knowledge regarding a particular subject area, or it can be observed in circumstances where an individual holds a position of authority within an organisation (Gorman & Clark, 1986). The health care environment is largely organised and structured to favour the authority of health professionals, rather than patients (Short, Sharman & Speedy, 1993). This provides insights into the fundamental nature of the professional-patient relationship, where professionals have the power to influence and senior health professionals have more influence than their junior counterparts.

The concept of influencing can be associated with two dimensions. As a constructive strategy it can be used when a health professional is intervening with colleagues or relatives in order to elucidate an issue, which may have gone unnoticed. It can also require some adroitness on the part of the treating team to successfully encourage refusing and reluctant patients to embark on the treatment journey when they are frightened, unsure or very ill. When it has the potential to be exerted in an adverse fashion, the behaviour of health professionals indicate they use their considerable influence by selectively providing information, or maintaining undue control of the treatment process. In the health care environment the professionals are recognised as the “experts” on disease and illness; they order therapy and it is on their direction that decisions are largely made. Patients and relatives can be elevated and included throughout the process, or they can be “managed” to a particular outcome. In turn, patients and their family members might accept the situation, or react and change the direction of care.

Divergent beliefs regarding the current or proposed therapy can generate varying degrees of antagonism. Conflict arises when individuals participate in activities that generate tension, resulting from disagreements or incompatible interests and activities (Gibson, 1986). Due to the sheer number of staff involved in the acute care setting, the decision-making processes can be fraught with disparate opinions, particularly when health professionals possess differing beliefs and are trying to

implement care they personally consider most appropriate. The data reveal two themes in which conflict emerges as a key contextual backdrop as strategies of influencing are employed: differences of opinion, and failing to address concerns.

### **11.2.1 Differences of opinion**

Differing views can be reflected in the delivery of care, sometimes to patients' benefit and at other times, possibly to their detriment. The greatest likelihood of beliefs creating conflict is an absence of adequate discussion, or individuals believing that they have not been able to participate, or their opinions have not been "heard" by the decision maker. The differences are usually important to the individuals involved and can interfere with the achievement of common goals (Wywialowski, 1997). The pace of work, the structure of the workplace and the work demands of acute clinical practice bring a wide diversity of staff and patients together. The segmented organisational structure of acute care work can create discrete groupings of staff. There can be collections of staff divided along professional lines, expertise, seniority, or according to when they work. Conflicting beliefs can emerge between any of these groupings. When there are differing opinions held between the most senior staff members this can create major discord for the patient or relatives, who grapple with the situation.

*... the family were grossly upset [with the ongoing treatment] and were just wanting to speak to our consultant [who supported their views, but had to try and work with the surgeon] and the surgeon [who believed treatment should go on, no matter what] insisted on his treatment [with everyone in conflict] ... then there came a time where the surgeon wouldn't speak to the family at all. ... it had put the family through two or three weeks more of misery than what they needed to go through.*  
(Nse 15/6)

Disparity of opinion between medical staff from differing therapeutic units has the ability to affect significant others, including nursing staff. In the excerpt above, staff in one unit genuinely believed the perspective of the patient and relatives was being disregarded during the clash of medical opinion. Whatever the grouping, when



conflicting beliefs surface they can produce stress and tense working associations among many health professionals and this can spill over into the timing of decisions and type of care provided, regardless of what the patient might want.

*... they [medical staff from another therapeutic unit] seemed to have a fair bit of clout and there was a lot of conflict between those doctors and our doctors [consultants] and we [nursing staff in our unit] wanted the patient and the family views to be heard ... (Nse 14/6)*

The data indicate that the differing opinions commonly emerge among staff, where one group accept the patient or families' view, but fail to persuade their colleagues. The resultant strategies are largely dependent on the approaches adopted by individual staff, although tension cannot be avoided when those in disagreement are perceived to share the same level of seniority. This highlights the blurred lines of authority between senior consultants.

### **11.2.2 Failing to address concerns**

As patient care is provided twenty-four hours each day, there are groups of staff that work during the day and those who work at night. The following excerpt demonstrates conflict arising from two groups of nursing staff working at different times of the day. One group of nurses, those working during the night, believed the treatment decisions made during the day failed to reflect key information they were imparting to the group of nurses working during the day. Instead of working together as one group, the night-time workers believed their input regarding the patient's refusal of a procedure, was not being acknowledged. This became a divisive issue between the two groups of nursing staff.

*... and the night staff would say to us, "Why aren't you telling the doctors that she [patient] doesn't want to live, that she doesn't want a PEG [percutaneous endoscopic gastrostomy] tube, she doesn't want to be artificially fed. Why aren't you telling them?" They [night staff] were going mad at us [day staff] and we're saying, "We are, we're telling them [the medical staff], we're writing it in the patient file", ... and it*

*was just really getting frustrating and there was major tension between us all. (Nse 02/3)*

Attempting to progress therapy can create divergent opinions among staff members and when there are insufficient mechanisms to address the situation professional relationships are affected. Where conflict has arisen it can make staff members more determined to deal with their concerns, or it can prevent or inhibit behaviour. The competing perspectives held and acted upon by those providing care drive the strategies used to persuade others.

### **11.3 STRATEGIES FOR INFLUENCING**

Attempting to manage a situation to give effect to health professionals' perspectives occurs where patients have refused a procedure or specific treatment. The manner and quantity of information communicated to patients is extremely powerful and important. It is a fundamental responsibility of staff members to provide appropriate information to patients in order to satisfy the common law of consent (McIlwraith & Madden, 2006). Often an initial broad description of the disease and the associated treatment is provided, and then minimal explanations for ongoing procedures and therapy. Staff members frequently appear satisfied that the provision of information has been sufficient, despite the myriad of investigations and procedures ordered, and are at times surprised when patients or relatives exhibit confusion, have questions or indeed, refuse care. This can give rise to strategies designed to produce conformity from patients and relatives. There are six strategies utilised by staff members when they are striving to influence: *Managing information selectively, Using mystifying language, Asserting authority, Maintaining control, Yielding to persistence, and Using relatives to attain leverage.*

#### **11.3.1 Managing information selectively**

One significant factor relevant to the formulation of a decision to accept or reject specific therapy is the provision of relevant and meaningful information, including expected outcomes. All decisions should ideally be based on full and complete disclosure of information, including alternatives or options of treatment. A number of participants highlight the situation where patients or relatives are given

information; however the manner and style of delivery is very selectively structured to ensure that a specific decision is reached.

*... one of the problems from my perspective is that the medical teams will often not explore other options with patients, ... they will make decisions about what's in the best management for a patient [from their perspective] and really present just that ... (Dr 05/2)*

Some health professionals believe that at times therapy options, if they exist in a particular situation, are not always adequately canvassed with patients or family. The outcome ensures that the patient will acquiesce to the therapeutic team's choice.

*... it depends on who the doctor is once again, but quite often ... the doctors set out the way that they would like the patient to be treated and then set it out: "Well there's your other options, you know. So this is the best one, this is the one we would want to go down. You could possibly do this, but it's not recommended, or you could quite possibly do that, but I still think you should do this one." (Nse 08/9)*

The provision of full and complete disclosure of information relating to the illness and treatment, and the ability to allow patients or relatives to satisfactorily weigh and consider their decisions, is fundamental for treatment outcomes. Nonetheless, this strategy illustrates the considerable influence the delivery of selective information can place on patient decisions.

### **11.3.2 Using mystifying language**

Explanations regarding treatment often include technical language which the patient or family do not understand. This was observed on many occasions, and attempts to simplify technical concepts into an understandable form are often less than complete. A very common practice is the use of acronyms to describe treatment, procedures or investigations. These terms directly contrast with the everyday language of laypeople and can sometimes unfairly position the patient or prove misleading. This behaviour is not necessarily intentional but occurs due to a number of factors such as brief periods spent with the patient, the myriad of data used investigating disease states,

and the desire of the professionals to quickly progress treatment. The means of treating and communicating to colleagues tends to become the prime focus. These conversations are frequently undertaken at the bedside in the presence of patients with the incorrect assumption that patients and relatives understand what is being conveyed.

*Yeah, I think perhaps there's just a lack of understanding of the terminology that they [staff] use and ... I find I need to, at times, get down to a patient's level of understanding ... to say HB [haemoglobin], FBC [full blood count] and U&E [urea and electrolytes] to them [patients] and they have no idea of what you're talking about, what's a HB, FBC and U and E? (Nse 14/11)*

Health professionals regularly use shorthand terminology to describe treatment and investigations that may be considered minor or unimportant from their perspective, nevertheless it can effectively exclude patients and relatives from the discussion. This is despite the fact that the provision of information is essential to enable a patient or relative to decide in relation to specific treatment. The language can easily be explained and is often not exacting or technical, yet frequently this is not addressed and patients are implicitly reminded of their lesser status.

*It's the abbreviations and all that, or we'll say, "Send out to BMR [the abbreviated name of a rehabilitation centre]" and they're [patients] like what's BMR? ... you know like they don't have a clue about our abbreviations and language. (Nse 11/14)*

This strategy provides ample opportunity for health professionals to influence the decision and abrogate any further discussion with the patient, as the patient is often left pondering the meaning of what has just been said. Some patients ask for clarification at the time, but many will not ask, or will raise queries at a later date, often after the conversation is considered settled.

### 11.3.3 Asserting authority

Health professionals are well positioned to influence patients and relatives due to a number of factors. They have an extensive knowledge base of disease states and related treatment and investigations, and they largely determine when and how treatment and care will occur. In addition, they are more attuned to, and familiar with, the environment in which treatment is delivered. Conversely, as patients and relatives are usually less knowledgeable in relation to illness and associated technologies, they must rely on the direction of staff regarding when and how procedures will occur. Even simple everyday activities, such as eating or showering, can be major activities for very ill patients. Moreover, patients and relatives find themselves in an unfamiliar environment. This positions health professionals with a certain degree of authority, which can be used to persuade patients to comply with their wishes. Some health professionals recognise the imbalance of the professional-patient relationship and the power they can assert when they seek to use their authority.

*You shouldn't actually just go in there with a consent form and say you're going to do this procedure, ... if you do that they [the patient] may well sign it because they feel intimidated by you ... that does happen sometimes ... (Nse 05/5)*

Other opinions expressed by some participants regarding the ability and desire of staff members to assert their authority in relation to patient decisions, were more frank. Health professionals are well positioned at times to influence a particular outcome. This might occur when the patient is frail, vulnerable and too ill to participate, or there are no supportive family members following through therapy plans and decisions.

*... they're [patients] allowed to have a choice, but not really because we'll [nursing and medical staff] override it or try and talk them out of it, when its contrary to our thoughts and they [patients] aren't in a position to do much about it. (Nse 06/4)*

At times there can be little or no acknowledgement from staff members of the reasons for ordering certain investigations or therapies. Health professionals proceed on the basis that if they recommend a particular therapy, then it should be accepted. The excerpt below reveals an example at one end of the continuum, where the patient was adversely influenced. The health professionals used their authority to ensure that their desired outcome was achieved.

*... a woman in her 50s with a psychiatric illness who has had treatment for that illness and had breast cancer ... but refusing the treatment [for the breast cancer] initially when this was diagnosed about three years ago [she was deemed legally competent]. ... the community psychiatrists thought that they should do some scans [to see whether the cancer had spread]. The patient didn't want to know that the breast cancer had spread. ... it was not something she wanted to know; she just believed in her faith and what she was doing and had refused any further treatment. Nothing at this stage was going to be curative because she obviously had nodes [indication of metastasis] ... I remember saying, "This woman has been deemed competent to refuse treatment in the past. What are you going to do with this information if you impose these tests upon her?" The medical team came up with the psychs [psychiatrists], to have a meeting and we [nursing staff] put forward a case for her; that she desperately didn't want her results, so why do the tests? In the end it was deemed more appropriate for her to be in psych [psychiatric unit] than in the general ward and of course when she was transferred to psych she actually ended up having the tests and once she had those tests she was allowed to go home, which is all she wanted to do. I just felt in some ways it was a bit of an abuse of power. (Nse 05/7, 8)*

The relationship is one-sided if patients are not well informed about proposed investigations, or their wishes are completely overlooked and they are unable to assert themselves. As procedures and treatment decisions are ongoing, there is a tendency to assume that the patient understands and is in agreement. Staff might offer treatment because they consider it necessary and potentially beneficial for the patient, or less frequently, they reveal a different agenda they wish to pursue.

#### 11.3.4 Maintaining control

The data show that some health professionals seek to be in charge of certain situations. For example, when they believe that the patient should not receive specific treatment, even when the patient has actually wanted the treatment. This situation highlights a tendency to want to control certain situations, rather than respond to a thoroughly considered treatment plan. This is relevant in relation to not-for-resuscitation orders (NFR).<sup>85</sup> At times there was an apparent eagerness of various nursing staff to raise these orders with their medical colleagues. Some participants expressed concern that the NFR orders were sometimes too readily requested, merely because of the advanced years of the patient.<sup>86</sup> Normally, several factors should be considered before a decision not to resuscitate is discussed, including the type and severity of the illness and likely prognosis. The determination of the type and range of care provided should reflect a decision, after adequate discussion with the patient or family. There are occasions when this issue needs to be addressed because it provides a clear indication of treatment for staff, particularly nurses, as they frequently have to initiate resuscitation. However, in this study the requests appeared to emerge prematurely from some nurses, in the absence of broader considerations and with little regard for what the patient wanted. When nursing staff had not successfully addressed the issue with the patient, they persistently raised the issue with medical staff until a discussion occurred with the patient or family.

*I often feel there seems to be a culture or attitude sometimes in nursing, that, you know, if they're [patients] over the age of 70, everyone should have a NFR order. I just think that's wrong; it sort of throws everyone into chaos because everyone feels that they're superior, with this medical knowledge that they know what's best. ... They [nursing staff] are really quick to raise it with medical staff and say, "Make a decision, you know,*

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<sup>85</sup> Definitions for a NFR order vary, for the purpose of the current study a not for resuscitation order indicates that should the patient deteriorate due to respiratory or cardiac collapse, active resuscitation will not be commenced by staff and the patient will probably die. In hospitals these decisions are a medical responsibility and must be documented.

<sup>86</sup> The tendency for some nursing staff to raise the issue of not for resuscitation orders was observed at the nurses change of shifts when the oncoming nurses frequently asked why there was no order for certain patients (Observational field notes February, 2006).

*encourage them [the patients] to make this decision, or have a discussion with them and find out why not". I have had patients that have said, "No, I don't want an NFR order" and they have been 90 or 95 [years old].*  
(Nse 14/15)

Another facet of the ability to control appears when there is a failure to comply with instructions regarding care. When a patient behaves in a manner the staff consider inappropriate, the ability to shape the outcome becomes evident, as the professional exercises power. This might include threats not to visit the patient in a timely manner, or coercion to encourage conformity. It can be effective, particularly if the professional is perceived to be senior and in command.

*... one day she [patient] was "arcing up" [speaking rudely and angrily to staff and generally failing to comply with their requests] and the consultant was around ... he [consultant] made a point of going in there[to the patient] and saying ... "We'll [medical staff] not come and see you, we will make you wait all day, if you're going to be like that," and it did stop her behaviour.* (Nse 11/10)

Despite the efforts of staff members to explain why they are organising various procedures or care, repeated failure on the patient's behalf to conform, can result in direct confrontation. The capacity of health professionals to prevail is evident when there is an ability to withhold something the patient is in need of, such as medications or a medical certificate, although this is not always successful and patients do prematurely discharge themselves.

*... he [patient] went, "Bugger you, I'm going" and they [medical staff] went "All right, sign this piece of paper," and I'd fully explained to him that if he goes [discharges himself], he won't get any treatment, he won't get any meds [medication], he won't get a proper discharge and they [medical staff] won't even sign a medical certificate.* (Nse 11/3)

Unlike many other professional associations the professional-patient relationship in acute care is quite unique. When patients are seriously ill it can be much more



difficult for them to negotiate outcomes. There is a greater likelihood of inequality in the relationship as the health professionals can to a certain degree, control the interaction.

### **11.3.5 Persevering to succeed**

When staff members hold a firm belief that treatment should continue, the more determined are their endeavours to convince the patient who has refused. A health professional with a fixed belief will continually defer to colleagues in an expectation they will join in and also support this position. There is a determined insistence then to recruit as many staff members as possible to persuade the patient that the decision to refuse is unwise. This is particularly the case when patients want to discharge themselves before treatment has been completed. There may be several attempts from a number of medical and nursing staff members to influence the patient to remain and accept the treatment.

*The registrar at that stage had spoken to her [the patient]; he had been the first to speak to her, ... the nurse in charge had spoken to her [the patient] too and ... the consultant had been in as well. There were lots of people [staff members] trying to convince her; we all persisted to try and get her to stay and have the treatment. She actually did in the end but many [patients] don't ... (Nse 07/10)*

This form of influence demonstrated a high degree of commitment by participants and was frequently linked with patient welfare as the guiding consideration.

### **11.3.6 Using relatives as leverage**

Another strategy adopted by staff members when they believe the patient is not accepting proposed treatment is to enlist the support of the family members. This can entail explaining to a family member why staff believe the treatment is important and highlighting the patient's reluctance to participate. It might be that the patient doesn't fully comprehend the treatment, is frightened, or exhausted with the barrage of tests and procedures organised. Health professionals recognise that patients often rely on their family members for support and this can be highly influential in

persuading patients to accept care. When staff members convince relatives that the therapy is important and beneficial, and where relatives share this belief they, in turn, use their leverage to influence the patient to persist with the proposed therapy.

*We [staff] will try and say something that might convince them [the patient to continue with treatment], ringing their family and saying, “Can you have a chat; we’re really worried. Do you think there’s anything you can say that can convince them to continue”. ... Patients who don’t speak English; getting their family on the phone and saying, “Can you just tell her you know its going to be okay and ask her what’s wrong and how can I help?” (Nse 11/7)*

While relatives can provide additional scope and opportunity to encourage the patient to accept care, there is also potential to utilise them to prevail upon or dominate a patient to decide in favour of accepting care. This approach tends to work effectively when staff recognise relatives’ authority in patient-family relationships. This can occur when individual procedures are clearly refused or when patients wish to terminate all treatment. Family members will be used in an attempt to pressure patients to accept the procedure or remain in hospital.

*... if you can’t talk them [patients] around ... if I feel like we’re [staff] not getting anywhere, ... sometimes family members can be influential, talking to them [patients], telling them why they must go ahead; they are good at convincing them that they should have the treatment ... (Dr 012/8)*

Conversely, the use of relatives to influence can have unintended consequences. Assertive relatives can provide uncertainty as they project their own agendas into patients’ decisions. Relying on the support of relatives to encourage therapy requires a certain unity and agreement amongst them. Where family members are in dispute they can influence a competent patient in whichever direction they choose, thereby negating the suggestions of the health professionals.

*... you will sometimes get family disagreements, different family members, siblings having different opinions and a patient who is totally competent, fluctuates [in their decision] because of the different influences from the family members. (Dr 013/4)*

For participants the incorporation of relatives into strategies can be helpful and it is frequently employed with considerable success. However, once relatives are informed and participating, they become aware of their ability to influence, and can promote their own values and beliefs.

#### **11.4 DISCUSSION**

The category *Influencing* illustrates an approach largely reinforced by the power differential between differing groups and individuals. The data reveal that nurses and medical staff largely engage in behaviour designed to shape outcomes they believe to be in the patients best interests, although some family members might also try to influence decisions the patient has made. The discussion largely concentrates on situations where nursing and medical staff, when faced with the dichotomous situation of addressing patient and family wishes, are at the same time wanting to implement therapy. These two positions might be mutually exclusive, particularly when patients refuse therapy and staff members want to embark on, or persist with treatment. There is potential for uncertainty and disagreement between participants, patients and families who are firmly inclined toward one or other of these positions.

A pivotal consideration in this category is the paramount role of the medical team regarding therapy decisions. In hospital settings there remains a significant degree of medical dominance, where medical staff assume principal responsibility for ordering patient therapy. This dominance is systematically tied to medical knowledge and technology (Wearing, 2004). Of the many health professionals involved in patient care, medical staff are afforded the widest authority to diagnose, order investigations and direct treatment (Petersen, 1990). As a direct result of this role, they define the illness and this legitimates their role to set about controlling it. Thus, one of the major characteristics of the clinical consultation, with patients and other health professionals, is the consultant's prevailing role in the encounter.

In terms of the professional-patient relationship, Atkinson (1995) notes that a key feature is the affirmation of control, whereby the medical consultant takes over patients' "problems" and then sets about controlling or guiding what should be done.

The focus of the interaction is usually determined by the consultant, who deals with medical issues, social concerns are relegated to marginal topics of conversation (Waitzkin, Britt & Williams, 1994). This study confirms that medical staff do largely define how interactions with patients and relatives occur and this can include the provision of selective information. As some participants stated, options to therapy are often not explored with patients, or there is a tendency to use technical language or terminology lay people are unlikely to comprehend. In the majority of situations the knowledge base between patients and families and the medical team is unequal and this provides scope for the latter group to shape the outcome of the interaction. There is ability for medical staff to cut short discussions and questions that they consider irrelevant or uncomfortable, or give information only when directly asked, and provide general rather than specific answers to questions (Weitz, 1999). In this way the medical staff, particularly senior staff, can influence the patients' or families' decisions.

Many studies have documented the ways medical staff, whether intentionally or not, increase their decision-making authority and reduce that of patients and families (e.g. Katz, 1984; Fisher, 1986; Waitzkin, 1991; Zussman, 1992; Anspach, 1993). It has been argued that medical practitioners often make decisions without asking patients' or relatives' opinions, on the assumption that they would automatically agree, or medical staff can respect patients' or families' wishes, only after first shaping those wishes through the selective provision of information about the situation (Wietz, 1999). In this way the senior medical staff can and do have a bearing on patient decisions. Cockerham (2007) provides further insight and suggests consultants exercise considerable authority through three basic factors:

- (i) professional prestige,
- (ii) situational authority, and

(iii) the situational dependency of the patient.

The prestige rests upon physicians' qualifications and specialist knowledge, while the situational power relates to physicians having what the patient wants or needs, and this contrasts with patients' dependency, due to a lack of expertise to treat the disorder. This serves to enhance the authority of senior medical staff, certainly from patients' perspectives, and can explain why patients can be prevailed upon with minimal understanding of proposed treatment or, on occasion, against their stated wishes.

In their haste to implement therapy or investigate illness states, medical staff order numerous investigatory tests, and in the absence of explanatory dialogue with the patient or family this can also appear to be a direct assertion of authority. However, as Groopman (2007) points out, illness states can and should be accurately defined and explained in clear accessible language to patients. Groopman (2007) believes cogent thinking and clear communication cannot be conducted like a race, because haste ensures cognitive errors are made; instead good physicians learn how to manage their communication and time effectively. In other words, despite time constraints placed on senior medical staff if they have greater insight into patients' perspectives they can communicate therapy clearly and thoroughly.

Brief dialogues with patients and families, the use of mystifying terminology and the clear authority to order and direct care can appear daunting to those not familiar with the delivery of treatment in acute settings. The observational data suggest these activities are often unintentional; rather they demonstrate a lack of sensitivity and the desire of participants to swiftly progress treatment for numerous patients. This behaviour suggests patients and relatives understanding as individuals are afforded a level of inattention or low priority. This might also reflect a lack of cohesion or understanding of the individual roles medical staff undertake. Senior medical staff, particularly consultants, appear to rely on their junior colleagues to provide explanations, thus placing the onus on registrars and residents to converse more with patients and families. Nevertheless, a study of resident medical practitioners found they spent little time with patients explaining the meaning of their diagnosis, or why they were having certain tests done. Many residents felt they did not have the time to

undertake these conversations and they were unable to provide good psychological support for their patients (Jagsi & Surender, 2004). This situation might explain the limitations or confusion of each member's role in a given medical team, and the differing abilities of junior and senior medical staff. When there is a range of experience and roles are not made clear, one level of the team can assume that others will and can, fill this void.

Further insight into the participants' ability to influence decisions is apparent when both nursing and medical staff members desire a specific therapy. Some participants openly acknowledge that there can be a tendency to talk patients around to the treating team's wishes. Some participants believed that this behaviour was more about ensuring treatment commenced or continued, while others considered it was, at times, encroaching into the patient's right to decide. This only emphasises the difficulties of the differing perceptions held by those involved and the skill required to balance patient involvement and wishes, with the imperative to treat. Despite the differing perceptions there were some examples of the assertion of overbearing authority, including the insistence of medical staff to complete specific investigations before a female patient could be discharged home, despite her refusal. As Thomas (2003) states, by maintaining control over the ordering of tests, hospital admission and discharge, senior medical staff can extend their influence far beyond their direct participation in patient care. Notwithstanding the legal assumptions that patients have a right to decide, there is evidence this can be easily abrogated.

The data highlight that differing foci and perceptions of staff can give rise to rivalry between groups of individuals as they attempt to prevail upon colleagues to heed patient or family requests not to continue with therapy. Examples included nurses working during the night, requesting their colleagues working during the day to communicate important patient information to the medical team, or when consultants from differing treating teams were unable to agree on patient treatment, because one consultant refused to listen to family requests. Often the purpose of staff behaviour is to influence colleagues however, the potential for dissent increases when the person or group in authority fully understands the information communicated, but is not prepared to acknowledge or agree with it. Factors contributing to this situation can

include the differing philosophies of individuals or their medical specialties. Bates and Linder-Pelz (1990) argue that the development of high technology medicine has resulted in the development of many medical and nursing specialities and one consequence is inter-specialty rivalry. Certain staff members demand technology and a plan of care emphasising their specialty, which may not necessarily be in the interests of the patient. In addition, should an individual or group attempt to incorporate the patient or relatives' refusal and there is a reluctance to confront impending death by some senior staff, friction arises amongst staff as complex pharmacological and interventional strategies continue (Wooton, Borbasi & Redden, 2005).

Nursing staff members also have the ability to assert their authority and ultimately influence patient treatment. From the observational and interview data there were instances of some nursing staff insisting that medical staff seek and implement NFR orders. The concept of discussing this with patients could be viewed as an enlightened approach to patient care. The consideration of all possible outcomes with patients, in order to ascertain their thoughts and wishes, could be considered a positive approach and one that recognises the patient's role in decision-making. Lynn (2000) however, contends that the not-for-resuscitation discussion in hospitals functions now as a ritual. Health professionals do not want to attempt resuscitation when the chances of success are minuscule or as the patient is dying, but importantly the discussion is a way to signal to those involved, that the patient can be treated as a dying person. Once the order is in place other treatments can come into question, the order marks the transition from maximal effort to a priority on comfort as the major goal (Lynn, 2000).

There was evidence that many nursing staff take a pragmatic view, as they are the individuals who usually commence resuscitation in the event a patient collapses. Their apparent haste to obtain an order was explained by some participants as a wholesale response to initiate discussion with patients and relatives, and thus pre-empt a potentially awkward situation. One study highlighted nurses' experiences where they believed patient treatment parameters were not adequately discussed with patients or relatives because the staff found the discussions confronting and the

medical practitioners were fearful of their legal obligations (Heland, 2003). The current study lends support to these findings, that the activities of nurses in raising and persisting with medical staff in an attempt to influence NFR orders can focus attention on to the patient's health outcomes and ensures discussion. This activity compels medical staff to consider the limitations to active therapy and often generated communication with the patient. The different foci of the professional groups becomes apparent, as an earlier research study demonstrated, the medical staff make decisions as to what medical intervention, if any, is appropriate, whereas nurses spend more time with patients and are more sensitive to the effects of such interventions on patients (Palliative Care Council South Australia, 1995). While nursing input into decision making instances like these does not enjoy official sanction, in that the medical staff still have the option to ignore the nurses' input, the fact that it occurs and occurs quite frequently, indicates a changing relationship between these groups (Porter, 1992).

Sidhu, Dunkley & Egan (2007) contend that many NFR policies do not define NFR orders and that this is problematical, as it has been shown that Australian medical and nursing staff differ in their perceptions of the order. Moreover, the fact that the order was valid only for a current admission meant that nurses faced a continually recurring problem; if medical staff did not address the previous order, nursing staff would need to request that it be reviewed for each admission (Wooton et al., 2005). The hospital policies should indicate that a new order be sought for every admission as patients' health status and preferences change (Sidhu et al., 2007), however, the responsibility in both hospitals in the present study was considered by participants, a medical responsibility to document. Sidhu et al. (2007) argue that policies should provide clear delegation of responsibility of NFR orders to avoid confusion between medical and nursing staff.

A final consideration relating to the ability to influence patient decisions is the utilisation by staff of family members. Nursing and medical staff use close relatives to achieve a degree of leverage with patients who are refusing therapy. Staff members recognise the important function family members provide interpreting information and communicating between patient and staff. Relatives are better



located to understand what patients actually want when they are critically ill and can usually interpret their feelings (Engstrom & Soderberg, 2007). Moreover, when relatives understood why certain interventions were occurring they demonstrated an ability to provide patients with explanations the patient was more likely to accept, and hence continue with treatment. The use of family members could also be considered problematic for some health professionals. The extent of family incorporation by staff was sometimes reduced when the family members accepted and supported the patient's decision to refuse treatment. The strategy of nursing and medical staff to use family members to persuade the patient in a particular direction sometimes rebounded, as relatives proved to have an ability to influence outcomes of an entirely independent nature, compared to that of staff.

## **11.5 SUMMARY**

The category *Influencing* demonstrates a broad continuum of participant activity that reflected positively, but to a greater extent, reflected detrimentally on patient outcomes. The strategies illustrate the numerous possibilities for nursing and medical staff, and sometimes relatives, to use their positions of authority or relationships, to exercise a degree of control over patient decisions and outcomes. The behaviour of health professionals occurs in a context comprising two dimensions. One where there are clear differences of opinion regarding therapy between members of staff, which has the tendency to create tension and conflict for all involved parties. The other dimension in which strategies unfold relates to the creation of tension between staff and involves the failure of participants to acknowledge or act on issues and concerns that have been raised by colleagues.

The approaches exhibited in the six strategies includes participants' use of mystifying language, which can confuse patients and relatives, or the selective choice or presentation of information, which can minimise or inhibit full and complete disclosure. These strategies diminish the capacity of patients or family to fully participate and make it easier for participants to shape outcomes. The ability of health professionals to assert a degree of authority and maintain a considerable level of control over the entire therapy process, demonstrates some negative aspects of participant behaviour. This highlights and confirms the power imbalance in the

professional-patient relationship and can extend to excessive measures, although this appeared less frequently. Conversely, where staff held fixed beliefs, their determination to persevere with colleagues, usually with the intention to achieve a major change in therapy, suggest that positive outcomes can equally result when *Influencing* occurs. Family members can also be utilised by health professionals as leverage, to change patient decisions when they refuse, with varying degrees of success. Relatives who agree with the proposed therapy are more inclined to assist in this endeavour. Family members with divergent views from those of participants, can use their familiar relationship to commandeer the process, proving that despite the considerable scope for health professionals to influence, they are not the only individuals with persuasive powers and they do not always prevail.

Using influence is not the sole domain of one professional group, but highlights differing degrees of power in a given situation. Nevertheless, vulnerable or passive patients and their care tend to be enmeshed, as divergent points of view emerge and have to be negotiated. The conflict generated can be constructive when it results in patient approval, or work satisfaction because it stimulates change. When beliefs are conflicting and there are insufficient mechanisms to incorporate everyone, this can negatively affect those involved. For the staff, unresolved tension or conflict can create stress, impact on future communication with colleagues and ultimately, the delivery of care. Staff can withdraw from colleagues or patients, or conversely become confrontational. From the patient's perspective conflict can inhibit or prolong the treatment decisions necessary to determine an agreed way forward.

## CHAPTER 12

### OVERALL DISCUSSION AND CONCLUSION

#### 12.1 INTRODUCTION

This chapter provides an overall discussion of the findings and the conclusion. The discussion moves beyond the categories and sub categories previously identified, to consider the overarching phenomena of the relationships between nursing and medical staff and how suitably current practice is positioned in light of existing legal expectations. The chapter begins by reiterating the advantages of the theory. It proceeds to explore decisions to refuse therapy, the relevance of the overall findings of the relationships of the two participant groups, and how their responses to refusal compare with the current legislative requirements. The final section of the chapter deals with the limitations of the study and the implications of the findings are addressed in relation to clinical practice, education, law and research.

#### 12.2 THE THEORY

The theory offers a possible explanation about the specific roles adopted by participants when they deal with patients refusing treatment. The theory *Endeavouring to Understand Refusal: Agreeing on a Way Forward* forms the central element of the research. It provides a comprehensive understanding of the conceptual links and interplay between the defined categories: *Seeking clarification, Responding to patient and families, Advocating* and *Influencing*. The categories have density such that all the salient properties and dimensions have been identified, allowing for precision and ensuring explanatory power of the theory. For instance, in the category *Influencing* the ability of participants to assert authority or control over the patient-professional interaction, is highly evident. The properties of this category are reflected in one dimension of the core problem, in so far as there are numerous competing perspectives in relation to the delivery of treatment. Moreover, the properties and dimensions of this category can be related to the first and second conceptual transitional themes of the theory.

The theory also accounts for variation. The three transitional themes of the theory: *struggling to come to terms with the centrality of patient self-determination*, *responding to the dynamics of patients and families*, and *changing the terms of reference: from the disease to the person*, facilitate an explanation of the differing roles adopted by participants. For instance, there is considerable variation, as some participants move more slowly than their colleagues, to recognise patients' decisions to refuse treatment. Conversely, some participants adopt processes that are more clearly designed to consider the perspective of patients from the outset of care. The varying responses of participants, identified and discussed in the categories are incorporated into the theory in the second and third transitional phases.

The various properties of the theory allow for generality because it provides a sufficiently broad scope to explain the processes, including the variation of roles adopted by the two professional groups. In addition, the theory provides some precision of prediction for the actions of nurses and medical practitioners. It highlights the specific roles of each professional group, but it also extends beyond individual roles to demonstrate the interplay between nurses, medical practitioners and others during episodes of treatment. The theory can be applied to nurses and medical practitioners in order to highlight the context in which they function and the roles they adopt. It provides input into the development of knowledge of the roles embraced by nurses and medical practitioners in acute care settings, in circumstances where patients refuse treatment. It specifically highlights a process, which sheds light on decision-making in different wards and units in acute care hospitals, and in doing so offers opportunities for positive changes in the education of the public, the practice of health professionals, and the opportunity for consideration of amendment of the pertinent legislation and hospital policies.

### **12.3 THE NATURE OF REFUSAL**

Despite the fact that all health professionals are potentially required to address a refusal of treatment decision at some time, as the theory suggests, it was evident that many participants did not expect patients or their relatives to actually refuse treatment. As one medical practitioner explained, "... not having treatment is something which isn't even on the radar" (014/7). Nurses and medical staff engage

with patients and families expecting to secure a diagnosis and then implement treatment, using contemporary technology, which is often concerted and invasive. Not surprisingly, the emphasis for health professionals is to provide the best available therapy given the illness or disease state. This reflects the availability of acute care technologies and the educational preparation and beliefs of health professionals as to their expected roles. As the theory reveals, the focus for many health professionals is the illness state rather than the individual beliefs and wishes of patients.

From the perspective of patients and families, refusal of treatment rarely manifests as an unequivocal decision early in the relationship with health professionals. Instead, refusal decisions tend to emerge as a concern, when the type of therapy or a particular procedure becomes relevant or important to them. Patients or relatives sometimes come to a realisation that these are not what they desire, or patients refuse when they become frustrated, angry or fearful. These scenarios were relatively common everyday occurrences. As to what type of treatments are refused, it appears that patients and relatives sometimes decline specific therapy but have no objection to continuing with other components of overall therapy. Specific types refused comprise invasive procedures, including the insertion of intra-venous lines, naso-gastric tubes, percutaneous endoscopic gastrostomy tubes, and less frequently, the transfusion of blood products. Other therapies refused include those which tend to have severe side effects, such as radiotherapy, and some pharmaceutical interventions, as well as various surgical procedures. Conversely, refusal decisions can include refusal of all further therapy, such as the provision of any artificial nutrition or extreme life support measures. The refusal of procedures can guide further discussion and might change the entire treatment plan.

Decisions to refuse therapy are sometimes driven by patients' or families' responses when there is a lack of understanding of what is entailed, or when there is a failure to adequately deal with their concerns.<sup>87</sup> Alternatively, when patients and families are not sufficiently included or informed, they can be overwhelmed, not quite

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<sup>87</sup> See Chapter 9, Sections 9.3.2 and 9.3.3.

participating and unable to indicate their clear refusal.<sup>88</sup> Therapy often continues for a variety of reasons, including the desire of health professionals to instigate therapy, a family member insisting upon ongoing invasive treatment, or disagreement between family members, or between health professionals themselves.<sup>89</sup>

Once patients or relatives raise concerns the insight and abilities to react, considered in the categories *Seeking Clarification*, *Responding*, *Advocating* and *Influencing* were crucial determinants for the eventual outcome. Some patients' concerns were addressed promptly; more often this was not the case. Despite this, when participants recognised that there was an issue and addressed it fittingly, there was often a reversal of the refusal decision. On other occasions the response of participants allowed for alternative treatment modalities, which incorporated patient and or family wishes. Conversely, the inappropriate reaction of the health professionals sometimes exacerbated a concern, which could then become a resolute refusal, or contribute to a less than optimal relationship between the parties, where frustration or even hostility were expressed toward health professionals. On occasion some patients deteriorated and died before an agreed plan was reached.<sup>90</sup> In exceptional situations patients discharged themselves, although in most circumstances in this study it was uncommon, often because patients were too ill or not sufficiently mobile to employ this option.

#### **12.4 NURSE-MEDICAL PRACTITIONER RELATIONSHIPS**

To understand the theory and specific factors that affect the processes utilised by nurses and medical practitioners when patients refuse treatment, an understanding of their work environment and the relationship between the two professional groups is necessary. There are two dynamics relevant to the relationship between the groups. They include the context of work and the relationship between nursing and medical staff, as they deal with patients' refusal of treatment decisions.

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<sup>88</sup> See Chapter 10, Section 10.3.1.

<sup>89</sup> See Chapter 6, Sections 6.4.2.1, 6.4.1.2.3 and 6.4.1.3.2, Chapter 9, Section 9.2.1, Chapter 11, Sections 11.3.3, 11.3.5 and 11.3.6.

<sup>90</sup> See Chapter 6, Section 6.4.1.1.

### 12.4.1 The context of work

Melia (1979) describes hospital wards as “turbulent” work environments. Currently, acute health care takes place in the milieu of highly variable fluctuations. In recent years patients are generally sicker and stay for relatively short periods of time and require more care (Duffield, Kearin, Johnston & Leonard, 2007). Their condition can change dramatically and there is constant movement as patients are admitted and discharged. Hospitals are complex, internally segmented organisations where patient care must be coordinated twenty-four hours a day, every day with numerous, often conflicting schedules (Zerubavel, 1979). In addition, hospitals are staffed by diverse occupational groups, including nurses and medical practitioners, each with their own culture, career structure and hierarchies. Allen (1997) argues that turbulence in organisations has important implications for relationships between nurses and medical practitioners. The features in the present study, which contributed to, and had particular implications for, nurse-medical practitioner relationships when patients refused treatment included the fragmented temporal-spatial organisation of work, the permanence or transience of staff, competing authority and rank hierarchies. These data largely mirror the findings of Allen (1997).

In the present study, the hospitals’ organisation of nursing and medical staff is designed in different ways to provide twenty-four hour coverage of patient care. Nursing care for patients is commonly provided by a three-shift rotation system, whereas residents and registrars routinely work extended hours, working long hours each week, including being rostered on-call.<sup>91</sup> Many medical staff work a two-shift system however, unlike nursing staff, the second shift is more likely to be an on-call shift where medical staff, residents and registrars, must cover not only their own therapeutic units but other units as well. Scallan (2003) notes that the way medicine is practised and the hours junior medical practitioners work are unacceptable for their own welfare, as well as that of the patients they treat. This affects their ability to relate to patients, where they spend little time asking patients about the impact of the illness upon their lives, explaining tests, or discussing the meanings of their

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<sup>91</sup> Junior medical staff work an average of more than 50 hours a week in these extended shifts and this can increase when on-call shifts are included (Scallan, 2003).

diagnoses (Jagsi & Surrender, 2004). These findings are mirrored in the current study, in so far as junior staff were less likely to satisfactorily answer questions and concerns raised by patients and deal comprehensively with patients or relatives who refused treatment. These factors contribute to the relationships between medical staff and patients, but also with nursing staff where many believed their time was taken satisfying patients and relatives with information only partly addressed by medical staff.

Studies have shown that junior medical staff claimed that there was a lack of clarity in the definition of roles and responsibilities of the members of the entire team (Bruce, Thomas, & Yates, 2003; Bunch, Bahrami, & MacDonald, 1997). Data in the current study supports this proposition, as junior medical staff, mainly residents, tend to respond and follow the direction of the registrars who, in turn, follow the advice and directions of the consultants. A great deal is dependent upon the clarity of directions and roles of team members and their ability to communicate with each other. For example, many registrars provide daily guidance for residents. Registrars regularly made decisions nevertheless, when refusal of treatment became apparent and this conflicted with the therapy plan decided by a consultant, registrars were more likely to try and encourage patients or relatives to rethink the decision, or wait until the consultant visited.

Consultants in many therapeutic units routinely attended the wards on specific days, unless they are requested to come at different times by registrars or nursing staff. This compared with specialised units where medical specialists are often employees and work extended shifts, more akin to the nurses. Speed and Luker (2006) found that where nurses and medical staff were both salaried and answerable to the same authority their interactions were notably more collaborative, even egalitarian. The cohesiveness of the medical team appeared to relate to the support and guidance consultants provided and this, in part, appeared to correlate with their accessibility and the level of experience of the registrar. Where these factors were present, a team approach to address refusal decisions was more likely and this also flowed on to relationships with nursing staff. On the other hand, where consultants kept visits and possibly communication or support to a bare minimum, a great deal was left to the



registrars to take responsibility for decisions. This was highly varied between therapeutic units and suggests, as one study found, when junior staff are assigned to senior medical staff for supervision, they must be able to provide support and teach them. To achieve successful mentorship requires commitment and education for senior practitioners (Paice, Moss, Heard, Winder & McManus, 2002). The current study found accessibility of senior medical staff to be a factor affecting the relationship between nursing and medical staff. This was especially evident when registrars and residents were newly assigned to therapeutic units and they had little experience working in that specialty area. Nurses skilled in the area often provided guidance and support in these situations. Once medical staff have gained some experience they were more attuned to the specific treatment modalities however, refusal of treatment still required discussion with the consultant. These factors are demonstrated in the theory where many staff are involved, each trying to do their utmost to understand what patients are saying to them.

The difference in spatial organisation also highlighted the organisation of medical and nursing work. Nurses were ward based but the majority of medical staff would be required to move to other wards or units, unless they worked in a specialised unit, where they were more constantly situated. The different temporal-spatial organisation for each professional group created different priorities and perspectives, particularly when medical staff were not situated near particular patient areas. This at times generated some tension between the groups, as long periods sometimes lapsed between the identification of a refusal and the involvement of a senior member of the medical team who was prepared to discuss issues with patients or relatives. The nurses were focused on the requirements of their individual patients, while the medical staff were required to concentrate more broadly, both on patients within the ward or unit but also those located elsewhere, including new admissions. This placed nurses in closer proximity to patients and their relatives, having to deal with their questions and concerns. Given that key treatment decisions, particularly refusal of therapy, required the involvement of the registrar and consultant, their accessibility was of fundamental importance. It suggested that in work practices where senior medical staff have a local presence, there is greater likelihood for increased continuity and ease of access. This assists and enables other members of the

therapeutic team to respond comprehensively to decisions to refuse treatment. In these circumstances important information can be shared promptly and discussions are more likely to occur, rather than information being fragmented, as individuals come and go at apparent random, from the ward.

Communication is impaired by the fragmentation of information and absence of defined responsibility of many staff. It is argued that it was more difficult for patients and relatives to confide in an array of practitioners, than with one or two individuals with whom they had been able to develop a relationship. It is equally difficult for practitioners to provide adequate support and information when they care for large numbers of patients, who they are unlikely to know well (Jagsi & Surrender, 2004). Therefore, in the absence of medical staff, the ability of nursing staff to facilitate this role was an important factor.

The permanence of staff also plays a major role in the relationship of the two professional groups and how they respond to patients' or families' concerns. In both hospitals there was considerable transience of the less experienced medical and nursing staff. The relative permanency of staff can augment their influence with each other, particularly nurse-doctor relationships (Hughes, 1988; Haas & Shaffir, 1987). Where staff were located in areas for longer periods, communication among nurses and medical staff was more akin to a two-way flow of ideas and information sharing. In addition, in one hospital many of the residents and registrars had come from overseas and their transient status was exacerbated by cultural differences, particularly their difficulties in communicating clearly in English, to many patients. Inexperience or cultural discrepancies on the part of medical staff, are noteworthy because refusal of treatment decisions are often ambiguous.

Factors that can also create difficulties when patients refuse therapy include the organisation of work into rank hierarchies or where one professional group is perceived as more authoritative. Rank hierarchies are particularly evident among medical staff, and visible to a somewhat lesser extent between the nurses. The line of authority entrenched in hierarchical structures directly impacts on how information and decisions are made. Imposts on decision making can be further exacerbated when one professional group, in this study medical staff, are deemed to be superior

to other professional groups. To enhance collaboration it is necessary to have management structures that ensure medical practitioners and nurses are “equals” (New South Wales Nurses Association, 1991). Where therapeutic units rely on an entrenched, well-defined hierarchy or authority of staff, they effectively narrow or actually inhibit the decision-making abilities of those lower down the rank, or those belonging to a different professional group. Therefore, junior nurses and those who are transient, such as agency nurses,<sup>92</sup> will tend to defer to more senior nurses. Given the temporal-spatial organisation of most nursing work, this generates fewer problems amongst nursing staff because the nurses are situated in the same ward and can communicate relatively quickly and spontaneously with each other. However, for junior medical staff the hierarchy creates barriers, as junior staff commonly would not, or feel they could not, accept patients’ refusals. The preference was to follow the consultant’s treatment plan and patients’ and relatives’ concerns were sometimes ignored or avoided. When residents attempted to convince patients or relatives of the merits of therapy but were unsuccessful, there was a delay as the registrar was asked to be involved and then lastly, the consultant. Significant time lapses occurred as various levels of medical staff were asked to visit and talk to patients or families, each new medical staff member not necessarily party to the approach or discussion between the earlier practitioner and patient. The nature and scope of the refusal is difficult to determine the more staff are involved and this highlights the complexities in the theory, that agreement amongst the parties takes time. Duffield et al. (2007) argue that structures should facilitate, not impede the provision of patient care.

Research findings relating to patient safety provide some insight into the current study, as the results highlight that some features, which relate to improved patient safety, are also pertinent to better patient outcomes when they refuse treatment. These features include work environments of both nursing and medical staff where there are non-hierarchical work environments and the existence of decision-making strategies between these groups (Armstrong & Laschinger, 2006). The present study found that these characteristics are highly relevant to the success of dealing with

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<sup>92</sup> Agency nurses are casual employees, employed through a nursing agent, they have varied levels of experience. They are engaged when there is a shortage of permanent nursing staff and are not always familiar with the hospital or specific ward.

situations where patients or relatives refuse treatment, in that therapeutic teams who encourage health professionals to share information and participate in decisions, tend to present as a unified group to patients. When this occurs conversations are not merely replicated numerous times, as different staff members become involved, changing and reinterpreting important data. Rather, information is presented with greater consistency and there is more chance the underlying reason for the refusal will be dealt with. This means the ideal environment where patients and their families are more likely to have their thoughts and concerns addressed are units where there is a shared vision among all staff members of how to deal with concerns or clear refusal decisions. The data highlight that this was the case in a minority of areas studied and thus, the numerous differing strategies adopted by participants. More commonly, there was evidence that health professionals react individually or randomly and this is reflected in their responses to patients, which can be indiscriminate, reducing the likelihood that the refusal decision will be attended to effectively (Holden, 2006). These factors explicate the many varied responses from participants and why these processes form an integral part of the resultant theory, especially the second transitional phase.

#### **12.4.2 Interaction between nursing and medical staff**

It is imperative to mention the manner in which nursing and medical staff interact and how this might impact on refusal decisions. As this study found, nursing staff are most likely to initially learn of a refusal, yet overall therapy plans remain the domain of senior medical staff. The manner of interaction of the two groups is decisive when patients refuse treatment. Early published work in this area emphasised the dominant authority of medical vis-à-vis nursing staff and the role nurses adopted in order for them to influence decisions. This is documented in Stein's (1967) analysis of the relationship between the two groups where:

... the nurse is to be bold, have initiative, and be responsible for making significant recommendations, while at the same time she must appear passive. This must be done in such a manner so as to make her recommendations appear to be initiated by the physician. (p.699)

According to this analysis, nurses must show initiative and offer advice, but it must be undertaken with the appearance that the physician makes the decision. To achieve this Stein (1967) observed that nurses use subtle verbal communication and cues to communicate their recommendations. The physician can choose to accept the coded information and incorporate it into a decision, thereby appearing to instigate the choice. This avoids conflict and obvious disagreement between them (Miers, 2000) and provides advantages as both have something to gain. Physicians benefit from nurses' knowledge and experience, and nurses have input into decisions regarding patients (Sweet & Norman, 1995). This decision-making style and interrelationship was coined the "doctor-nurse game" and was considered to be influenced by the education of each respective group (Stein, 1967). Medical practitioners were considered totally in charge, unable to be seen to make mistakes. Nurses on the other hand, were trained to be subservient to medical staff, they learned this behaviour through their disciplined schools of nursing and work in the hospitals. Wright (1985) found that the result was poor communication between the two groups, as information was coded and "shared" in a distorted, nebulous fashion, particularly as cues could easily be misinterpreted (Sweet & Norman, 1995).

In the present study, factors militating against positive interaction between nursing and medical staff included the perceived enforcement of hierarchies and the context of work. Furthermore, medical practitioners have the authority to make therapy decisions and this can be used to enforce the unequal power balance between the two groups when nursing staff are not included. Consultants and registrars who take a formal and authoritarian approach in their interaction with nursing staff tend to discourage nurses' involvement in decisions. Conversely, nurses who comply with this arrangement fail to demonstrate their expertise and forego the opportunity of being acknowledged as having valuable information to contribute. This situation diminishes the likelihood of effective information exchange and this, in turn, can support a professional gulf, which fails to completely address patients' and families' wishes. Moreover, nurses are more likely to exhibit the "doctor-nurse game" when they are uncertain of the responsiveness of the consultant or registrar.

More recent studies have found that the doctor-nurse game is still enacted, although nurses in some areas are more assertive in offering suggestions to therapy or challenging decisions made by medical staff. Hughes (1988) reported that nurses working in an accident and emergency department were candid and assertive. Porter (1991) found nurses working in intensive care and a medical ward were less dependent on subordinate modes of interaction and were more forthright in their exchanges, and this behaviour did influence more positive patient outcomes. Subordinate forms of interaction, as described by Stein (1967), were much less commonly utilised. Instead, Porter (1991) found informal, overt decision-making was more frequently evident between nursing and medical staff. The exception involved interactions between nurses and consultants, which reflected the “doctor-nurse game”, possibly due to the consultants’ high status, when the power gap between the two individuals was wider (Porter, 1991; Bradford, 1989). In the present study, because nursing staff frequently recognised that patients or relatives did not want treatment, nurses assumed a significant role in the whole process. They communicated and on many occasions, advocated patients’ perspectives to medical staff. The data indicate that for many experienced nurses there was generally little hesitation to directly raise issues with medical staff. The findings in the current study reflect other research studies that show increased levels of education,<sup>93</sup> significant clinical experience, the relative permanence of staff, and the period of time nurses had worked with consultants, were factors more likely to produce a direct and open exchange between the two professional groups (Porter, 1991; Mackay, 1993).

The culture of a ward or unit area has a major impact on the relationships between nursing and medical staff. As the data suggests in the varied methods of responding, participants largely relied upon their own methods of interacting with patients and relatives, or those of the unit in which they worked. For example, some less experienced nursing staff seemed less keen to initiate information to consultants unless specifically asked, instead they enlisted the support of senior nursing colleagues to ensure the information was aired. Thus, in some areas the junior nursing staff were not acknowledged for their part in the whole process and often

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<sup>93</sup> See Chapter 4, Table 1: Demographic information about nurses, which reveals that the participants working in the intensive care unit more frequently held post graduate qualifications.

remained invisible. Equally, this was the case for residents, who exerted minimal power over refusal decisions. Much was dependent upon the roles adopted by senior nurses and medical staff and the culture of a particular ward. In therapeutic units where there were routine processes and expectations of senior staff to include and consult, regardless of rank hierarchy, junior medical and nursing staff tended to offer frank opinions more freely. Socialisation processes allow behaviours to be institutionalised and adopted by those new to the environment, thus different forms of conduct form part of the culture of a therapeutic unit (Duddle & Boughton, 2007), and this assists in the education of junior staff. The data in this study indicated that this did impact on patient outcomes in the sphere of refusal of treatment. Where the majority of staff felt confident to openly voice information, it was shared, allowing clarification and responses to be clearer and timely, and more likely to address the needs of patients and their families. Therapy was discussed and altered accordingly, reducing the potential for delay and the associated frustration or possible conflict, which can develop among any of the parties. When the interaction among nurses and medical practitioners was governed by mutual respect and trust, there was less friction and divergent behaviour between them (Speed & Luker, 2006).

The relationships between nursing and medical personnel, is largely dependent upon the professionalism and collegiality created and demonstrated by the senior members of each group. When these traits exist senior staff invite opinions, or when views were offered freely, junior staff observe and assimilate this behaviour. This optimises the perspectives and input both professional groups have to offer and reduces the need for game playing. This was evident to varying degrees in the wards and units, where each group respected the others' contribution, and time was specifically taken to ensure dialogues occurred when key treatment decisions were made. Many staff interviewed expressed their preference for this arrangement and indicated that it was an important factor increasing their work satisfaction and desire to remain working in that unit. The resultant effect was an increased responsiveness to patients' and families' concerns as they interacted with the myriad of staff involved in the delivery of care. It also tended to follow that patients' and relatives' wishes were more likely to be valued and incorporated into treatment plans. As the theory illustrates, some health professionals favour the acknowledgement of individual patients' wishes,

recognising the significance of patient self-determination. The relationships could be described as interdependent, adaptable and supportive of each other, rather than self-orientated, autonomous or dominant (Davies, 1995). The latter features were consistent with several other areas observed in the present study, where there were arbitrary exchanges and little consideration given to varying perspectives and opinions. There were minimal or no customary processes in place to allow or encourage input from various staff members in a way they considered meaningful. In these wards or units, medical dominance was perceived as a negative contribution to relationships and it commonly followed that rank hierarchies were more evident. Interdependence and negotiated outcomes were less likely to occur, leaving patients and relatives to deal with a disorderly group of health professionals.

## **12.5 LEGAL PRINCIPLES AND THE LEGISLATION**

The principle that competent adults have a legal right to refuse treatment, which underscores the Medical Treatment Act (MTA), is not commonly a key consideration. The reasons for this are multifactorial. First, this may be due in part to the fact that the majority of patients and families accept care, and this reduces the propensity of health professionals to consider that therapy will not suit all patients. Health professionals practise with the intention of sustaining life wherever possible and in many situations there are immediate interventions available in order to achieve this goal. Second, a great deal is dependent upon the interaction and communication of health professionals with each other, and with patients and relatives, at critical times throughout the patient's stay. These interactions can be influenced by the manner and environment in which acute care is practised. Third, the data highlight that educational preparedness and the diverse attitudes held by health professionals play a role in their decisions. Other dynamics were shown to be equally influential, such as the wishes of assertive relatives, irrespective of patients' wishes not to continue with specific treatment. It appears that the overwhelming expectation of health professionals offering acute care is to provide treatment if it is available. Therefore, consideration of withdrawal of treatment or palliation is often avoided and not necessarily addressed until it is clear the patient is not responding to treatment. Even then, in some circumstances aggressive treatment continues. This



has the effect of removing or delaying the need to discuss important issues. Nevertheless, patients and relatives often initiate discussion by raising their concerns or stating their wishes not to continue with certain treatment. Fourth, the findings of this study show that a majority of participants revealed a fundamental lack of understanding of the relevant legal principles and consequently how the MTA could be utilised.<sup>94</sup>

A minority of senior staff who did have some knowledge of the MTA believed that it was confusing and this was the key reason why many of their colleagues failed to employ it. Health professionals, who had “heard” of the MTA, claimed a lack of confidence in their knowledge to actually implement it and felt that it was not an essential prerequisite for their everyday practice. The majority of health professionals were clearly not familiar with the MTA. This introduces a broader issue related to the level in which other legal principles, in particular those relating to the law of consent, are integrated into everyday clinical practice.

In relation to health care, the law requires health professionals to be familiar with issues such as patient competence, who has legal authority to consent to treatment, the quantity or detail of information necessary in order to make a decision, and the circumstances in which therapy should be withdrawn. These issues are all underpinned by legal principles, which are pertinent to the law of consent and indeed refusal of treatment (Forrester & Griffiths, 2005). If the principles remain implicit, seldom discussed or raised, as was the case in many scenarios observed in the current study, then thorough application of the principles tends not to occur. It is widely assumed that health professionals have a clear understanding of relevant legal principles and how to incorporate them into their clinical practice however, as demonstrated in this study, there is a significant shortfall in this regard.

For most participants these important principles are not openly or regularly articulated in any detail and this suggests that they remain less than clear, are certainly not reinforced, or possibly considered irrelevant, until a controversial situation arises. This applies to the practice of many staff. Nurse participants either

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<sup>94</sup> See Chapter 6, Section 6.5.1.1 *Knowledge of policy and law*.

deferred to the authority of medical staff, or sought assistance from others, to confirm their belief that an important principle had been overlooked. For example, in several instances allied health professionals, such as social workers, were left to fathom the significance of certain relatives making decisions on behalf of patients. It seemed the practice employed by many medical staff was to concentrate on the therapy plan, rather than determine which individual was legally able to decide. This also reflected the common belief that patients and their relatives will always accept the treatment plan. Nonetheless, discussion considering the limits to acceptable therapy and use of the various schedules in the MTA was infrequent in most therapeutic units.

The need to address legal principles was abrogated at times in the way information was communicated from health professionals to patients and their families. Where conversations were brief, details were kept to a minimum. Where there is little encouragement allowed to incorporate patients or relatives into decisions, there was less opportunity for them to indicate, or indeed thoroughly consider, alternatives such as not accepting therapy, or specific aspects of it. Interestingly, the few participants who did have some understanding of the MTA, and pertinent legal principles, were more likely to approach the provision of information and decisions in a different style. The intensive care unit, where treatment plans frequently changed, had customary practices to allow discussion of both patients' and relatives' wishes at different stages of therapy, when treatment changed or issues regarding therapy were raised by any involved party. This allowed further interaction between health professionals, patients and relatives and enabled their wishes to be introduced. Most importantly, their thoughts were encouraged and actively sought, and frequently were reflected in treatment plans. This highlighted an all-embracing approach to decisions made, where an inclusive approach was preferred and this demonstrated a focus on the patient as a person, rather than the illness state. This meant that as consensus was frequently reached, the need to utilise the specific schedules in the MTA was considered unnecessary. Instead, staff documented the conversations in the patient file. Patient records reflected more detail, and usually justification, for the various choices made as patients or relatives reacted to therapy.

Using this approach, decisions to refuse treatment or specific aspects of it, formed part of the overall therapy plan.

One other important feature relating to the MTA was the pro-forma or standardised forms provided by the hospitals. Two distinct issues were apparent, which additionally highlighted the lack of understanding and incorporation of the relevant legal principles relating to refusal of treatment. The first related to identification of a power of attorney document. This finding in the present study is consistent with Sidhu, Dunkley and Egan (2007), where the researchers found that 62 per cent of NFR policies in Australian public hospitals did not address the issue of advance directives. In the present study, one hospital provided documentation where a small box was to be ticked, if the patient had appointed an attorney. The documentation merely referred to a "Power of Attorney", without clearly specifying which type of attorney had been appointed. The confusion was evident when health professionals were completing the documentation or reading it, they nearly always failed to distinguish with the patient or relatives which type of attorney was in place. The lack of appreciation on the part of health professionals was apparent when interviewed, they were not cognisant of the different types of powers of attorney. On most occasions there had not been an appointment made but where this was the case and patients or their families acknowledged a specific individual, it was not always clarified with them, which power the individual actually held. On a few occasions it was discovered later, and not always by nursing or medical staff, that the family member held a financial power of attorney, not a medical power. This reveals a general lack of understanding of the function of the legal principles relevant to the MTA and the need to clarify or distinguish between the different appointments. Furthermore, neither of the two professional groups ever asked to actually sight the original document and nor were they usually copied and included in patient files.

The second issue relating to documentation and comprehension of the law, involved the manner in which NFR orders were recorded. On many occasions NFR decisions were made after consultation with patients or their family, very occasionally it was an indication emanating from the patient or relatives. The two hospitals studied tend to have pro-forma documents to record this decision. However, the patient files

observed revealed that the medical practitioners documentation of the order was overly brief, recording the words “Not for resuscitation” and then signing their name. The documentation lacked any detail of how or why the decision was reached and who was party to the decision. In situations where the decision was reached after careful consideration with patients or family members, and thus was in fact a refusal decision, the documentation failed to demonstrate key legal principles, including who had made the decision. This contrasts with the findings of Castle, Owen, Kenward and Ineson (2003), who found that the documentation of individuals involved in decisions was commonly recorded. It is prudent practice if the documentation clearly reflects a refusal decision made by the patient, or appropriate person, on behalf of the patient (Forrester & Griffiths, 2005; Wallace, 2001). The MTA requires that hospitals take reasonable steps to place a copy of refusal documents in patients’ files (section 5E(1)). Certainly, hospital policies compel specific duties on practice, such as the signing of not-for-resuscitation or discharge forms however, they generally do not prescribe the level of detail necessary, enabling a degree of discretion for health professionals. Utilisation of hospital policies or guidelines obliges certain behaviour, and in this study the policies clearly indicated patients had a right to refuse treatment. Although, the methods in which they are implemented reflect a distinct lack of understanding of the underpinning legal principles. This leads to a final issue of concern relating to the practices of health professionals and their understanding of who can legally make a decision to refuse therapy.

When patients are incompetent, health professionals tend to automatically assume that whoever is listed as the next of kin in the patient file, are persons who can consent to, and refuse, therapy. As this study demonstrates, family members are frequently included and can provide significant influence in therapy decisions. This is particularly evident when family members are assertive and articulate a desire for therapy to continue, even when a patient had clearly refused. The role of family members in the area of patient refusal of care can be distressing and fraught with problems for health professionals. This is, arguably, exacerbated as the law in Victoria is somewhat convoluted. The MTA allows for competent adults to choose a proxy decision maker, who can be a relative or a friend. This person has the legal

power to consent to, and refuse, medical treatment on behalf of the incompetent patient. This means proxy decision makers should only be included when patients are incompetent however, close relatives are frequently included and have influence on decisions even before this occurs. In addition, the law distinguishes between those who can consent and those who can refuse.<sup>95</sup> This is not reflected in current health care practice, as participants tend to include the next-of-kin in decisions and frequently defer to them when patients are unable to state their wishes. This reflects the reality of clinical practice where most patients who are unable to provide instructions tend not to have proxy decision makers in place. It becomes onerous for health professionals to be required to have a guardian appointed in every situation where a patient is incompetent. However, when disagreement among any of the parties occurs, it is particularly evident that an understanding of the legal avenues and principles is necessary, in order to provide the basis for a resolution. The lack of incorporation of existing legal principles into every day practice provides a glimpse of why many nurses and medical practitioners neglect to allow patients or suitable proxies to be sufficiently incorporated in decisions. It also helps to explain why the focus for many health professionals might remain on the illness state rather than the patient as a person.

## **12.6 LIMITATIONS OF THE STUDY**

Although the study aimed to identify and explore how nursing and medical staff deal with patients' refusal of medical treatment, it has three limitations. The first limitation relates to it being a qualitative study, where the findings are applicable to the participants and the context in which the study took place, that is, acute care hospital wards or units. The results are not generalisable to other health care

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<sup>95</sup> It is clear that an agent appointed using an Enduring Power of Attorney Medical Treatment can refuse medical treatment the patient would consider unreasonable. However, the Guardianship and Administration Act 1986 (Vic) which applies to incompetent adults, establishes a scheme where a 'Person responsible' is identified according to a list of individuals, including spouses, partners and then children etc. They may provide consent to health care, but are not legally able to refuse health care. In addition, the Guardianship and Administration Act allows for the appointment of a proxy decision maker to make decisions regarding lifestyle, but the proxy is not lawfully permitted to refuse treatment on behalf of the patient. These changes might allow for various contingencies, they appear to contribute to the confusion and burdens necessary for a comprehensive approach in the clinical environment.

environments. Given theories that relate to social phenomena are not replicable, they can be verified. The results, nevertheless, do provide a valuable point of reference for nurses and medical practitioners working in other settings.

The second limitation is that there were time constraints associated with doctoral degree study, particularly regarding simultaneous data collection and analysis. The process of data collection, compiling fieldwork notes, memoing, observing, interviewing, and examining patient files were methods that enabled the researcher to extract rich sources of data, but there were time constraints. Whilst saturation of the data was reached, and the numbers of participants from the two professional groups reflected their proportionate numbers in the hospitals, the researcher would have preferred more time to explore the medical practitioner group. This professional group were more difficult to engage, possibly due to time, and their perspectives revealed an emphasis on the technology.

The third limitation relates to the needs of patients and families. While these groups were integral to the phenomenon of this present study, they were not active participants. The perspectives gained and discussed in this study are those identified by the nursing and medical participants and not those of the patients and relatives. The perspectives of patients and relatives are also required in order to provide a comprehensive understanding of their perspectives and processes.

## **12.7 IMPLICATIONS OF THE STUDY**

Recognising the importance of addressing patient refusal of therapy, the theory *Endeavouring to Understand Refusal: Agreeing on a Way Forward* is timely because it provides a framework for, and insight into, the current practices and offers opportunities to identify the ways in which it can be improved. The theory, comprising three transitions, provides the basis from which change might emanate. There are four broad implications of the findings of the study relating to clinical practice, education, research and the law.

### **12.7.1 Implications of the study for clinical practice**

In terms of clinical practice, the findings reveal both the commonalities and the differing roles adopted by the two professional groups. More importantly, the findings highlight the inextricable links between nursing and medical roles if outcomes are to be patient centred. For instance, nurses, due to their proximity to patients and families gain insight into specific information, particularly patient thoughts and reactions to therapy, which are not always acquired by the medical staff, and this must be acknowledged and incorporated into treatment decisions. Medical staff, with their ultimate responsibility for treatment plans, must be constantly updated and involved. Both of these roles are fundamental to patient decisions, despite the fact that they are not always aligned. The work arrangements must therefore, enable a closer connection between the two professional groups, throughout the entire treatment process. This could be achieved with greater emphasis on nursing and medical staff understanding their respective roles and purposefully working together to discuss treatment plans. A commitment to the exchange of information between both groups, including more frequent and purposeful consultations, or designated meetings including both professional groups prior to patient visits, to ensure a thorough briefing of patients' mental and physical states, would provide an opportunity to bring respective knowledge together. This would enable both nursing and medical staff to discuss matters with each other to identify key issues and concerns, before proceeding to patients and families in a more unified way.

The findings of the study indicate that the hierarchical organisation of work environments impacts on the information shared amongst staff, where decision-making can be restrictive and slow. Formal hierarchical lines of communication can have the effect of reinforcing a chain of command type of information exchange, where information that has not been requested, is not necessarily included in the discussion. This limits the opportunities for less experienced staff to participate, as they are less inclined to reciprocate in terms of information and, therefore, valuable perspectives. Such rigidity and formality can also result in a lack of integration between the professional groups, where collaboration and team approaches to decisions can be stifled. Collegiate relationships between nursing and medical staff

are important and appear to be enhanced when communication is not restricted along lines of authority or individual professional groups, but rather, senior staff lead discussions and encourage the input of their less experienced colleagues. This form of interaction, ideally, needs to be frequent and overt to encourage collaborative work practices. In the present study this is demonstrated in the sub-category: *Engaging as a unified group*, where participants implement frequent group meetings in order to draw on the input of staff with specific skills or information, whilst educating those less experienced on how to approach conversations with patients and families.

Additional factors impacting on clinical practice, such as the temporal-spatial organisation of wards and the continuity and experience of staff, can also impede the development of optimal working relationships amongst nursing and medical staff. In the present study this occurs in terms of the geography and the time medical staff can contribute to the decision-making process. Where medical staff have a continuous presence in the wards, there is a greater likelihood that they are accessible when concerns arise to forego therapy. In the present study, this was highlighted by participants in the intensive care unit in which the senior consultants were permanently located as a significant factor contributing to familiarity and good working relationships between all staff. In addition, the continuity of nursing staff in the therapeutic units also was highlighted as a contributing factor. The relative continuity aided the transition for less experienced staff, of both professional groups, to the specific work practices of each unit, and this is a relevant implication for workforce planning.

The utilisation of external teams, such as the palliative care staff, is an important adjunct when decisions to forego therapy occur. Acute care hospitals tend to be organised according to medical specialties where expert knowledge is separated into silos, with limited sharing between each specialty. Where health professionals in the wards have established relationships with members of external teams, there is an increased likelihood the external staff will be consulted. The difficulty highlighted in the present study is that the existing referral mechanism is the domain of the consultant. It is acknowledged that broadening the scope of who can refer might



create confusion in treatment plans, an alternative approach is to allow any staff to consult for advice and this needs to be supported by hospital management. External team involvement should be encouraged as their skills can be utilised to establish early collaborative interventions before problems develop, preventing disputes among clinicians, or between clinicians and patients or relatives (Boyle, Miller & Forbes-Thompson, 2005). The external teams can provide advice on possible alternative approaches to therapy plans, they can also provide an additional perspective for staff.

In terms of implications for clinical practice, there is a need for consistent design in the forms and documentation used in patient files. Hospital documentation, including the appointment of an attorney, patient requests and NFR decisions, should be readily accessible. All staff should know where to find this information, what it means in relation to treatment plans and decisions, and how to appropriately document relevant information. This requires staff to be cognisant of hospital policies, which should reflect existing legal principles.

### **12.7.2 Implications of the study for education**

The study highlights the need for praxis between education and practice. The insights and work of each professional group are integral to the management of patient decisions to refuse treatment. Nurses and medical practitioners, ideally should understand and appreciate each other's work and input into the clinical process. This can be achieved when the two groups jointly share education, possibly during continuing and in-service education. To encourage inclusiveness in patient management, multidisciplinary educational sessions could be incorporated into undergraduate study. The message of collaboration is even more powerful once individuals begin practising their professions and for this reason, shared education would be useful at post graduate level. The ability of health professionals to communicate clearly is also an important factor, particularly noted in this study is the need for medical staff to be equipped to discuss treatment plans in a meaningful way with patients and families. It is necessary to further explore undergraduate medical curricula to identify the areas in which communication skills could be enhanced.

The findings of the study confirm that nurses and medical practitioners lack a clear understanding of the relevant legal principles, including the provisions of the MTA. The various professional guidelines, such as codes of conduct<sup>96</sup> outlining expectations that nurses and medical staff understand relevant legal principles are not successfully transferring from educational programs into clinical practice. Health professionals could benefit from a shift in focus, from merely being introduced to legal principles, to education that requires them to apply the principles in their clinical practice. Educational sessions where the use of problem based scenarios are introduced once they are practising their professional skills, are more appropriate, as practitioners can relate to, and concentrate on, authentic situations involving the law. Furthermore, skills relating to encouraging coherent and sufficiently detailed documentation are necessary, particularly for medical staff, who take responsibility for recording treatment plans, including patient decisions and NFR orders.

Lastly, the public need to have a better understanding of the MTA. If the public understand their rights and responsibilities there is an increased likelihood that individuals will indicate their wishes more freely when receiving medical treatment. Educational programs specifically designed to target and educate members of the public are necessary.

### **12.7.3 Implications of the study for the law**

The research findings indicate that the MTA is poorly utilised in the groups studied. This particular legislation was enacted to support individual patients and health professionals. If legislation is to be effective in the context of health care delivery it must be accessible, understandable and practicable. Ideally, those seeking to rely on the MTA should be able to do so. While health professionals must have an awareness of relevant legal principles, when they are uncertain or require clarification, mechanisms should be in place for this to occur with relative ease and within a reasonable time frame. The nexus between clinical practice and decision-making, and access to relevant legal information requires further investigation.

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<sup>96</sup> See Chapter 6, Section 6.5.

Finally, the law of consent and refusal of treatment is, arguably, somewhat cumbersome, where agents can refuse treatment, but nearest relatives appear to be limited to the provision of consent. This is despite the common practice of relying on relatives to direct health professionals regarding treatment plans. The law as it currently exists in Victoria has been developed in attempts to respond to the needs of various groups in the community at different times. Nevertheless, it is argued that this development has been fitful and confusing, failing to adequately address decisions in the acute care context and this has perhaps contributed to the laws relative disregard.

#### **12.7.4 Implications of the study for research**

The outcome of this study was identification of a number of roles and behaviours adopted by nursing and medical staff and these raise several potential areas for future study. For instance, in the category *Seeking Clarification* determination of mental competence was raised as a focal point when deciding whether patients possess the ability to make decisions regarding therapy. Yet the data suggest that mental competence assessments were dependent upon individual practitioner's understanding of the concept and it was surprisingly, a process that is seldom openly discussed among health professionals. The ability of patients to make decisions to accept or forego therapy is fundamental to all health care and further research in this area could provide clarity and insight for future practice.

In the category *Advocating*, the data reveal that nurses play a major part in this strategy, and can be extremely influential in shaping treatment outcomes, although the frequency and extent to which participants advocate depends on the particular culture of any given area. This role is not formally recognised or sanctioned in many work environments and there appears to be an absence of process to support it. In addition, the contextual determinant *Context of Work* highlights that rank hierarchies can provide barriers to decision-making and limit the input of less experienced staff, particularly junior medical staff. There is a scarcity of research studies in Australia examining the organisation and work practices of medical teams in acute care hospitals. The emphasis has largely concentrated on reporting extended working hours and stress levels of junior medical staff. Further, local research is necessary in

hospitals to examine the organisation and working relationships of members of medical teams, including the supervision practices of less experienced staff, if each member's potential is to be fulfilled. Closer scrutiny of the curricula of nurses and medical practitioners is also required to understand the development of the nature and extent of their understanding of shared roles and individual work practices.

This study examined the roles of nursing and medical staff; however, there are other health professionals involved with patient care. For instance, the data highlighted the involvement of social workers. The perspectives of patients and their families also indicate that these individuals shape and influence decisions. There have been some efforts to identify patients' perceptions and needs, although there is little local research indicating an Australian perspective of patients and relatives, and there appears modest data indicating the influences of other health professionals. Further research could examine the input adopted by other key parties when decisions are made to refuse therapy.

Hospital policies play an important part in guiding clinical practice and participants in the study did refer to individual hospital policies when discussing expected practice. There was acknowledgement from participants that there was insufficient guidance when patients or relatives refused treatment. Hospital guidelines were clear that patients can refuse therapy, but it is evident that this message has failed to translate to practice. Hospital policies or guidelines are often formulated by senior clinical staff, as was the case in the intensive care unit in the study. The formulation and utilisation of such policies is often restricted to individual settings or hospitals, with limited distribution or discussion between hospitals. The effects and import of policies affecting clinical practice requires further investigation. Lastly, further research could consider the practical effects of existing law and any changes necessary, in order to streamline a more practicable framework.

## **12.8 CONCLUDING STATEMENTS**

This study examines how nursing and medical staff deal with patients' refusal of medical treatment in acute care hospitals, in order to understand current practices and investigate their sufficiency to address patient wishes regarding refusal of treatment

and boundaries of acceptable care. The theory of *Endeavouring to Understand Refusal: Agreeing on a Way Forward* confirms that refusal of treatment is not necessarily limited to end-of-life decisions and the approaches adopted by nurses and medical practitioners reveal that competing perspectives exist as differing ideas and beliefs emerge regarding expectations, therapy and outcomes. The diverse situations highlight that the formulation of treatment plans provides insight into the intricacies of modern health care, which incorporate an amalgam of individualised behaviours.

A theory that provides a comprehensive overview addressing the actual refusal of therapy, the relationships between nursing and medical staff, and the evaluation of their practice in light of the legislation, serves to assist a practical consideration of the delivery of current health care. These insights reveal the influence and effect of the contextual determinants and the processes utilised by nurses and medical practitioners, when they deal with refusal of treatment decisions in acute care environments. Understanding the nature of decisions to refuse, the manner and frequency in which they often initially emerge, and the fact that specific or expansive aspects of therapy can be rejected, alert and enlighten health professionals in preparation for such encounters. Despite the overwhelming desire of many practitioners to implement therapy, the issue of refusal of treatment is an important consideration, which needs to be incorporated into practice and properly addressed. Acknowledgement that patients might refuse treatment is indeed an indication that therapy is sufficiently tailored to individuals' needs, instead of the same treatment for similar illness states.

There is an important need to consider the effects on patients and relatives, who tend to rely heavily on the guidance of, and react to health professionals, regarding the processes associated with decision-making. Where health professionals lack understanding, when fundamental legal principles are not observed, or the law is considered confusing, then patients and their families are potentially prejudiced and denied the protection of the very laws meant to support and allow them to exercise their right of choice. While emphasis has been placed on advance care planning in recent years, the theory developed in this study reveals the need to understand the processes utilised by nursing and medical professionals and thus the need to adopt a

comprehensive approach when caring for patients and their families. This must occur continually throughout episodes of care, not just at the outset of care, or when health professionals believe that it is necessary to consider the therapy plan. It is important to continually identify and assess individual patient wishes and include nursing and medical perspectives. This does not inevitably require huge time constraints, instead it necessitates an awareness and acknowledgement that desires and mindsets change, and effective communication skills ensure that information and cues are suitably addressed. The exemplars of this study clearly demonstrate that striving for agreement throughout the delivery of therapy is a process more likely to conclude with encouraging recollections of everyone involved because it enables differing perspectives to be shared and respected. Ultimately, it allows patients the right to determine specific treatment plans that are most appropriate for their individual needs at particular times in their lives.

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**APPENDICES**

**APPENDIX A**

**SCHEDULE 1**

Sections 3, 5(2)

**REFUSAL OF TREATMENT CERTIFICATE: COMPETENT PERSON**

We certify that we are satisfied—

- (a) that ..... (name of patient) has clearly expressed or indicated a decision, in relation to a current condition, to refuse—

\*medical treatment generally;

or

\*medical treatment, being .....  
(specify particular kind of medical treatment);

- (b) that the patient's decision is made voluntarily and without inducement or compulsion;
- (c) that the patient has been informed about the nature of his/her current condition to an extent which is reasonably sufficient to enable him/her to make a decision about whether or not to refuse medical treatment generally or of a particular kind (as the case requires) and that he/she has appeared to understand that information; and
- (d) that the patient is of sound mind and has attained the age of 18 years.

Dated:

Signed ..... (Registered Medical Practitioner)

Signed ..... (Another Person)

Patient's current condition

The patient's current condition is ..... (describe condition)

Dated:

Signed: .....  
(To be signed by the same registered medical practitioner)

*Verification to be completed by patient, if physically able to do so.*

In relation to my current condition, I refuse—

\*medical treatment generally

or

\*medical treatment, being .....  
(specify particular kind of medical treatment).

I give the following instructions as to palliative care:

Dated:

Signed ..... (Patient)

**NOTICE OF CANCELLATION** (*for completion where patient cancels the certificate under section 7 of the **Medical Treatment Act 1988***)

I cancel this certificate

Dated:

Signed ..... (Patient)

or

The patient clearly expressed or indicated a decision to cancel this certificate on (Date).

Signed ..... (Person witnessing patient's decision)

\*Delete whichever is not applicable

**NOTE: "Medical treatment"** means the carrying out of—

- (a) an operation; or
- (b) the administration of a drug or other like substance; or
- (c) any other medical procedure—

but does not include palliative care.

**"Palliative care"** includes—

- (a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or
- (b) the reasonable provision of food and water.

The refusal of palliative care is not covered by the **Medical Treatment Act 1988**.



**SCHEDULE 2**

Section 5A(2)

**ENDURING POWER OF ATTORNEY (MEDICAL TREATMENT)**

**THIS ENDURING POWER OF ATTORNEY** is given on the [insert date] day of [insert month] [insert year], by [insert name] of [insert address] under section 5A of the **Medical Treatment Act 1988**.

**1. I APPOINT**

[insert name] of [insert address] to be my agent.

\*[insert second named person] of [insert address] to be my alternate agent.

(\* a second agent is optional)

**2. I AUTHORISE** my agent or, if applicable, my alternate agent, to make decisions about medical treatment on my behalf.

**3. I REVOKE** all other enduring powers of attorney (medical treatment) previously given by me.

**SIGNED SEALED AND DELIVERED by:**

We ..... (names of witnesses) each believe that [the donor] in making this enduring power of attorney (medical treatment) is of sound mind and understands the import of this document.

**WITNESSED by:**

(Signature of Witness 1)

(Signature of Witness 2)

(Name of Witness 1)

(Name of Witness 2)

(Address of Witness 1)

(Address of Witness 2)

NOTE: Section 5A(2)(a) requires at least one of the witnesses to this instrument to be a person authorised by law to take and receive statutory declarations.

\_\_\_\_\_

SCHEDULE 3

Sections 3, 5B

**REFUSAL OF TREATMENT CERTIFICATE  
AGENT OR GUARDIAN OF INCOMPETENT PERSON**

I ..... [name]..... [address] certify that I am empowered to act in relation to decisions about medical treatment of..... [name of patient] ("the patient").

I have been appointed to act by—

- \* an enduring power of attorney (medical treatment) issued under the **Medical Treatment Act 1988**.
- \* an appropriate guardianship order of the Victorian Civil and Administrative Tribunal under the **Guardianship and Administration Act 1986** that provides for decisions about medical treatment.

I certify that—

- (a) the patient has attained the age of 18 years;
- (b) I have been informed about and understand the nature of the patient's current condition to an extent that would be reasonably sufficient to enable the patient, if he/she were competent, to make a decision about whether or not to refuse medical treatment generally or of a particular kind for that condition. I believe that the patient would request that no medical treatment, or no medical treatment of the particular kind mentioned below, be administered to him/her.

On behalf of the patient, in relation to his/her current condition, I refuse—

- \* medical treatment generally.
- \* medical treatment, being .....  
(specify particular kind of medical treatment).

Dated:

Signed: ..... (Agent/Guardian for ..... [Name of patient])

\*Delete whichever is not applicable

Verification

We each certify as follows:

- (a) I am satisfied that ..... [name of agent or guardian] has been informed about the nature of the patient's current condition to an extent that would be reasonably sufficient to enable the patient, if he/she were competent, to make a decision about whether or not to refuse medical treatment generally or of a particular kind for that condition and that the agent/guardian understands that information;
- (b) I was not a witness to the enduring power of attorney (medical treatment) under which ..... (name of agent) was appointed.

Dated:

Signed: ..... Signed: .....

(Registered Medical Practitioner)

(Another Person)

Patient's current condition

The patient's current condition is ..... (describe condition)

The patient is incompetent.

Dated:

Signed: .....

(To be signed by the same registered medical practitioner)

**NOTICE OF CANCELLATION** *(For completion where patient agent or guardian cancels the certificate under section 7 of the **Medical Treatment Act 1988**)*

I cancel this certificate

Dated:

Signed ..... (Patient, agent or guardian)

or

The patient, agent or guardian clearly expressed or indicated a decision to cancel this certificate

on ..... (Date)

Signed .....

(Person witnessing patient's agent's or guardian's decision)

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July 2005

## PARTICIPANT INFORMATION SHEET

This explanatory statement contains information about a research project. Its purpose is to explain to you as openly and as clearly as possible what is involved in the study, before you decide whether or not to participate.

**Project Title:** Managing patients' refusal of treatment decisions: the processes used by nurses and medical staff in Victorian public hospitals.

**Chief Investigator:** Professor Helen Baker.

**Associate Investigator:** Ms Debra Griffiths – Debra is the person who will be actually collecting the data and with whom you will have direct contact during the existence of the project.

**About the project:** We would like to invite you to be a part of a study into the processes used by registered nurses and medical practitioners, when identifying and managing patient/agents', refusal of treatment decisions. The study will examine the practices of health professionals working in acute care settings in public hospitals, who are largely in contact and involved with client care and decision-making. The possible benefits of the study include insights into decision-making between health professionals and their patients and might highlight problems with the existing legal framework and/or pertinent organisational constraints. Such insights may allow for recommendations to enhance practice, in the clinical and education environments, and/or acknowledge an insufficiency of the current law.

**What is required from participants:** Participation in this study will involve you being observed while interacting with your patients and other health professionals at times when discussion relates to treatment and in particular, when patients indicate that they wish to refuse treatment. The patient files, where refusal of treatment decisions are recorded at the time a decision is made, will form part of the study and will be observed. The researcher will also wish to interview you (for a period of up to 60 minutes), regarding your clinical practice when discussing patient refusal of treatment decisions. This interview will be one-on-one and will be audio taped and you will be given the opportunity to review and change the transcript of your interview.

**Potential benefits:** Identification of nurses' and medical practitioners' practice will assist an understanding of the knowledge and beliefs of these groups regarding patient's rights to refuse proposed treatment and how these might be constrained by contextual factors. The results of the study

Campuses at:  
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will contribute to the education of nurses and medical practitioners working with patients in the acute care sector, as many nurses and medical practitioners are required to do at some point in their careers. Identification of the beliefs and practice of these health professionals may also highlight whether the existing law presents any problems of implementation that might require modification either in current practice, institutional policy or legislative change. Health professionals who understand and practice within the ambit of the existing legislation are more likely to be respecting and assisting patient rights, which serves to promote quality care, together with the maintenance of high professional standards.

**Potential risks:** Participating in this project could give rise to some stress or concern regarding your clinical practice or interview answers, to potentially contentious or sensitive material. You may feel you must provide the “correct” answers. Please be aware that there is no correct answer to any question and that all responses are equally valid. The aim of the study is to understand the way you manage patient refusal of treatment in clinical practice.

**Confidentiality:** You are not required to disclose your name or any other form of identification and as such, your identity will be anonymous. This study will involve participants from other hospitals and all data will be de-identified. While the nature of this study may deal with potentially sensitive information, your responses (and those of your patients) will remain completely confidential. Maintaining confidentiality is important and any information in connection with this project that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law.

If you provide your consent and become a participant, on completion of the study a summary of the main findings will be made available to you upon your request. You are free to contact the Principal Researcher (Professor Helen Baker) if you have any questions about the results. We also plan to publish the results in medical or nursing journals, as well as it forming Ms Griffiths’ research thesis. In any publication, the information will be provided in such a way that you cannot be identified. Results will simply state that participants were recruited from regional public hospitals in Victorian.

**Freedom to refuse or withdraw from the project:** Completion and return of the Consent Form in the stamped, self addressed envelope supplied means that you have given your consent. If at any time you do not want to continue, simply inform the researcher that you do not wish her to observe your discussions with a patient/s, or that you are uncomfortable with any of the material raised during the interview. Participation in any research is voluntary. If you do not wish to take part, you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Any decision you make, either to take part in the study or not, will not affect your employment position. Moreover, this project will be undertaken according to the National Health and Medical Research Council Guidelines involving human research, the *National Statement on Ethical Conduct in Research Involving Humans* (June 1999). The ethical aspects of this study have been approved by the Victorian University’s Human Research Ethics Committee and the Berkley Health Research and Ethics Committee.

#### **Complaints and Queries**

If you have any queries you would like answered before you provide your consent, or should you have any complaints about the way you were treated, you may contact either the principal researcher, Professor Helen Baker, telephone 03/99192152 or email [Helen.Baker@vu.edu.au](mailto:Helen.Baker@vu.edu.au) or the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MCMC, Melbourne, 8001 or telephone: 03/ 99194710.

Thank you for your time.

**AIDE MEMOIRE USED FOR INTERVIEWS WITH PARTICIPANT  
NURSES AND MEDICAL PRACTITIONERS**

Managing patients' refusal of treatment decisions: the processes used by nurses and medical staff in Victorian public hospitals.

**Introduction**

Introduce researcher

Provide participant with a brief explanation of the study, including some examples of what may constitute refusal of treatment.

Ensure that written explanatory information is provided to the participant and the appropriate consent form is completed.

**Body of interview**

Can you tell me about your experiences of patients refusing treatment?

What do you do in situations where a patient refuses treatment?

What factors influence the way you respond to patients who refuse treatment?

What do other staff do in situations where a patient has refused treatment?

Can you think of any other way that this whole process could be undertaken?

Is there anything else that you would like to say about this issue?

**Conclude**

Do you have any further questions or queries?

Would you like an executive summary of this study when it is completed?

Debrief the participant – may involve highlighting the contact details on the information sheet.

May I have your permission to contact you again should I require further clarification of the data?

Lastly, thank the participant.