

**A problem-solving based peer support program for enhancing
adherence to oral antipsychotic medication in consumers with
schizophrenia.**

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**A research thesis submitted in fulfilment of the requirements
for the degree of Doctor of Philosophy
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(September, 2012)

ABSTRACT

Many people with schizophrenia are reluctant to take their antipsychotic medications, and this might have adverse implications for their recovery. Numerous approaches have been implemented to enhance medication taking for this population, but results have varied. The overall aim of the study was to assess if consumers with schizophrenia had improved adherence to their oral antipsychotic medication after participation in a problem-solving based peer support program.

This was a mixed method study comprising a time-series design and semi-structured interviews. Participants included 22 consumers with a diagnosis of schizophrenia who were non-adherent to their medication and who were recruited through an outpatient service in Melbourne, Victoria. Six peers were recruited following recommendations from this same outpatient service. Peers contacted consumers by a weekly 20-minute telephone call for eight weeks. Quantitative data were collected at baseline, post-intervention (Week 8) and follow-up (Week 14) and analysed using SPSS. Thematic analysis was used to develop themes from follow-up peer interviews.

The study found statistically significant improvements in adherence, overall mental state and negative symptoms from baseline to post-intervention, and these were maintained at follow-up. Peers were interviewed by the researcher following completion of the intervention. Helping others was an important motivator for peers in agreeing to participate in the study. They reported that telephone delivery was a convenient way to deliver the peer support program. However, at times it was difficult to contact consumers by telephone and this caused some frustration. Despite these difficulties, peers recognised that being involved in the program increased their confidence and made them feel worthwhile.

Overall, the findings support the use of a problem-solving based peer support program as an adjunct intervention to promote adherence in consumers with schizophrenia.

STUDENT DECLARATION

Doctor of Philosophy Declaration

"I, Gayelene Helene Boardman, declare that the PhD thesis entitled 'A problem-solving based peer support program for enhancing adherence to oral antipsychotic medication in consumers with schizophrenia' is no more than 100,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work."

Signature

Date

ACKNOWLEDGEMENT

I would like to acknowledge and sincerely thank those who have been closely involved in the undertaking of this thesis. Without their support, encouragement, assistance, and contribution this would not have been possible.

To my husband, Brett, and children, Gabby and James, thank you for all of your support and encouragement. You have been wonderful and accepting of the time I needed to work on this thesis.

My sincere gratitude to my principal supervisor Professor Terence McCann for his patience, guidance, and invaluable advice and support; it has been much appreciated and I have learnt so much. To my associate supervisor Dr Deb Kerr, my sincerest appreciation for the support and advice you gave me, especially with my writing, helping me with statistics and editing my work. To Dr Sue Cotton of ORYGEN Research Centre, University of Melbourne, I am very grateful for your invaluable advice regarding statistical issues. To Eileen Clarke, thank you for editing my thesis.

To the staff of the Area Mental Health Service, especially Area manager Gary Monkley, CCT manager Christine Brown and MST/CCU manager Brett Boardman, thank you so much for allowing me to spend nine months at your service recruiting consumers for the study. Without your continued support this study would not have been possible.

Special thanks to the academic staff at the School of Nursing & Midwifery Victoria University, especially my colleagues Dr Val Goodwin and Rob Ryan. Without your encouragement and support, extra teaching and academic responsibilities, I would not

have finished this thesis on time. You have been fantastic colleagues and friends; I appreciate the sacrifices that you have undertaken.

To my current Head of School, Professor Kris Martin-McDonald, previous Head, Professor Judy Parker and the HES Faculty Research Committee, thank you so much for approving two dedicated six-month periods of study leave to concentrate fully on data collection and writing up of my thesis.

My special thanks to the six peers who participated in the study. Without your enthusiasm and professionalism the study would not have been possible. You spent 18 months delivering the program with dedication and commitment, and it was a privilege to get to know each of you personally. Thank you for sharing your stories of the challenges and successes in your own mental health care. It has given me a different view on how consumers perceive the positive and negative aspects of the mental health system and how this can impact on recovery. Finally, to the consumer participants with schizophrenia who took part in the study, thank you for your involvement and willingness to participate, without this, the study would not have been possible.

CONFERENCE PRESENTATIONS

1. “A timed series study of a peer support intervention for enhancing medication adherence in consumers with schizophrenia.” Platform presentation. Faculty of Health, Engineering and Science postgraduate research conference, November 2009, Victoria University, St. Albans, Melbourne, Australia.
2. “A peer support program for enhancing medication adherence in consumers with schizophrenia.” Platform presentation. Australian College of Mental Health Nurses’ conference, August 2010, Hobart, Tasmania, Australia.
3. “Does peer support improve consumers’ medication adherence?” Platform presentation. Faculty of Health, Engineering & Science postgraduate research conference, July 2010, Victoria University, St. Albans, Melbourne, Australia.
4. “The rewards and challenges of providing peer support.” Keynote speaker. Faculty of Health, Engineering and Science postgraduate research conference, July 2011, Victoria University, St. Albans, Melbourne, Australia.
5. “A problem-solving based peer support program for enhancing adherence to oral antipsychotic medication in mental health consumers with schizophrenia.” Platform presentation. Australian College of Mental Health Nurses’ conference, October 2012 Darwin, NT, Australia.

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

In this chapter, an overview of the study on the effectiveness of a problem-solving based peer support program for enhancing adherence to oral antipsychotic medication in mental health consumers with schizophrenia is presented. The chapter begins by introducing the background of the study, then the research question, aims of the study, definition of terms, and justification for the study. The chapter concludes with a description of the structure of the thesis.

1.2 Background of the Study

Schizophrenia is one of the most severe of all psychiatric disorders. It accounts for 80% of psychiatric admissions in Australia amongst the 18 to 64-year-old-age group (Carr, Neil, Halpin, Holmes, & Lewin, 2003) and contributes to 2.3% of the global burden of disease and disability (Jablensky, 2011). Although the incidence¹ of schizophrenia is low (15.2 per 100,000) the prevalence² is quite high (7.2 per 1000), the early onset of the disorder and significant proportion of chronicity, subsequently increases the prevalence (Picchioni & Murray, 2009). Presentation of schizophrenia is similar in all cultures (El-Badri & Mellsop, 2011); however, it is more prevalent in migrants and individuals born in cities (Picchioni & Murray, 2009). The impact of schizophrenia on the community is considerable; hospital admissions, community

¹Incidence is the rate of occurrence of new conditions, diseases or cases in a specific time period (usually one year) (Crichton, 2000).

²Prevalence is the number of cases of a specific disease or condition in a population at any given time (Crichton, 2000).

follow-up care, accommodation needs, lost earnings for sufferers and carers, and income support all place a heavy drain on public and family resources. Moreover, the cost to individuals with the illness is not restricted to symptoms, but includes the burden of discrimination, negative attitudes from others, and their own self-stigma, including loss of hope, self-esteem, quality of life and identity (Brohan, Elgie, Sartorius, & Thornicroft, 2010).

Antipsychotic medications can improve quality of life and well-being in consumers diagnosed with this disorder. Unfortunately, many are non-adherent with their medication and this may eventually lead to a relapse of their illness (Chabungbam, Avasthi, & Sharan, 2007). This study is unique because a problem-solving approach that involved peers was used to provide support to consumers with a history of non-adherence to antipsychotic medication. Consumers were contacted by telephone on a weekly basis, for a period of eight weeks. Consumers were individuals who lived in the community and received treatment for schizophrenia in a large mental health service in Melbourne, Australia.

1.3 Research Question

What effect does a problem-solving based peer support program have on individuals with schizophrenia who have a history of non-adherence to oral antipsychotic medication?

1.4 Aims of the Study

The primary aim of the study was to assess if non-adherent consumers with schizophrenia, have improved adherence to their antipsychotic medication after participation in a problem-solving based peer support program. The secondary aims of

the study were to: (1) evaluate if the peer support program improved consumers' mental state, side effect profile, satisfaction with antipsychotic medication, and quality of life following participation; and (2) evaluate the consumers' and peers' perspectives about the usefulness of the peer support program.

1.5 Definition of Terms

Terms that are frequently used in the thesis are described in this section.

- A *consumer* is an individual who is a patient of a public mental health service. In Australia, an individual with a mental illness is commonly referred to as a mental health consumer (hereafter, consumer). In other countries, terms such as 'patient', 'client' or 'service user' are used.
- A *peer* is an individual who has a history of mental illness and has experienced significant improvement in his or her psychiatric condition, and who then offers support to other individuals with a serious mental illness (Davidson, Chinman, Sells, & Rowe, 2006).
- *Non-adherence* in this study refers to when the consumer has missed taking prescribed oral antipsychotic medication on five or more occasions in the past four weeks.
- *Schizophrenia* is a syndrome or disease process that has many different symptoms and sub-types. For diagnosis, a person would need to have continual signs of the disorder for at least six months, with one month of acute symptoms and considerable dysfunction in the areas of work performance, interpersonal relationships and self-care (American Psychiatric Association, 2000). According to the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision* (DSM-IV-TR), schizophrenia is

diagnosed when there are:

Two or more of the following symptoms present for a significant amount of time in a one-month period: delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behaviour or negative symptoms. Only one of these symptoms is required if the delusions are of a bizarre nature or the hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other (American Psychiatric Association, 2000, p. 312).

- The *problem-solving approach* is a cognitive behavioural process that helps individuals recognise and identify solutions to specific problems (D'Zurilla & Nezu, 2007).

1.6 Justification for the Study

There is a need for a study that examines the effectiveness of a problem-based peer support program to improve medication adherence in consumers with schizophrenia. Consumers are at risk of being non-adherent. Adherence rates for antipsychotic medications range from 29% to 77%³ (Novick, et al., 2010; Ascher-Svanum, et al., 2006; Dolder, Lacro, Dunn, & Jeste, 2002; Lacro, Dunn, Dolder, Leckband, & Jeste, 2002) with an average rate of 49.5% (Lacro, et al., 2002). There have been no studies to date that have used a problem-solving based approach in individuals with schizophrenia. However, promising results have emerged for peer support programs in mental health consumers, with positive outcomes such as decreased hospitalisation, improvement in well-being, quality of life, symptoms management and confidence with illness (Lucksted, McNulty, Brayboy, & Forbes, 2009; Rivera, Sullivan, &

³This adherence range is dependent on the type of research and methodology used by the authors and their definition of adherence.

Valenti, 2007). Despite the introduction of various strategies such as adherence and cognitive behavioural therapy, psychoeducation and use of depot medication, there continues to be a wide range of non-adherence rates.

Non-adherence is associated with poorer functional outcomes, including relapse of the illness, readmission to hospital, greater use of psychiatric emergency services, poorer life satisfaction, an increase in substance use problems and suicide attempts (Ascher-Svanum, et al., 2006; Sreenath, Reddy, Tacchi, & Scott, 2010; Novick, et al., 2010). There is also an increased risk of homelessness, aggression to self and others, and development of chronic psychotic symptoms (Byerly, Nakonezny, & Lescouflair, 2007; Novick, et al., 2010). Non-adherence not only affects the individual with the illness, it also affects carers. Individuals who care for consumers with schizophrenia feel isolated, alone and stigmatised by the community (Fiorillo, Bassi, de Girolamo, Catapano, & Romeo, 2011). There is also a cost to the health care system. In Australia, the estimated annual direct cost is \$661 million and the indirect cost \$722 million, with an annual individual cost of \$18,000 (RANZCP, 2005).

Justification for the study can also be premised on the concept of peer support. A considerable number of interventions have been used to improve adherence in individuals with schizophrenia; however, these have had limited success overall. There are potential benefits in using a peer support program to address medication adherence in this population. Peers have experience in taking antipsychotic medication and, combined with using the problem-solving approach, may improve antipsychotic medication adherence in consumers with schizophrenia. Improving adherence may improve the consumers' mental state, quality of life, and satisfaction

with medication. In addition, using the problem-solving approach may equip consumers to develop new skills to assist in managing their everyday stresses.

1.7 Structure of the Thesis

This thesis is presented in eight chapters. In Chapter Two, the literature pertaining to schizophrenia is examined. In Chapter Three, adherence to antipsychotic medication is investigated. In Chapter Four, the literature on peer support is explored. In Chapter Five, the design and methods of the study are outlined. In Chapter Six, the quantitative findings of the peer support program are presented. In Chapter Seven, the qualitative findings of the peer interview are explored. In Chapter Eight, a discussion of the findings is undertaken into the effect of the peer support program on adherence, mental state, side effect profile, quality of life, satisfaction with medication, and consumers' and peers' perspectives of the program. Finally, the conclusion, recommendations, strengths and limitations of the study are presented, and the implications for clinical practice and future research are outlined.

CHAPTER TWO

SCHIZOPHRENIA

2.1 Introduction

The chapter begins with a description of the search strategy undertaken for the literature review, followed by an overview of the history of schizophrenia. Next, a description of the clinical features of the disorder, its onset and course, and aetiology are presented. This is followed by an overview of treatment modalities, including pharmacological and psychosocial interventions. Finally, relapse and recovery are explained.

2.2 Search Strategy

The literature search began with a general title search of English language articles from the databases CINAHL, MedLine, EMBASE, PsycINFO, and SCOPUS using the keywords: 'mental health', 'consumer', 'peer support', 'schizophrenia', 'psychosis', 'adherence', 'compliance', 'telephone', 'antipsychotic', and 'problem-solving approach'. In addition, specific searches of the Cochrane Library, Johanna Briggs Institute, and extensive hand searches of a selection of mental health journals were also undertaken. The period covered by the search was from 1990 to 2012.

2.3 Overview

Schizophrenia is a mental illness that dates back in history to 1400 BC, when it was believed that symptoms of nudity, filth, lack of self-control and confusion were brought on by the devil (Adityanjee, Aderibigbe, Theodoridis, & Vieweg, 1999). It

was only during the industrial and social revolution in the 1800s that these symptoms were clarified (Africa & Schwartz, 1995). In 1801, French psychiatrist Phillippe Pinel gave the first description of *demence* or loss of mind, to describe the decline of mental abilities in chronically ill patients who were hospitalised (Adityanjee, et al., 1999). By the mid to late 1800s, two German psychiatrists, Kahlbaum and Hecker, were classifying many psychotic symptoms and introduced some of the terms that are still used today, including dysthymia,⁴ verbigeration,⁵ and catatonia⁶ (Adityanjee, et al., 1999). Kahlbaum was the first psychiatrist to classify disorders based on syndromes. In 1871, Heckler coined the term hebephrenia, which originated from *Hebes*, the Greek goddess of youth. This term was used to describe younger patients who presented with psychosis, and the course of their illness was likely to deteriorate over time (Adityanjee, et al., 1999).

In 1896, Emil Kraepelin [1856–1926] recommended that the condition dementia praecox should be classified as a distinct disease (Kraepelin, 1989). He also recognised that there were other presentations that did not fit into the dementia praecox classification, including paraphrenia where the individual experienced symptoms such as delusions⁷ of persecution, hallucinations,⁸ ideas of influence⁹ and

⁴Dysthymia is a term that means ill-humoured and it can be a chronic feeling of sadness (Harris, Nagy, & Vardaxis, 2010).

⁵Verbigeration is meaningless and stereotyped repetition of words or phrases (Sadock & Sadock, 2007).

⁶Catatonia is a rare condition characterised by motor immobility or purposeless excessive mobility, mutism, waxy flexibility, negativism and echolalia (Sadock & Sadock, 2007).

⁷Delusions are fixed false beliefs based on incorrect conclusions about external stimuli. They are firmly held despite objections or proof from others. They are out of keeping with a person's cultural or religious beliefs (Sadock & Sadock, 2007). They may contain a variety of themes, including persecutory, grandiose, somatic, religious and referential. Delusions of persecution occur when an individual believes that he or she is being mistreated, conspired against, harassed or someone is trying to harm them (Harris, et al., 2010).

manic–depressive insanity¹⁰ (Kraepelin, 1989). Similarly, in 1911, the Swiss psychiatrist, Eugen Bleuler [1857–1939] stated that the term ‘demented’ did not fit the condition adequately and coined the term schizophrenia, meaning splitting of different psychic functions. He believed this better suited the group of psychoses previously known as dementia praecox (Bleuler, 1952). He described the fundamental symptoms of schizophrenia, which are recognised today as Bleuler’s four ‘As’ and include looseness of association,¹¹ affective flattening,¹² autism¹³ and ambivalence¹⁴ (Adityanjee, et al., 1999). He considered symptoms such as hallucinations, delusions, memory and speech disturbances were accessory symptoms that usually led to social difficulties (Bleuler, 1952). He categorised the disorder into subgroups of paranoid, catatonic, hebephrenic, simplex and latent schizophrenia (Bleuler, 1952).

In the 1950s German psychiatrist Kurt Schneider saw the importance of diagnosing schizophrenia based on unbiased observation. He emphasised that abnormal experiences and expression were diagnostically significant and needed to be ranked in order to achieve an accurate diagnosis (Schneider, 1959). He used these symptoms to diagnose patients who did not have a brain disease. The differences between Bleuler’s

⁸Hallucinations are a sensory perception not related to external stimuli, and can be auditory, gustatory, olfactory or visual (Harris, et al., 2010).

⁹Ideas of influence is a false belief where an individual believes that their feelings, thoughts and acts are under the influence of an external force (Harris, et al., 2010).

¹⁰Manic–depressive insanity was a term used to describe a person who had manic, depressed or mixed states of mood (Kraepelin, 1989).

¹¹Looseness of association occurs when ideas fail to follow each other in a logical flow, resulting in the shift from one idea to another and loss of the significant meaning (Elder, Evans, & Nizette, 2009).

¹²Affective flattening is an emotional response that is insufficiently intense in a situation that would require a stronger reaction (Kniesl & Trigoboff, 2009).

¹³Autism occurs when individuals retreat into their own fantasy world and isolate themselves from others (Elder, et al., 2009).

¹⁴Ambivalence is when an individual finds it difficult to make decisions because of conflicting thoughts and feelings (Elder, et al., 2009).

and Schneider's diagnostic models caused ambiguities in the diagnosis of schizophrenia between continents. Individuals in the United States (US) diagnosed with schizophrenia would be given a different diagnosis to those in the United Kingdom (UK) (Bennett, Fossey, Farhall, & Grigg, 2007). This eventually led to the development of the two diagnostic standards that are available today: International Classification of Disease (ICD), published by the World Health Organization; and Diagnostic Statistical Manual (DSM), published by the American Psychiatric Association (APA). Both of these originated from Kraepelin and Schneider's concepts (Adityanjee, et al., 1999). The DSM is now in a fourth revised edition (DSM-IV-R), and is the diagnostic tool widely used in mental health services in Australia. It was used in the current study to classify schizophrenia.

2.4 Clinical Features

Individuals with schizophrenia¹⁵ may present with a range of clinical features including positive,¹⁶ negative,¹⁷ affective,¹⁸ and cognitive¹⁹ symptoms that can change over the course of the illness (Falkai & Schmitt, 2011). Positive symptoms are believed to be the result of a subcortical dopaminergic process, where there is too much dopamine affecting the cortical area of the brain (Keltner, Schwecke, & Bostrum, 2003). Excess dopamine causes a distortion of normal functions, where the

¹⁵See Chapter 1.5 for DSM-IV-R diagnostic criteria for schizophrenia.

¹⁶Positive symptoms are an exaggeration of normal function and include delusions, hallucinations and disorganised symptoms (Falkai & Schmitt, 2011).

¹⁷Negative symptoms are a decrease in normal function and include affective blunting, alogia, avolition, anhedonia and reduced social interaction (Falkai & Schmitt, 2011).

¹⁸Affective symptoms are produced from the individual's subjective and immediate emotional reaction to objects and ideas (Sadock & Sadock, 2007).

¹⁹Cognitive symptoms are related to mental process of comprehension, judgement, reasoning and knowing (Harris, et al., 2010).

person may experience delusions, hallucinations, and disorganised symptoms²⁰ (Falkai & Schmitt, 2011). Delusions are commonly bizarre in nature and hallucinations are usually auditory and experienced as ‘voices’, which are distinct from the person’s own voice. Disorganised thinking or formal thought disorder is an important feature and is based on the person’s disorganised speech and behaviour. This can lead to problems with goal directed behaviour, daily living and unpredicted agitation (American Psychiatric Association, 2000).

Negative symptoms are believed to be caused by a hypo-dopaminergic process that causes changes to the cortical structure; this means that there is a reduced blood flow especially in the frontal areas of the brain that can lead to cerebral atrophy (Keltner, et al., 2003). These changes lead to a loss of normal functioning, often evidenced by a decrease in thought and speech productivity, loss of ability to experience pleasure, blunting of emotional expression, social withdrawal, cognitive impairment including poor concentration and memory, and difficulty following through and paying attention to tasks (Minzenberg, Yoon, & Carter, 2008).

Individuals may also experience a range of affective and cognitive dysfunctions. Common affective symptoms in schizophrenia can include reduced, inappropriate or overactive emotions. The person may present with poor emotional responsiveness, which can be in the form of a blunted or flat affect that can be a symptom of the illness, side effects of antipsychotic medication, or a symptom of depression (Sadock

²⁰Disorganised symptoms or ‘formal thought disorder’ affects speech and behaviour. Disorganised speech may occur when a person goes from one topic to another or answers questions tangentially, or it may be so severe that speech is not recognisable. Disorganised behaviour includes the person being dishevelled or dressing unsuitably for the weather, displaying inappropriate sexual behaviour, with unpredictable agitation, or having difficulties attending to daily living activities (American Psychiatric Association, 2000).

& Sadock, 2007). They may also exhibit inappropriate affect²¹ (American Psychiatric Association, 2000) or overactive emotions of extreme agitation, hostile or aggressive behaviour, anxiety or happiness (Sadock & Sadock, 2007). Individuals with schizophrenia will experience slight cognitive dysfunction in the areas of working and episodic memory, attention and executive function. Orientation to time, place and person is not usually affected and other areas of memory remain intact (Sadock & Sadock, 2007). There can also be impairments to occupational and social functioning. Education may have been disrupted because of the onset of illness; long-term employment may be difficult and few social friends exist (American Psychiatric Association, 2000).

Schizophrenia has five subtypes: paranoid, disorganised, catatonic, undifferentiated, and residual. Schizophreniform and schizoaffective disorders are other psychotic disorders that share similar characteristics with schizophrenia (American Psychiatric Association, 2000). In paranoid schizophrenia, paranoid delusions and auditory hallucinations are prominent, but there is better premorbid functioning, later age of onset and better social and occupational functioning. Individuals with this type of schizophrenia will have fewer cognitive deficits (Minzenberg, et al., 2008). Disorganised schizophrenia includes characteristics of disorganised speech and behaviour, and the person will have flat or inappropriate affect. This is a more severe type, with an earlier onset and poor social and occupational functioning. Individuals with this type have a poor long-term prognosis (Minzenberg, et al., 2008). Catatonic schizophrenia is diagnosed when a person has stupor with waxy flexibility or overexcitement, sometimes with rapid movements. The person can present with

²¹Inappropriate affect is when the individual's emotional tone does not match the idea, thought or speech accompanying it (Sadock & Sadock, 2007).

immobility, mutism, strange postures, grimacing and unusual mannerisms (Minzenberg, et al., 2008). Residual schizophrenia is diagnosed when the person has inactive positive symptoms and two or more of the negative symptoms. Undifferentiated schizophrenia is diagnosed when none of the previous subtypes are met (Minzenberg, et al., 2008). Schizoaffective disorder occurs when an individual experiences a prominent mood disturbance and symptoms of schizophrenia. Individuals with schizophreniform disorder will have the same presentation as schizophrenia; however, the duration of the illness will be less than six months (Bennett, et al., 2007).

The impact of diagnostic criteria and the prevalence of schizophrenic subtypes in 220 individuals with schizophrenia was investigated by Stompe, Ortwein-Swoboda, Ritter, Marquart, and Schanda (2005). They found that paranoid schizophrenia was the most common (65%) subtype, followed by catatonic (9.5%), residual (9.1%), schizoaffective (7.7%), disorganised (6.4%) and undifferentiated (2.5%). Catatonic and disorganised subtypes are considered less common than in the past, because of the positive effects of antipsychotic medications and rehabilitation (Williamson, 2006).

2.5 Onset and Course

Schizophrenia is equally common among men and women, and consistent in presentation throughout the world (Haro, et al., 2003). Age of onset is usually between the ages of 15 and 24 years. Males tend to have younger onset and higher lifetime risk (30–40%) of developing the illness (Messias, Chen, & Eaton, 2007). Women develop the illness approximately three to four years later than men (Gaebel, et al., 2000), and have a second peak when they are aged 53–64 years (Messias, et al., 2007). On average, males first present for treatment at 27.6 years and females at 30.6

years (Haro, et al., 2003). Early onset of schizophrenia in childhood and adolescence is rare, only affecting 4% of individuals with the disorder. Outcomes for the younger population are poorer than for those with adult onset (Kinros & Frangou, 2010). This review will focus on individuals who are presenting with schizophrenia in the 18 to 64-year-old-age range, as this is representative of the participants in the current study.

Schizophrenia is an illness with individualised clinical presentation that varies through the course of the illness (Frangou & Murray, 2000). Onset may be sudden, but in most cases there are early warning signs or symptoms, referred to as the prodromal phase. These signs are usually a collection of sensory, motor and cognitive impairments, including not paying attention at school, poor academic grades, and clumsiness (Weiden, Buckley, & Grody, 2007). There could also be significant behavioural and psychiatric symptoms that include depression, irritability, sleep disturbance, social anxiety, social withdrawal, aggressive behaviour and substance use (Minzenberg, et al., 2008; Weiden, et al., 2007), and mild psychotic symptoms such as illusions,²² magical thinking,²³ and suspiciousness (Lieberman, et al., 2001).

The duration of the prodromal phase is unpredictable and almost impossible to estimate; it is a slow and insidious onset that can last several years (RANZCP, 2005). There is a notable change in the person's presentation for some time before the diagnosis of first-episode schizophrenia; 25% would have experienced some psychotic symptoms during their childhood years (Weiden, et al., 2007). Following the prodromal phase, the individual presents with an initial psychosis that lasts for one or more years on average (Hafner, 2003). The length of the early phase of the illness

²²Illusions are distortions of real sensations or images and may occur in the acute phase of illness (Sadock & Sadock, 2007).

²³Magical thinking is where a person believes his or her thoughts, words or actions may cause or prevent something from happening (Sadock & Sadock, 2007).

can help predict whether the course of the illness will be short- or long-term (Hafner, 2003). The American Psychiatric Association has classified the illness into three stages: acute psychotic phase, where individuals experience the first episode or an exacerbation of their illness; stabilisation phase, where acute symptoms are stable but there is risk of having another episode; and maintenance phase, when the illness is in remission and the goal is to prevent relapse (Sherin & Marder, 2011).

Full or partial positive symptom remission occurs in 75–90% of individuals in the first year after treatment following the first episode of schizophrenia (Addington, Piskulic, & Marshall, 2010). However, following a first episode and subsequent diagnosis, 80–85% of individuals can expect to have further psychotic episodes throughout their lifetime (Altamura, Bobo, & Meltzer, 2007). This was quantified in a study by Ventura et al. (2011) for individuals in the first year of outpatient treatment. The rate of full symptom remission at six months was 36% and rate of recovery was 10%. After one year, the remission rate decreased to 22% and only 1% of individuals obtained full recovery. The sample in this study was only prescribed a depot²⁴ typical antipsychotic, which may have influenced results. The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE)²⁵ study investigated five commonly used antipsychotics in a large sample of 1460 consumers with chronic schizophrenia (Levine, et al., 2011), 16.2% after six months, met the criteria for remission. The remaining individuals who were not in remission were examined again 18 months later, and a further 11.7% met the criteria for remission.

²⁴Depot antipsychotics are long-acting injectable form of a drug, that is given intramuscularly every 2-4 weeks (Usher, Foster, & Bullock, 2009).

²⁵CATIE study: Clinical Antipsychotic Trials of Intervention Effectiveness was conducted between January 2001 and December 2004 at 57 US sites (Levine, Rabinowitz, Ascher-Svanum, Faries, & Lawson, 2011).

Individuals with schizophrenia have a high risk of relapse, and if the psychosis is left untreated the individual can expect a poorer outcome (RANZCP, 2005). In 35% of cases, each episode of the illness leads to further impairment in functioning with no return to normal functioning (Gaebel, et al., 2000). This is believed to be related to a neurodegenerative process that occurs when an individual experiences psychosis. It is hypothesised that persistent damage to neuron function occurs if the psychosis is untreated (Altamura, et al., 2007).

Differences have been observed between men and women. In an Australian study by Morgan, Castle, and Jablensky (2008) of how men and women experience and express psychosis, women reported lower levels of disability, milder illness, better premorbid functioning and were less likely to have a chronic course of illness. The study also found that women were more able to engage socially with others, and had better long-term relationships than their male counterparts (Morgan, et al., 2008).

Morbidity and mortality in schizophrenia are high compared with the general population (McGrath & Susser, 2009). Within one year of diagnosis 60% of individuals with schizophrenia are receiving disability benefits (Andreasen, 1999): 20% will achieve full employment and 30% develop a stable relationship (Falkai & Schmitt, 2011). Compared with the general population, people with schizophrenia have a 20% shorter lifespan (Casey, 2005) and higher suicide rate (10–20 times) (Seeman, 2007). More than two-thirds of people with schizophrenia will die from coronary heart disease, with cigarette smoking, obesity, diabetes, and hypertension contributing to their risk of disease (Seeman, 2007). Risk factors for suicide include having greater insight into the illness (Gonzalez, 2008), higher social class (Lewine & Shriner, 2009), five to ten years post diagnosis, poor treatment adherence, frequent

relapses, repeated brief hospitalisation and early discharge (Bolton, Gooding, Kapur, Barrowclough, & Tarrier, 2007).

2.6 Aetiology

There are a number of theories regarding the aetiology of schizophrenia that include genetic factors, neurodevelopment factors, environmental risks and cannabis use (Silverstein, Spaulding, & Menditto, 2006). A single factor has not been established as the cause of the disorder; however, it is believed that multiple factors lead to the development of the illness (Williamson, 2006). Generally, it is believed to stem from the behavioural outcomes of abnormalities in the neurodevelopmental process, which when combined with genetic factors and the effect of environmental factors, subsequently lead to the development of schizophrenia (Klar, 2010; Rapoport, Addington, Frangou, & Psych, 2005).

2.6.1 Genetic factors

The majority of individuals (63%) presenting with schizophrenia have no known family history of the illness (Bennett, et al., 2007; Frisch & Frisch, 2006). Nevertheless, genetic factors play an important role in determining whether someone may be susceptible to the disorder. Walters, O'Donovan, and Owen (2011) report that the probability of heritability for schizophrenia is approximately 80%. For an individual with one parent with schizophrenia, there is a 7–13% risk that the disorder will be inherited, which is 10–12 times higher than in the general population. If both parents have schizophrenia the genetic risk increases to 27–46%, and in monozygotic twins the risk increases to 41–65% (Cannon, Tarrant, Huttunen, & Jones, 2003; Walters, et al., 2011). Researchers are making advances in genome studies with the

identification of common genetic variants and specific chromosomal abnormalities or copy number variations²⁶ that are present in individuals with schizophrenia compared with health individuals (Doherty, O'Donovan, & Owen, 2012; Walters, et al., 2011). Previous genetic research was based on pooled DNA, and findings suggested that *reelin (RELN)* was a potentially susceptible gene for schizophrenia in women. Researchers are now studying individual sample genotyping. This has resulted in the gene *ZNF804A* being associated with schizophrenia and psychosis (Walters, et al., 2011).

2.6.2 Neurodevelopment factors

It has been widely hypothesised that schizophrenia is a consequence of prenatal abnormalities that result from the interaction of genetic and environmental factors (Da Fonseca, et al., 2011). Recent research using brain images has found early structural abnormalities and irregular progressive brain changes in individuals with schizophrenia (Falkai & Schmitt, 2011; Pantelis, Yucel, Wood, McGorry, & Velakoulis, 2003). Three possible explanations for the impairment in neurodevelopment are prenatal influences, the dopamine hypothesis and structural changes in the brain.

2.6.2.1 Prenatal influences

There appears to be a relationship between pregnancy and complications during childbirth (Williamson, 2006) and the later development of schizophrenia in the offspring. In a meta-analytic review, Cannon, Jones, and Murray (2002) found three obstetric influences that may contribute to the risk of schizophrenia: complications

²⁶Copy number variants consist of the duplication and deletion of chromosomal segments (Walters, et al., 2011).

during pregnancy (bleeding, pre-eclampsia, and Rhesus incompatibility), abnormal growth and development of the foetus, and complications following delivery (asphyxia, emergency caesarean section, and loss of uterine tone).

One study identified maternal exposure to influenza infection during the second trimester of gestation as a significant risk factor for schizophrenia (Limosin, Rouillon, Payan, Cohen, & Strub, 2003). However, another study by Takei et al. (1996) found that prenatal exposure to influenza occurred in only 1.4% of individuals with schizophrenia. A more recent study (Sørensen, Mortensen, Reinisch, & Mednick, 2009) found exposure to bacterial infections during the first trimester of pregnancy increased the risk considerably (OR=2.53) while exposure to gonococcal infections in first trimester was significant for increased risk.

Environmental influences such as lead and Vitamin D have been found to play an important role in the development of schizophrenia during the prenatal period. Opler et al. (2008) found exposure to lead during pregnancy doubled the risk of schizophrenia. This study attributes high levels of lead to the use of lead-based paints in pre-1950s housing. In a Danish population, McGrath et al. (2010) found that neonates with either high or low concentrations of Vitamin D had double the risk of later developing schizophrenia compared with those with normal concentrations.

2.6.2.2 Dopamine hypothesis

The dopamine hypothesis is a neurophysiologic theory that has dominated research over many years (Heinz & Schlagenhauf, 2010; Silverstein, et al., 2006). This hypothesis emerged from studies of individuals who misused cocaine, patients with Parkinson's disease and the pharmacokinetics of antipsychotic medication. Cocaine

misuse causes an increased level of dopamine in the brain and this leads to the development of psychotic symptoms. Patients with Parkinson's disease develop similar symptoms when they receive large doses of L-dopa, a dopamine precursor. Furthermore, all antipsychotic medications share a common action to date, which is to block the synaptic action of dopamine at the dopamine D2 receptor (Silverstein, et al., 2006). *In vivo* imagery has also found evidence that dopamine signalling is altered in individuals with schizophrenia and appears to contribute to the development of delusions, hallucinations, and formal thought disorder (Heinz & Schlagenhauf, 2010; Meadows, et al., 2012). These observations form the basis for this simple theory of a dopamine hypothesis of schizophrenia. This theory however has a number of limitations. No deficit has been observed within the dopamine system to account for this dopamine hyperactivity, nor does this explain the other symptoms of schizophrenia or the neurocognitive dysfunction that can also occur (Javitt, 2010).

Other neurotransmitters (glutamate, serotonin, *gamma*-aminobutyric acid [GABA]) are also associated with schizophrenia, with post-mortem studies showing an increase in glutamine receptors (Williamson, 2006). This has been referred to as the glutamate hypothesis. When individuals are given phencyclidine and ketamine (dopamine antagonists that block glutamine receptors), psychotic symptoms are induced in healthy and schizophrenic patients. Recent studies have also linked the influence of risk genes on the glutamate NMDA (N-methyl-D-aspartate) receptor (Falkai & Schmitt, 2011).

2.6.2.3 Structural changes in the brain

Individuals with schizophrenia usually have a reduction in cerebral brain matter over time (Rais, et al., 2008). Meta-analyses of structural magnetic resonance imaging have revealed deficits in the medial temporal lobe (hippocampus and parahippocampal gyrus), the heteromodal association cortex (prefrontal and parietal cortex) and superior temporal gyrus (Falkai & Schmitt, 2011). A decrease in the hippocampus area is the most common abnormality, and this is associated with positive symptoms of schizophrenia (Falkai & Schmitt, 2011). However, in a review of the timing of structural changes in schizophrenia, Pantelis et al. (2003) found that although there is an initial decrease in the volume of the hippocampus or temporal lobe in people with first-episode psychosis, it has not yet been determined whether the decrease continues in subsequent years. Furthermore, they found that the volume of both brain hemispheres in first-episode and chronic schizophrenia declines at a rate of 1–2% per year.

Different theories exist regarding neurodevelopmental factors. Pantelis et al. (2003) theorise that a particular prenatal neurodevelopmental lesion may increase an individual's vulnerability to schizophrenia. Additionally, it is proposed that abnormal brain development caused by adverse or environmental effects can occur at any time from the prenatal period until the early adult years when brain maturity is complete (Falkai & Schmitt, 2011; Kinros & Frangou, 2010). This theory is popular because pre-schizophrenic individuals exhibit delays in motor, cognitive and social development (Rapoport, et al., 2005). In a review of early onset schizophrenia, Kinros and Frangou (2010) reported that children and adolescents exhibited premorbid delay

and impairment in the areas of language, motor and social development and this was a factor in the development of schizophrenia.

2.6.3 Environmental factors

Environmental risks that may contribute to the onset of schizophrenia include season of birth, place of birth, and migrant status (Bennett, et al., 2007; McGrath & Susser, 2009; Mortensen, et al., 1999). A large study in Denmark by Mortensen et al. (1999), found an increased incidence in people born in February and March, during winter and early spring. This is consistent with findings from a review of over 250 studies that report an incidence of 5–8% in individuals born at this time (Bennett, et al., 2007). Mortensen et al. (1999) also found a relationship between the incidence of schizophrenia and urban place of birth and upbringing. Explanations for this include infections during pregnancy and childhood, overcrowded living conditions, complications during the perinatal period, exposure to toxic industrial by-products and problematic social/psychological variables (Bennett, et al., 2007; Mortensen, et al., 1999). Cantor-Graae and Selten (2005) showed that first and second generation migrants have an increased risk of developing schizophrenia; this was twice as high for migrants from areas where the predominant skin colour was black.

2.6.4 Cannabis use

Heavy cannabis use may result in acute psychotic episodes and, for some, the development of chronic schizophrenia (DeLisi, 2008). Cannabis use occurs in 28–50% of individuals with schizophrenia (Rais, et al., 2008) and 51% of first episode patients (Fernandez-Espejo, Viveros, Núñez, Ellenbroek, & Rodriguez de Fonseca, 2009). Sevy et al. (2010) found that 74% of individuals had onset of cannabis use

disorders prior to the onset of psychotic symptoms and only 8% used cannabis after the onset of positive symptoms.

Although there is increasing evidence that using cannabis results in an increase in psychotic symptoms (Fergusson, 2010), there is compelling evidence that cannabis use at a younger age may increase the risk of developing schizophrenia (Arseneault, et al.2002). Arseneault et al. (2002) found that individuals who used cannabis before the age of 15 years were four times more likely to develop a schizophreniform disorder by the age of 26 years. This has been supported by Dragt et al. (2012) who found that use of cannabis at a younger age, places individuals at a higher risk of psychosis. Cannabis has also been shown to affect neurodevelopment in adolescents, especially of the endocannabinoid system²⁷ and this increases the risk of developing schizophrenia (Fernandez-Espejo, et al., 2009). This was supported in a study by Rais et al. (2008), who found a more pronounced reduction in brain volume in individuals with first-episode schizophrenia who had used cannabis.

2.7 Treatment Modalities

The management and treatment of individuals with schizophrenia include pharmacological, psychosocial and early intervention approaches. These are separated in this literature review for ease of description; however, in most cases, individuals receive a combination of pharmacological and psychosocial interventions. The emphasis of treatment varies depending on the treating professional and the individual's identified areas of need.

²⁷‘Endocannabinoid system refers to a range of process group of neuromodulatory lipids that play an important role in a diverse range of neurophysiological processes including neural development, neuroimmune function, synaptic plasticity, pain, reward and affective state’ (Buczynski & Parsons, 2010, p. 423).

2.7.1 Pharmacological intervention

The medications commonly used to treat individuals with mental illness are referred to as psychotropic drugs. This group of medications has been available since the introduction of Lithium by John Cade in 1949 (Altamura, et al., 2007). There are five main types of psychotropics: antipsychotics, antidepressants, anxiolytics, monoamine oxidase inhibitors and mood stabilisers, and these are used to treat a range of mental illnesses, including schizophrenia, depression, anxiety and bipolar disorder (Usher, et al., 2009).

Antipsychotics are the recommended medication for nearly all people experiencing an episode of schizophrenia (Sherin & Marder, 2011). The first antipsychotic was Chlorpromazine, discovered in 1952, and this was a major turning point in the treatment of all psychotic disorders, especially schizophrenia (Altamura, et al., 2007).

There are two broad groups of antipsychotics: typical (conventional, first generation, or classic) and atypical (newer or second generation) (Lieberman, Stroup, & McEvoy, 2005). They are available as tablets, wafers, syrups, intramuscular and depot (long acting) injections. Typical antipsychotics block the dopamine D2 receptors in the brain. They have good efficacy and specifically target positive symptoms. However, they are less tolerable than atypical antipsychotics, causing sedation and unpleasant side effects, the most distressing of which are extrapyramidal side effects (EPSE)²⁸ and tardive dyskinesia²⁹ (Lieberman, et al., 2005).

²⁸Extrapyramidal side effects (EPSE) include Parkinsonian symptoms (shuffling gait, rigidity, and tremor), akathisia, and acute dystonic reactions (torticollis, oculogyric crisis) which are reversible (Tiziani, 2010).

²⁹Tardive dyskinesia is an extrapyramidal side effect that is irreversible; it appears late in treatment and presents as uncontrollable twitching and purposeless muscle protrusion. Behaviours include lip

In Australia, the newer atypical antipsychotics were introduced in the 1990s. Risperidone was the first to be prescribed in 1995, followed by Olanzapine in 1997 and Quetiapine in 2000 (Hollingworth, Siskind, Nissen, Robinson, & Hall, 2010). While atypical antipsychotics consist of similar compounds to the older typical antipsychotics, they have an additional blocking action on serotonin receptors that reduces the severity of side effects and negative symptoms experienced by individuals (Herz & Marder, 2002). Though atypicals give rise to fewer EPSEs, recipients can experience other side effects, including sedation, hypotension, convulsions and anticholinergic effects³⁰ (Bennett, 1999). Antipsychotics not only have an effect on neurotransmitters but also cause metabolic changes within the body, referred to as the metabolic syndrome.³¹ This includes weight gain, hypertension, glucose intolerance, altered blood lipids and an increase in Type 2 diabetes (Bennett, et al., 2007). All antipsychotics have the potential to increase weight; however, individuals taking Clozapine, Olanzapine and, to a degree, Quetiapine are more prone to obesity (Therapeutic Guidelines: Psychotropics, 2000).

The decision to use typical or atypical antipsychotics depends on the presentation of individuals and their response to treatment. Schizophrenia guidelines from the Patient Outcome Research Team (PORT³²) (Buchanan, et al., 2010) and Royal Australian and

smacking, jaw protrusion and side-to-side movement, movements of legs, neck, body and pelvis area (Rankin, 2000).

³⁰Anticholinergic effects are side effects caused by the blocking of cholinergic receptors through the use of antipsychotic medications. Common effects include dry mouth, blurred vision, sedation, urinary retention, and constipation (Tiziani, 2010).

³¹Metabolic syndrome is a group of abnormalities that can be life threatening and which include abdominal obesity, raised triglyceride and high density cholesterol levels, raised blood pressure and fasting glucose levels (Jones & Jones, 2008).

³²Patient Outcome Research Team (PORT) was funded through the Agency for Health Care Policy and Research and the National Institute of Mental Health in the US, and provides recommendations for

New Zealand College of Psychiatrists (RANZCP, 2005) recommend the moderate use of antipsychotics (except Clozapine) as the first line of treatment for acute positive symptoms, until a beneficial response is evident. For first-episode psychosis, the dosage should be low at first and slowly titrated up; however, Olanzapine and Clozapine should be avoided.

In individuals who are responsive to treatment, maintenance antipsychotic treatment should be continued to reduce the risk of relapse. Individuals with symptoms resistant to treatment should be given Clozapine only after a trial of two other antipsychotics. The use of long acting depot antipsychotics should only be considered for maintenance treatment (Buchanan, et al., 2010). There is conflicting opinion about whether atypicals have superior efficacy than typicals. Both have been found to be effective in reducing positive symptoms (Foussias & Remington, 2010); however, atypicals are superior in improving cognition, mood and negative symptoms and are recognised as decreasing suicidality (Altamura, et al., 2007). Lieberman et al. (2005), in the CATIE study, found little evidence to support the claim that atypicals are superior; however, they believe atypicals are more efficacious in reducing negative symptoms and are similar to typicals in reducing positive symptoms. In a Cochrane review of 23 randomised controlled trials (RCT), by Hunter, Kennedy, Song, Gadon, and Irving Claire (2003), the effects of Risperidone on consumers was compared to typical antipsychotics. Treatment with Risperidone was associated with fewer relapses, and less side effects; however, weight gain was problematic. In contrast, Patel, Dorson, Edwards, Mendelson, and Crismon (2002) found no difference in rehospitalisation rates after 12 months of treatment in a study comparing use of one

pharmacological and psychosocial treatment interventions for persons with schizophrenia based on scientific evidence (Buchanan et al., 2010; Dixon et al., 2010).

typical and two atypical antipsychotics (Risperidone and Olanzapine). Furthermore, six months after discharge, consumers receiving Olanzapine had a higher rehospitalisation rate than those taking typical antipsychotics.

Overall, atypical antipsychotics are now considered the first line of treatment for individuals with schizophrenia (Rosenheck, 2005). A recent study by Hollingworth et al. (2010) found that prescriptions in Australia for atypicals increased from 61% in 2002 to 77% in 2007, with Olanzapine being the most commonly prescribed medication for males between the ages of 25 and 55 years.

2.7.2 Psychosocial interventions

Psychosocial interventions are treatments that are used adjunctively with antipsychotics, with the aim of improving symptoms and functional outcomes in individuals with schizophrenia (Addington, et al., 2010). They can include psychological support, social skills training, psychoeducation and family intervention.

For the past 15 years, these interventions have shown positive results in addressing the symptoms of schizophrenia (RANZCP, 2005). The PORT guidelines recommend eight psychosocial interventions for the treatment of schizophrenia: assertive community treatment,³³ supported employment, cognitive behavioural therapy (CBT)³⁴, family-based services, token economy, skills training, psychosocial interventions for alcohol and substance use disorders, and interventions for weight management (Dixon, et al., 2010). A review by the Royal Australian and New

³³Assertive community treatment teams are made up of multidisciplinary clinicians who manage consumers at risk of repeated hospitalisation. They have a high frequency of contact and low staff-consumer ratios (Dixon, et al., 2010).

³⁴Cognitive behavioural therapy (CBT) focuses on the consumer's emotions, thoughts and behaviours, teaches better coping responses and enables problem-solving (Tarrier et al., 1998).

Zealand College of Psychiatry (RANZCP) in 2005 also produced clinical practice guidelines for psychosocial interventions. These included family intervention, cognitive intervention, social skills training, vocational rehabilitation, case management, adherence therapy, and psychodynamic therapies (RANZCP, 2005).

The purposes of psychosocial interventions are to improve consumers' quality of life, have a positive effect on negative symptoms, reduce rehospitalisation rates and improve recovery (RANZCP, 2005). Velligan and Gonzalez (2007) describe psychosocial interventions as 'focusing on instilling hope for the future, setting individual goals, capitalising on strengths, and building skills to allow the individual to grow and to achieve meaningful work, supportive social relationships, and a better quality of life' (p. 535). The following interventions will be discussed in this section: psychological support, social skills training, psychoeducation and family intervention.

2.2.7.1 Psychological support

Psychological support consists of establishing a therapeutic relationship with the consumer and using techniques such as supportive counselling³⁵ and CBT to enhance social functioning and improve cognitive deficits (Frangou & Murray, 2000). A therapeutic relationship involves a purposeful conversation with the consumer, to assist the person to develop insight, control symptoms, and recover (Frisch & Frisch, 2006). According to Hewitt and Coffey (2005), the combination of a therapeutic relationship and CBT may be the most effective psychological treatment for schizophrenia.

³⁵Supportive counselling involves developing rapport and unconditional positive regard for a consumer in a supportive environment, allowing consumers to talk through their problems (Tarrier, et al., 1998).

When undertaking CBT with individuals with schizophrenia, the clinician addresses the positive symptoms that remain following medication treatment. With the help of the clinician, consumers explore and develop their own understanding of positive symptoms and aim to find a reason for their maladaptive behaviour. Stressors that preceded these symptoms are discussed and the goal is to try and reduce or prevent distress from these symptoms (Turkington, Kingdon, & Weiden, 2006). In a Cochrane review of CBT by Cormac, Jones, and Campbell (2009), CBT plus standard care did not make any difference to relapse or rehospitalisation compared with standard care. However, it did help the consumers' mental state over the medium term (13–26 weeks following onset of therapy), but after one year there was no difference. A recent meta-analysis by Lynch, Laws, and McKenna (2010) found that CBT did not prevent relapse and was ineffective in reducing symptoms in schizophrenia.

2.2.7.2 Social skills training

Individuals with schizophrenia have cognitive deficits that prevent the development of adequate social skills. They have difficulty in maintaining relationships, gaining employment, and achieving independent living (Velligan & Gonzalez, 2007). Social skills training encompasses many areas of the consumer's life and may include training in personal hygiene and care, social relations, budgeting, housing arrangements, leisure activities and employment skills (Turner, 1997). Social skills' training typically includes the development of conversation and assertiveness skills. Individuals learn how to interact with others through enhancing their communication skills and thereby learning to express openly their ideas and opinions (Chien, et al., 2003).

While most individuals with schizophrenia express a desire to gain employment, only 10–20% are successful. Hospitalisation, cognitive deficits, negative symptoms and persistent psychotic symptoms hinder employment (Velligan & Gonzalez, 2007). Linking individuals into vocational programs is the most successful means of enhancing the rate of employment for those with schizophrenia (Velligan & Gonzalez, 2007).

Several studies have examined the effectiveness of social skills training in preventing readmission to hospital, improving positive and negative symptoms and generally improving social interaction with others. Granholm (2005), in an RCT of cognitive behavioural social skills group training, found that group sessions had a positive impact on the social functioning of middle-aged to older consumers. They were able to learn new coping skills and objectively evaluate unusual experiences. Seo, Ahn, Byun, and Kim (2007) examined the effects of social skills training on the self-esteem of consumers with chronic schizophrenia. They found significant improvement in self-esteem, interpersonal, conversational, and assertiveness skills following the intervention.

Not all individuals with schizophrenia respond to social skills training. A Cochrane review by Tungpunkom, Maayan, and Soares-Weiser (2012) compared life skill programs to standard care in individuals with chronic schizophrenia. While life skill programs assisted and encouraged individuals to become independent in areas such as communication, managing finances, domestic tasks and personal hygiene, no differences were found on any of the outcome measures (Positive and Negative Syndrome Scale scores, quality of life, or social performance skills).

2.2.7.3 Psychoeducation

Psychoeducation involves educating consumers and families about schizophrenia and available treatments (Herz & Marder, 2002). Education is important because the majority of consumers either lack or have a reduced awareness of their mental illness (Frangou & Murray, 2000). A shared-care model of education is preferred, where there is collaboration between consumers, immediate carers and health professionals. Education sessions should be ongoing so that an understanding of the illness and available treatment strategies are developed (Falloon, Held, Roncone, Coverdale, & Laidlaw, 1998). Psychoeducation was found to reduce relapse rates and rehospitalisation if the carer and consumer participated in education sessions (Rummel-Kluge & Kissling, 2008). The RANZCP recommends that psychoeducation be offered as a core intervention. The focus should be on supporting and educating consumers and carers about illness and then as a consumer recovers, the focus moves to life skills and management of illness (RANZCP, 2005).

A Cochrane review of all RCTs between 1988 and 2009 by Xia, Merinder, and Belgamwar (2011) evaluated the effects of psychoeducation compared with standard education for consumers with schizophrenia. The reviewers found that in psychoeducation groups, relapse and readmission were reduced, and consumers had better social and global functioning, better quality of life and were more satisfied with mental health services than the standard education groups. The efficacy of psychoeducation has also been evaluated over an extended period of time. Bäuml, Pitschel-Walz, Volz, Engel, and Kessling (2007), in a multicentre RCT study, investigated the effects of psychoeducation for consumers and their families over a seven-year period. The consumer group intervention consisted of one 60-minute

session per week for four weeks followed by one session per month for four months. The family group intervention comprised eight fortnightly sessions lasting 90–120 minutes. The control group received usual treatment. The psychoeducation sessions commenced while the consumers were in hospital and continued after discharge. After seven years, the rate of rehospitalisation for the consumer intervention group was significantly lower (54%) than the control group (88%). The amount of time spent in hospital was significantly less in the consumer intervention group (75 days) compared with the control group (225 days). McWilliams et al. (2012) had similar results in a study of 101 caregivers who completed a psychoeducation program between 2002 and 2005. At follow-up, five years after completion of the program, consumers whose carers completed a six-week course had significantly better outcomes than the control group, including longer period of time to relapse, fewer relapses, shorter duration of admission when relapse occurred and lower bed days over the five years.

2.2.7.4 Family intervention

Having a family member diagnosed with schizophrenia causes distress and places a huge burden on families (Addington, et al., 2010). In some families, caring for someone with a mental illness can result in anxiety, depression and financial strain (Addington, et al., 2010). Corring (2002) found that caring for a family member with a mental illness was a 24-hour job that left no time for leisure. Parents felt they were constantly living with uncertainty, like they were “walking on eggshells,” with their adult child now a stranger to them, and they were concerned for the future.

Despite the burden that families can experience when caring for someone with a mental illness, their support does make a difference. A Cochrane review of family intervention by Pharoah, Mari, Rathbone, and Wong (2011) evaluated the effects of

family psychosocial intervention compared with standard care in individuals with schizophrenia. Interventions included family therapy, motivational therapy and various forms of education. Consumers had significantly less hospitalisation, fewer days in hospital, improvement in general social functioning and quality of life, and reduced levels of expressed emotion within the family, compared with standard care.

Having ongoing contact with family can result in reduced relapse rates and rehospitalisation (Dixon, et al., 2010). In a recent update of the PORT psychosocial treatment recommendations for schizophrenia, Dixon et al. (2010) reported that six to nine months of family intervention was necessary to have positive outcomes for consumers with schizophrenia. Similarly, Glick, Stekoll, and Hays (2011) examined the role of the family in treatment maintenance in the CATIE study. They found that 85% of consumers with family support remained in treatment, and of those, 89% improved on global outcomes. Those who did not have family support either dropped out of treatment (86%) or had no change or worsening symptoms post baseline (61%).

2.7.3 Early intervention

There is a large body of evidence strongly supporting that early intervention is critical in ensuring long-term recovery (Lambert, et al., 2008). Prolonged delay in treating first-episode psychosis can lead to poorer response in treatment and prognosis (RANZCP, 2005). Authors of the forthcoming Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-V), are considering the inclusion of a diagnosis of attenuate psychotic symptoms syndrome, in the hope of identifying individuals in the prodromal phase who are at risk of developing a psychosis. This has raised several ethical issues; early prescribing of antipsychotics and subsequent risk of harmful effects, misclassification of prodromal symptoms when psychosis may be related to a

stressful incident, and the psychosocial issues that develop when someone receives this diagnosis (Singh, Mirzakhania, Fusar-Poli, de la Fuente-Sandoval, & Cadenhead, 2012; Weiser, 2011).

Several studies have reviewed the effects of early intervention on first-episode psychosis and prodromal symptom presentation. A Cochrane review by Marshall and Rathbone (2009) evaluated seven studies into the effects of early detection, treatment and intervention for individuals with prodromal symptoms or first-episode psychosis from 2003–2006. Because they used dissimilar interventions each of the seven studies was evaluated separately. Only three studies had significant outcomes. In one, prodromal consumers who were prescribed low doses of Risperidone and CBT were less likely to develop psychosis at six-month follow-up. In the second study, family therapy and outpatient care led to reduced admission rates. The third study found that Global Assessment Functioning increased following family therapy and a specialised team approach at one year follow-up. In the other studies the interventions had no significant effects, and the reviewers concluded that there were insufficient trials to allow them to draw definitive conclusions. A more recent review of the literature by de Koning et al. (2009) examined whether early intervention in the prodromal phase had a favourable outcome in the benefit/risk ratio. In three RCTs using antipsychotic treatment and/or CBT there were positive outcomes at the end of treatment; however, this was not sustained in follow-up periods of one to four years. In these studies, non-adherence to antipsychotics and the experience of side effects were common problems.

2.8 Relapse

There is overwhelming evidence that medication can be effective in treating schizophrenia (Miyamoto, Duncan, Marx, & Lieberman, 2005; Sherin & Marder, 2011). Combined with various psychosocial therapies, such as psychoeducation, counselling and supported employment, treatment can be effective and may prevent relapse (Miyamoto, et al., 2005). There are differing opinions about how relapse is defined (Leucht & Kane, 2006). It can be defined in several ways; when an individual deteriorates significantly and rehospitalisation is imminent, the return of acute psychotic features and social dysfunction, or when it is necessary to recommence antipsychotic medication (Chabungbam, et al., 2007). Furthermore, when an individual does have a relapse, it is often associated with poor prognosis, deterioration in personal, social, and occupational functioning, and financial burden (Chabungbam, et al., 2007). There is an increased use of inpatient and outpatient services that continues over a 12-month period. The health costs associated with this are reported to be \$11,246 for each individual who relapses (Fitzgerald, et al., 2009).

There are a multitude of reasons for an individual with schizophrenia to relapse. These include failure to adhere to medication prescriptions (Weiden, Kozma, Grogg, & Locklear, 2004), the number of psychotic episodes a person experiences, side effects of medication (Chabungbam, et al., 2007), psychological stress (Dawson, et al., 2010), residual positive, negative or depressive symptoms, early age of onset, male gender, comorbid substance use disorder, poor insight into illness, social isolation and cognitive impairment (Altamura, et al., 2007).

In a study by Agarwal, Sharma, Kumar, and Lowe (1998), the most influential factor that led to relapse was a lack of medication taking. Likewise, a study by Lambert et

al. (2010) assessing medication adherence in an early psychosis prevention and intervention service, found individuals who refused medication were more likely to disengage from services, have more inpatient admissions, and have persistent substance abuse. They also had worse illness outcomes, with less remission of symptoms at discharge and increased severity of symptoms. Marcus and Olfson (2008) found that when individuals with chronic schizophrenia discontinued their medication, the risk of hospital readmission doubled in the three months following discharge.

Relapse is not always related to medication adherence; individuals may still relapse despite adhering to medication regimes (Weiden & Glazer, 1997). Approximately 15% of individuals do not respond to antipsychotic treatment and 30–50% will continue to experience some positive symptomatology.

2.9 Recovery

Recovery is defined as occurring when an individual with a mental illness can overcome or learn to live with the symptoms and dysfunction of their mental illness and achieve meaningful employment and independent living (Corrigan, 2006b). For consumers with schizophrenia, this can be determined when they have relief from their psychotic symptoms, are independent in housing arrangements, have obtained at least part-time work or school attendance, and are engaged in regular social and recreational activities. Importantly, they also have hope for the future, have psychological well-being, personal empowerment and goal direction (Corrigan, 2006b). Good recovery outcomes have also been associated with family living, increased self-esteem, and peer support (Warner, 2009). Interventions that target

social and work functioning in conjunction with medication taking are considered necessary to increase the chance of recovery (Ventura, et al., 2011).

With current treatments, over 50% of consumers with schizophrenia will have an episodic illness interspersed with periods of recovery (Jobe & Harrow, 2010). The potential for complete recovery is poor. Most consumers are vulnerable to recurrent positive symptoms and high functional impairment, including difficulties in social relationships and occupational functioning. Each relapse is dependent on internal and external risk factors, including anxiety, low self-esteem, adverse environmental influences and poor cognitive skills (Jobe & Harrow, 2010). It is also dependent on adherence to and efficacy of antipsychotic medication. It may take time for a consumer's positive symptoms to abate, while for others the medication has a limited effect (Addington, et al., 2010).

Many mental health services now work under the framework of recovery models (Warner, 2009). These models encompass all areas of psychosocial intervention and replace the outdated medically dominated model where the consumer followed the directions of the doctor. The recovery model is a shared model, with a partnership between the consumer and clinician in areas of decision making, focusing on the consumer's abilities to cope with daily challenges, and building on strengths and competencies, ensuring each consumer has an individualised plan (Caldwell, Sclafani, Swarbrick, & Piren, 2010).

Two recovery focused services have recently been evaluated. Fardig, Lewander, Melin, Folke, and Fredriksson (2011) evaluated an illness management and recovery model (IMR) based in Sweden. This model was individual and group based and provided over 40 sessions on recovery focused material. Consumers were randomly

allocated into the IMR program and a usual treatment group. Assessment was at baseline, nine months and follow-up (21 months). Results indicated that the IMR program significantly improved the ability of consumers to manage their illness, and improved psychiatric symptoms, depression and insight, and reduced suicidal ideation. A Collaborative Recovery Model (CRM) that incorporated evidence-based practices related to recovery principles was evaluated by Marshall, Oades, and Crowe (2009). Clinical staff were trained in CRM over two days, with follow-up training at six and 12 months. The findings showed that consumers managed by CRM trained workers took responsibility for their recovery, including collaborating with staff, setting goals and completing homework activities.

2.10 Summary

Schizophrenia is a psychotic disorder that includes positive and negative symptoms with significant dysfunction in occupational, social and interpersonal relationships. It occurs in late adolescence to early adulthood and can be a chronic episodic illness with periods of remission and recovery for some.

Early intervention shows favourable outcomes, with treatment comprised of a combination of pharmacological and psychosocial interventions. Antipsychotics are the recommended medication and consumers may experience a range of side effects, some of which can be intolerable. However, they have been found to be effective in reducing positive symptoms and improving cognition, mood and negative symptoms. Psychosocial interventions aim to improve symptom and functional outcomes and include psychological support, social skills training, psychoeducation and family intervention.

Although psychosocial and pharmacological interventions have been found to be successful in treating individuals with schizophrenia, relapse still occurs. Relapse has been associated with a range of issues, one of which is non-adherence to medication. This will be discussed further in the next chapter.

CHAPTER THREE

ADHERENCE

3.1 Introduction

In this chapter the literature relating to adherence with antipsychotic medication in consumers with schizophrenia is examined. The first section gives an overview of adherence. Next, the factors influencing adherence are discussed including risk factors related to the consumer, illness, treatment and the environment. The final section discusses interventions available to improve adherence, including behavioural therapies, psychoeducation sessions, use of depot medication and use of technology.

3.2 Overview of Adherence

Adherence is a term used to describe a situation where an individual's behaviour coincides with a prescriber's advice (Julius, Novitsky, & Dubin, 2009). Medication non-adherence can involve missing one or more doses, at times taking medications different from those prescribed, or rejecting the medication completely (Julius, et al., 2009).

The term "noncompliance" is used extensively in the literature and has been criticised as denoting obedience and following the doctor's orders (Mullen, 1997). It suggests that individuals have not done as they were told (Gray, Wykes, & Gournay, 2002). According to Thorne (1990), 'Noncompliant behaviour involves two parties; the one who gives the order, and the one who does not follow it' (p. 67). Gray et al. (2002) have suggested that the term "concordance" should replace the term compliance because it emphasises individuals' right to make decisions about their medication,

even if it is against clinicians' wishes. Julius et al. (2009) proposes that the term "adherence" is superior to the term compliance which has negative connotations and a sense of blaming the consumer. In the present study the term adherence is used.

3.3 Adherence rates

Adherence to medication is problematic in patients with psychiatric and physical disorders. However for people with chronic disorders, such as schizophrenia, it can be challenging, as treatments are intended to prevent symptoms from returning (Velligan, et al. 2009). Adherence plays an important role in a disorder like schizophrenia as it has a chronic course and individuals are often required to be on medication for the rest of their lives (Rittmannsberger, Pachinger, Keppelmüller, & Wancata, 2004). With the introduction of the atypical antipsychotics, it was hoped that adherence rates would improve.

Several studies have measured the rate of adherence with antipsychotic medication in consumers with schizophrenia. Verdoux et al. (2000) compared adherence on admission in individuals with first-episode psychosis and at six-month intervals over two years in a psychiatric hospital in France. The results indicated that adherence varied, with rates of 61%, 56.3%, 60% and 67% consecutively over the two years. Similarly, Lambert et al. (2010) found that during an 18-month treatment period in an early intervention and prevention centre in Australia, 33.7% consumers were fully adherent, 47.4% had one phase of non-adherence (one week or more) and 18.8% consistently refused medication. Pharmacy refill records in a Veteran Affairs service in the US were examined by Dolder et al. (2002). Over a 12-month period, they compared adherence between typical and atypical antipsychotics. At six months, adherence was 57.4% for typicals and 49.9% for atypicals, and at 12 months it was

50.1% for typicals and 54.9% for atypicals. This demonstrated a small increase in adherence rate for atypicals and a decrease for typical antipsychotics.

Non-adherence to medication is problematic in other physical illnesses and mental health disorders. Individuals with physical illnesses have a non-adherence rate of approximately 55%, and 20% of these individuals are completely non-adherent (Griffith, 2006). Adherence is higher for individuals with Human Immunodeficiency Virus (HIV) infection, arthritis, cancer and gastrointestinal disorders, and lower in pulmonary disease, diabetes and sleep disorders (Dimatteo, 2004). Rates of non-adherence in other mental health disorders include: bipolar disorder (20-50%), major depressive disorder (28-52%) and anxiety disorders (57%) (Julius, et al., 2009).

Poor adherence to treatment can have devastating consequences for consumers with schizophrenia. Including poorer functional outcomes, readmission to hospital, greater use of psychiatric emergency services, poorer life satisfaction and an increase in substance use problems (Ascher-Svanum, et al., 2006). There is also an increased risk of homelessness, aggression to self and others, suicide attempts, resistance to antipsychotic medications, and development of chronic psychotic symptoms (Byerly, et al., 2007; Novick, et al., 2010). It is, important therefore, to be aware of the factors that may influence adherence to treatment.

3.4 Measuring adherence

Various methods are used by health professionals to collect medication adherence information from consumers. In a review of the literature, Velligan et al. (2010a) found that subjective self-report and physician report were the most common approaches to measuring adherence, used in more than 77% of studies. Objective

reporting was used in 23% of the reviewed studies, involving pill counts, electronic monitoring, and blood or urine analysis. However, these objective measures can be unreliable; for instance, consumers may leave the cap off their electronic monitoring medication bottle, remove more than one tablet at a time, and their behaviour may be unpredictable prior to blood plasma testing (Velligan, et al., 2010a). Other studies have measured non-adherence by noting the extent of non-collection of prescribed medication from pharmacies (Bodén, Brandt, Kieler, Andersen, & Reutfors, 2011) or level of engagement with services by clinician entry in case notes (Lambert, et al., 2010). Inaccurate measurements of non-adherence may lead to unnecessary alterations in dosage or changes in medication, which in turn, may increase the risk of relapse and further hospitalisation (Velligan, et al., 2010a).

3.5 Factors Influencing Adherence

It is well documented that there are many factors associated with adherence in individuals with schizophrenia. For ease of description these factors are discussed as four risk factor groups: consumer, illness, treatment, and environment (Lacro, et al., 2002; Llorca, 2008).

3.5.1 Consumer related risk factors

Information about a consumer is important when identifying risk factors that may lead to non-adherence behaviour. Consumer related risk factors include demographic variables, attitude towards medication, and behavioural variables.

3.5.1.1 Demographic variables

Consumers who are significantly younger and those who had a younger age onset of their illness have reduced adherence to antipsychotic medication regimes (Coldham, Addington, & Addington, 2002; Lang, et al., 2010; Linden, Godemann, Gaedel, & Kopke, 2001; Novick, et al., 2010; Valenstein, et al., 2004). In a study of first-episode psychosis, Kampman et al. (2002) found that being male, younger age, and having a lack of social activities increased the risk of non-adherence to antipsychotics in the first three months of treatment. In a three-year European Schizophrenia Outpatients Health Outcomes³⁶ (SOHO) study (Novick, et al., 2010), younger age and living independently six months before hospitalisation were found to be associated with non-adherence. Other factors included current substance and alcohol use, and exhibiting hostility.

Similarly, other studies have identified that older consumers are less likely to be non-adherent. McCann, Boardman, Clark, and Lu (2008), Gilmer et al. (2004) and Valenstein et al. (2004) found that consumers with schizophrenia were more likely to adhere to medication as they age. However, other studies (Garavan, et al., 1998; Olfson, et al., 2000; Rabinovitch, Bechard-Evans, Schmitz, Joober, & Malla, 2009; Tattan & Creed, 2001; Trauer & Sacks, 1998) have found no correlation between age and adherence.

Demographic factors that influence non-adherence also include unemployment and education level. Lack of employment was found to be a factor influencing non-adherence following first admission to an inpatient service in studies by Verdoux et

³⁶European Schizophrenia Outpatients Health Outcomes (SOHO) was an observational and naturalistic study of outpatients with schizophrenia who initiated or changed antipsychotic medication during treatment. The study included 1096 psychiatrists and 10,972 patients from over 10 European countries, including Italy, Portugal, Spain, Ireland and the UK, from 2000–2005 (Haro, et al., 2003).

al. (2000) and Lambert et al. (2010). Consumers who were unemployed at baseline were 2.8 times more likely to present with poor medication adherence (Verdoux, et al., 2000). Maeda et al. (2006) found that when consumers participated in a rehabilitation inpatient program aimed at improving social, coping and job related skills, there was a positive association between education and adherence. The authors suggested that patients with higher education tended to be more adherent.

3.5.1.2 Attitude towards medication

The attitude that a consumer has towards antipsychotic medication also plays an important role in adherence. A naturalistic study by Schennach-Wolff et al. (2009) assessed individuals on their attitudes towards adherence. While 67% of individuals accepted the need for active participation in medication adherence, the remainder had a passive acceptance or refused treatment. Positive attitude to adherence was associated with higher levels of education, employment, prescription of atypical antipsychotics, improved psychopathology and insight. A similar study by Baloush-Kleinman et al. (2011) found that six months after discharge of first-episode consumers, the main predictor of adherence was attitude to medication. Adherent consumers were aware of the need for treatment, more competent in making decisions about their medication and had increased levels of insight.

Other studies have focused on reasons for changes in attitude by consumers towards treatment. Negative attitudes towards treatment at the beginning of medication prescription resulted in poor adherence in first-episode consumers (Mutsatsa, et al., 2003). Negative beliefs about the need for treatment and the efficacy of medication resulted in non-adherence for one week or longer in a similar study by Perkins et al. (2006). Vauth, Loschmann, Rusch, and Corrigan (2004) found that if individuals

perceived everyday benefits from their antipsychotic medication they would be more adherent. They also found that adherence improved in the absence of any social pressure or force.

Three studies specifically examined the attitudes of consumers with schizophrenia towards medication (Freudenreich, Cather, Evins, Henderson, & Goff, 2004; Goodman, Knoll, Isakov, & Silver, 2005; Jónsdóttir, et al., 2009). In a multivariate analysis of outpatients' attitudes towards medication, Freudenreich et al. (2004) found that when consumers had a positive attitude they were able to recognise the therapeutic values of the drug. However, consumers who were employed had a negative attitude and the authors hypothesised that this may be due to stigma issues. In examining negative attitudes toward medication and its impact on memory impairment, Goodman et al. (2005) found that consumers with positive attitudes performed better on a cognitive measure and those with negative attitudes had a poorer ability to learn and store information about drug treatment. In a study of beliefs about medications, Jónsdóttir et al. (2009) found that consumers with schizophrenia had more negative attitudes about medication than those with bipolar disorder, and perceived medication as more addictive, harmful and overused by doctors.

Not all consumers have a negative attitude to medication. Puschner et al. (2009) investigated the relationship between quality of life and adherence and found that there was no relationship between them. Individuals viewed taking medication in a positive light and associated it with an improvement in their symptoms. These findings are supported in other studies (Mohamed, et al., 2009; Rettenbacher, et al., 2004) where consumers who could see a positive benefit of antipsychotic medication on their illness and their everyday lives were more likely to be adherent. Mohamed et

al. (2009) also found that positive attitudes towards medication were significant in lowering symptom levels and functioning well in the community. In contrast, Heinrichs, Goldberg, Miles, and McDermid-Vaz (2008) found that consumers' feelings and attitudes about their drug treatment did not vary with adherence to antipsychotic medication.

3.5.1.3 Behavioural variables

Behavioural variables that can affect non-adherence include alteration of drug regime, having a history of non-adherence and the temperament of a person.

There is compelling evidence that people who have schizophrenia frequently alter their own drug regimes. When exploring consumers' reasons for taking antipsychotic medication and the ways in which they self-regulate their medication, Rogers et al. (1998) found that consumers increased or decreased their dosage and changed the time of the day they took medication. This was dependent on their perceived knowledge of what levels of medication they needed to manage symptoms, how they used the medication to cope with distress, and whether the medication would interfere with social interactions. Similarly, Holzinger, Loffler, Muller, Priebe, and Angermeyer (2002) found that 33.7% of individuals discharged on Clozapine reported not taking their medication regularly and 16.9% changed the dose themselves. In a study about attitudes toward medication and factors affecting medication adherence in a group of individuals in an inpatient setting, Ruschner, De Witt, and Mazmanian (1997) reported a higher incidence of consumers altering their drug regime. Almost 66% of individuals changed the way they took medication and 47.5% ceased taking medication without talking to their psychiatrist. In the same study, 30.6% of individuals cited reluctance to take medication as the most common reason for not

taking medications, 25.8% stated the medication did not work, 25.8% stated non-adherence was due to side effects, and 17.8% attributed it to psychological effects like mood change.

Consumers' previous history of non-adherence can determine whether they are more likely to adhere to current antipsychotic medication. Novick et al. (2010) found that a high proportion of consumers who were non-adherent at follow-up were also non-adherent at baseline. These consumers also had current substance abuse, were hostile and had been in hospital in the previous six months.

Temperament and a person's character were important factors in influencing adherence in a study by Margetić, Jakovljević, Ivanec, Tošić, and Margetić (2010). Being male, having novelty seeking traits, such as impulsivity, curiosity, attention seeking, self indulgence and self directedness, contributed to higher non-adherence rates in individuals with schizophrenia. This was also found in a study by Lambert et al. (2010). They found that being male, having a history of physical abuse, forensic history, less education and lower premorbid functioning were all risk factors for non-adherence.

3.5.2 Illness related risk factors

Schizophrenia can be a debilitating illness with varied clinical presentations, and this may increase the risk of non-adherence. Illness related factors include insight and clinical symptoms.

3.5.2.1 Insight

Individuals with schizophrenia are often unaware they have a mental illness. In everyday use, insight can be defined as the capacity to discern the true nature of a situation (Mintz, Dobson, & Romney, 2003). In medical terms, it means having an awareness of an illness and the need for treatment, being aware of specific signs and symptoms of the illness, understanding the social consequences of the illness and being able to attribute the symptoms to an illness (Mintz, et al., 2003).

Insight is thought to be one of the major factors influencing adherence (Llorca, 2008). Individuals with schizophrenia can have problems relating their psychotic symptoms to a mental illness and are therefore less likely to recognise the need for treatment (Garavan, et al., 1998). This can vary from complete denial of having schizophrenia to reduced awareness of the illness (Frangou & Murray, 2000). In a meta-analysis examining insight in schizophrenia, Mintz et al. (2003) estimated that between 50% and 80% of individuals with schizophrenia do not believe they have a mental illness. However, McCann, Boardman et al. (2008) found that 84.3% of consumers believed that they had a mental illness and 87.8% considered they needed medication.

There have been conflicting reports about the influence of insight on medication taking. Impaired insight has been linked to poorer medication taking and poorer treatment outcomes (Kao & Liu, 2010; Lysaker, Bryson, & Bell, 2002; Olfson, Marcus, Wilk, & West, 2006). In examining consumers' experiences with depot antipsychotic medication, Smith, Hughes, and Budd (1999) found that half the individuals who failed to adhere with prescribing regimes did so because they believed they were no longer ill and would not relapse. Similar results were found by Holzinger et al. (2002), who investigated subjective illness theories and antipsychotic

medication adherence. In the study, 50% of consumers who were discharged from hospital on Clozapine considered themselves mentally ill, while the remaining 50% denied they were mentally ill or believed they were not ill at the time of the study. Donohoe et al. (2001) evaluated adherence levels as 'poor,' 'partial' and 'regular' and found that only consumers who had poor adherence had a lower level of insight.

Individuals who gain insight into their illness are more likely to have positive outcomes for adherence. In a study on the extent of non-adherence the month before inpatient treatment, Rittmannsberger et al. (2004) found that consumers with good insight were hospitalised for significantly fewer days than those with poor insight. Non-adherent consumers who gained insight while in hospital had significantly fewer days of inpatient treatment in the following year than those who had low insight (mean of 19.2 days compared with 73.2 days).

A positive correlation between insight and adherence has been reported in many other studies (Beck, Cavelti, Kvrjic, Kleim, & Vauth, 2011; Kao & Liu, 2010; Klingberg, Schneider, Wittorf, Buchkremer, & Wiedemann, 2008; McCann, Boardman, et al., 2008; Mutsatsa, et al., 2003; Pyne, et al., 2006).

In contrast, other research has shown that insight does not influence medication adherence in consumers with schizophrenia. Education sessions about medication were presented to a group of individuals who were detained involuntarily in a psychiatric inpatient unit and then compared with a control group receiving standard care (Kavanagh, Duncan-McConnell, Greenwood, Trivedi, & Wykes, 2003). The authors found that the intervention group had an improvement in insight and knowledge about the medication, but there was no effect on adherence behaviour or factors that influenced medication taking. Garavan et al. (1998) investigated attitudes

towards medication and insight in consumers with schizophrenia in an outpatient setting. Results indicated that the level of insight did not influence the extent to which individuals adhered to treatment. Individuals who regularly adhered to medication did not have more insight than individuals who were non-adherent. Puschner et al. (2009) reiterated both these findings and found no correlation between insight and attitude to medication in a multicentre study on quality of life and adherence to medication. Instead they found psychopathology, level of functioning and unwanted side effects as the reasons for non-adherence.

3.5.2.2 Clinical symptoms

Failure to recognise clinical symptoms and experiencing positive, negative, or cognitive symptoms all may influence adherence to antipsychotic medication.

In a study by Olfson et al. (2000), failure to recognise clinical symptoms led to non-adherence in individuals discharged from an acute psychiatric hospital. Most consumers believed they had a mental illness; however, when the symptoms of illness exacerbated, they were non-adherent. Agarwal et al. (1998), Donohoe et al. (2001), and Kumar and Sedgwick (2001) found similar results. All reported that an individual's ability to recognise positive symptoms increased adherence to medication.

There is a direct association between having positive symptoms and medication non-adherence. In studies by Verdoux et al. (2000) and Coldham et al. (2002), non-adherence in first-episode psychosis was associated with positive symptoms in the majority of consumers and, subsequently, increased periods of relapse and rehospitalisation. Improvement in positive symptoms can also increase adherence. Both Yang et al. (2012) and Gharabawi et al. (2006) found that symptom

improvement, especially psychotic symptoms, was associated with treatment satisfaction and adherence.

Negative symptoms of schizophrenia have also been shown to influence non-adherence. In a study of negative symptoms in consumers prescribed depot medication, Tattan and Creed (2001) found that individuals with more severe negative symptoms, especially avolition,³⁷ apathy, and alogia,³⁸ were less likely to adhere with depot medication. This was similar to the findings of Baloush-Kleinman et al. (2011) who found that the severity of negative symptoms predicted attitudes and, consequently, influenced adherence. In contrast, Rettenbacher et al. (2004) found adherent and partially adherent consumers showed significant negative symptoms compared with non-adherent consumers.

Significant cognitive impairment occurs in 80% of consumers with schizophrenia. This can affect verbal and non-verbal intelligence (Bora, Yücel, & Pantelis, 2010), and can consequently lead to poor adherence with medication. This was demonstrated in two studies where memory impairment resulted in poor adherence (Donohoe, 2006; Kim, et al., 2006). Forgetting to take medication is another common reason for non-adherence. In the UK 2000 National Psychiatric Morbidity survey, Cooper et al. (2007) found that 37.4% of consumers who were non-adherent with psychotropic medication either forgot, lost or ran out of their medication. Another study by Hudson et al. (2004) in community and inpatient services found that forgetfulness, stigma, side effects and lack of social support were all patient-reported barriers to adherence.

³⁷Avolition is the inability to follow and persevere in goal-directed activities (Kniesl & Trigoboff, 2009).

³⁸Alogia is the inability to verbalise because of mental condition (Sadock & Sadock, 2007).

Having lower premorbid functioning can be a risk factor for non-adherence. Lambert et al. (2010), in their study on adherence in first-episode psychosis, compared consumers' best Global Assessment of Functioning Scale (GAF)³⁹ level in the year preceding the onset of illness. They found that consumers who continually refused medication during the 18-month treatment period, had significantly lower GAF levels compared with adherent consumers.

3.5.3 Treatment related risk factors

The first line of treatment for individuals with schizophrenia is antipsychotic medication (Sherin & Marder, 2011). Treatment related factors that may influence non-adherence are treatment efficacy and side effects.

3.5.3.1 Treatment efficacy

The effectiveness of antipsychotic medication in relieving symptoms of schizophrenia is an important factor in determining adherence. Most consumers will discontinue their antipsychotic medication within the first 18 months of treatment irrespective of the drug they are taking (Krebs, Leopold, Hinzpeter, & Schaefer, 2006). Fifty per cent will discontinue due to lack of efficacy, side effects or intolerance of the antipsychotic medication (Krebs et al., 2006).

Few studies have identified whether treatment efficacy is an important factor in adherence. In the large CUtLASS⁴¹ and CATIE trials, findings suggested that typical and atypical antipsychotics are equally effective in treating schizophrenia and no differences have been found in adherence between the treatment groups (Foussias &

³⁹Global Assessment of Functioning is a clinician rated scale that measures psychological, social, and occupational functioning (American Psychiatric Association, 2000).

Remington, 2010). Furthermore, individuals who are treatment-resistant⁴² respond more effectively to Clozapine compared with other atypicals (Foussias & Remington, 2010). Although they are both effective overall, atypicals are more efficacious than typicals in treating negative and cognitive symptoms, as well as reducing the risk of extrapyramidal and tardive dyskinesia side effects. Atypicals have also been found to improve consumers' well-being and quality of life (Krebs, et al., 2006).

Consumers rely on health professionals to inform them about the positive and negative effects of antipsychotic medication. In a qualitative study by Kikkert et al. (2006) health professionals, consumers and carers did not have a shared viewpoint on factors influencing adherence. Treatment efficacy was rated the most important factor for medication adherence by consumers and carers, followed by external factors, insight, side effects and attitudes towards medication. In contrast, health professionals rated negative attitudes and beliefs as the most important factors in adherence. Day et al. (2005) found that adherence improves when consumers have a positive relationship with their prescriber and are involved in treatment decisions. Happell, Manias, and Roper (2004) explored how consumers are educated about their medication. The findings showed that consumers received few details of their medication when commencing treatment. Consumers also felt that if they were told about potential side effects, they would be better prepared to deal with them. Instead, they managed their side effects by independently changing the dose and were then reluctant to inform their doctor or nurse about modification of their medication in case of repercussion.

Other studies have found that increased adherence depends on the dosage or type of antipsychotic medication prescribed. Psychopharmacological guidelines recommend

depot antipsychotic medication as an alternative for individuals who require medication maintenance treatment (Buchanan, et al., 2010). Depot medication may also be effective for individuals who are at risk of non-adherence to oral antipsychotic medication (Sherin & Marder, 2011). However, in a systematic review and meta-analysis of RCTs by Leucht et al. (2011) the route of medication administration made no difference to adherence. Nevertheless, they reported that depot medication significantly decreased relapse rates (33.3% depot, 21.6% oral), but made no difference to the rate of rehospitalisation. Additionally, when examining consumers' perspectives with oral or depot antipsychotics, Patel, De Zoysa, Bernadt, and David (2008) found that consumers on depot had higher non-adherence scores when they measured factors that influence medication adherence and perceived no daily benefit by taking depot, compared with consumers on oral antipsychotics.

Use of medication prescribed for comorbid disorders was found to contribute to non-adherence. Lang et al. (2010) found that concurrent use of mood stabilisers, antidepressants, anxiolytics or anticholinergic medications all contributed to non-adherence in consumers prescribed oral and depot antipsychotics.

3.5.3.2 Side effects

While antipsychotic medications help reduce the symptoms of schizophrenia, they also produce a wide range of side effects. Side effects that specifically influence adherence include extrapyramidal side effects, weight gain, sexual dysfunction and dysphoria⁴⁰ (Krebs, et al., 2006). Furthermore, the most commonly reported side effects include difficulty concentrating, restlessness, insomnia, weight gain and drowsiness (Dibonaventura, Gabriel, Dupclay, Gupta, & Kim, 2012).

⁴⁰Dysphoria is a feeling of uneasiness and general dissatisfaction usually found in depression (Kaplan & Sadock, 2007).

Several studies have investigated the influence of side effects on medication taking. In a three-month study of consumers' non-adherence with antipsychotic medication, Kumar and Sedgwick (2001) found that intolerable side effects were the most frequently identified reason for not taking antipsychotic medication (non-adherent group 34.4%, adherent group 4.2%). Likewise, in a study of risk profiles for medication non-adherence, 70% of participants stated that they had experienced annoying side effects and that this reduced adherence by one-fifth in these individuals (McCann, Boardman, et al., 2008). Similar results were found by Gray, Rofail, Allen, and Newey (2005) when examining consumers' satisfaction and experiences taking antipsychotic medication. Overall, 54% of consumers reported having side effects, and of these, 34% found them intolerable. Tiredness, poor concentration, lack of emotion, and Parkinsonism-like effects were the most common. In addition, 64% of consumers in this study reported that no written information about the possible side effects had been given when commencing treatment, and 46% were not informed about the side effects they could expect.

Weight gain was a reason for discontinuing treatment in the two antipsychotic effectiveness trials (CUtLASS and CATIE) for the treatment of schizophrenia (Foussias & Remington, 2010). In these trials, 68% of consumers cited weight gain (consumers gained an average of 0.9 kg per month) as a reason to discontinue treatment before the completion of the study.

The presence of side effects, however, does not necessarily undermine medication taking. In a study by Agarwal et al. (1998), adherent consumers had a much higher incidence of side effects and their presence, did not always adversely affect medication adherence. In a recent qualitative study of consumers' experiences with

antipsychotic treatment, Tranulis, Goff, Henderson, and Freudenreich (2011) found that 35% cited side effects as a reason to stop medication. However, consumers could see the benefit of antipsychotic medication to their mental state and were able to tolerate the side effects for many years. Holzinger et al. (2002) also could not find any significant relationship between adherence and side effects in a group of outpatients of whom 33.7% were not taking their medication regularly following discharge three months previously.

3.5.4 Environment related risk factors

External influences, such as the environment the consumer lives in, may influence medication adherence. These environmental influences include support by others, health professional support, stigma and substance use.

3.5.4.1 Support by others

The level of support provided by others has been shown to influence consumers' medication taking. This support may be provided by family, friends and significant others. Adherence is dependent on the impact of education, level of involvement by families and how families are engaged in treatment.

There is conflicting evidence in recent research studies regarding the impact education has on families, family support and medication taking. Some families are reluctant to be involved in education, treatment and discharge planning for their relative with schizophrenia. Olfson et al. (2000) found that consumers whose families refused to participate in treatment while they were hospitalised, were at high risk of stopping their medication. It was also reported that there was little evidence that

family visits or family therapy programs during hospitalisation were significant in influencing future medication taking.

The level of involvement consumers have with their families has been found to influence medication taking. In a study by Coldham et al. (2002), having family involved with a first episode of schizophrenia was found to be a positive indicator for adherence, with 80% of the adherent group having family involvement compared with only 51% of the non-adherent group. This was supported by Glick et al. (2011) in a study of the role of family involvement in treatment, adherence and outcomes as part of the CATIE study. Consumers with a supportive family were more likely to remain in treatment (85%) and have improvement in symptoms (89%) compared with those who had no family support (56% dropped out, 61% no change or worsening symptoms). Adherence was associated with connectedness with families, who assisted consumers with their medication taking. Even though consumers may want to cease taking their antipsychotic medication, Tranulis et al. (2011) found that families and friends can externally reinforce adherence as a condition of residence. One consumer in this study stated: “Basically, [I am taking medication] so I can still live with my mum” (p. 890).

The ways in which psychiatrists use families of consumers with adherence issues was evaluated by Wilk et al. (2008), who compared high and low levels of family contact in consumers who were non-adherent with antipsychotic medication. Surveys were sent to treating psychiatrists about the level of contact non-adherent consumers had with their families. The findings showed that 56% had a high level of contact and those with low levels of contact were more likely to be male, older, single, history of anxiety disorder, prescribed an atypical antipsychotic, and with a history of injuring

others. Treating psychiatrists in this study were more likely to use family interventions to manage non-adherence in high contact families than in the low contact group.

3.3.5.2 Health professional support

The support of health professionals has been shown to have an impact on medication adherence. This is dependent on the relationship with the consumer, ease of access to the health professional, and the professional's knowledge about antipsychotic medications. Health professionals may include case managers from different disciplines including nursing, social work, psychology and occupational therapy, doctors who specialise in general practice or psychiatry, and psychiatrists.

The relationship the consumer has with mental health professionals is an important determinant in medication taking. It is influenced by personal experiences and knowledge of the professional's actions, including compulsory admission to hospital and the enforcement of treatment (Rogers, et al., 1998). Consumers with mental illness may be admitted to hospital and discharged under an involuntary (or community) treatment order⁴¹ and are required to take medication. According to Rogers et al. (1998), this form of coercion by professionals led individuals with schizophrenia to filter what they told their psychiatrist: "If I mentioned it, if my psychiatrist knew you know that I take herbal remedies, he'd just put my medication up; he'd think it was a sign of illness" (p. 1320).

The presence of a positive therapeutic relationship has been identified as the best single predictor of adherence (Holzinger, et al., 2002). The quality of the relationship

⁴¹An involuntary treatment order allows a consumer to be treated in the community as an involuntary patient under various Mental Health Acts.

between consumers and health professionals during an acute admission was examined by Day et al. (2005). They found that a positive relationship, involvement in treatment, minimal adverse effects with medication and lack of coercion encouraged adherence. Olfson et al. (2000) confirmed this, claiming that individuals who became medication non-adherent were less likely to have formed a good therapeutic alliance during hospital admission. Linden et al. (2001) found that adherent individuals were more likely than those who were non-adherent to trust their physicians and expect them to be helpful in treatment.

Some individuals have difficulty accessing a psychiatrist, especially in lower socioeconomic areas, and this was found to be a predictor of non-adherence in a study by McCann, Boardman et al. (2008). In a study on consumer satisfaction and experiences with antipsychotic medication by Gray et al. (2005), the majority of consumers were satisfied with the communication they received from their psychiatrist. However, 59% of these did not feel they were involved in treatment decisions and only took their medication because they were told to. A similar study by Boardman, et al. (2008) found that most individuals with schizophrenia felt that the majority of health professionals had adequate knowledge about antipsychotic medications but some were dissatisfied with general practitioners' knowledge of these medications.

3.5.4.3 Stigma

Stigma is socially discrediting, permanent and affects the perception of the person as a whole (Bunton, 1997). It is a global evaluation based on a person's characteristics that makes him or her different to others, and can be related to a group that is unpopular, devalued or ostracised by society. Stigmatisation results in the person feeling

disgraced, shameful, inferior, and invisible (Hinshaw, 2007; Hornby, 2005). The stigma of mental illness, particularly schizophrenia, can prevent consumers from accessing mental health care (Sartorius & Schulze, 2005).

In 1996, the World Psychiatric Association undertook an extensive worldwide intervention program called 'Open the Doors' to tackle stigma against individuals with schizophrenia. In participating countries, ($n=20$) including Australia, the public were surveyed about their attitudes towards schizophrenia, and development of programs to enhance positive attitudes in the public (Sartorius & Schulze, 2005). In the UK, educational workshops had small but positive effects on stigma; women were more receptive, the general public found hearing personal experiences had a lasting impact on their views about schizophrenia, and those with their own previous experience of the illness held positive views of schizophrenia (Sartorius & Schulze, 2005). In Australia, SANE⁴² used a popular television program and pamphlets to spread information about schizophrenia, with the aim of reducing stigma. However, no evaluation has occurred, because of lack of funding (http://www.openthedoors.com/english/media/vol_4.pdf).

The experience of stigma can impede a person in obtaining education, employment and relationships (Üçok, et al., 2012). A large multisite study (27 countries) by Üçok et al. evaluated the level of anticipated discrimination in 732 consumers with schizophrenia. Many (64%) stopped applying for work or further education because of anticipated discrimination, and 72% felt they needed to hide their diagnosis. Over half had ceased looking for a close relationship.

⁴²SANE is an independent national charity for individuals with a mental illness.

Stigma attached to mental illness can place a huge burden on families, who may be reluctant to talk about the mental illness and endure feelings of embarrassment, guilt and disappointment (Epstein & Olsen, 2007). A study by Tsang, Tam, Chan, and Chang (2003) found that there were two sources of burden on families, stigmatisation and lack of accessible psychiatric and rehabilitation services. As a result, families experienced social isolation, ineffective and inadequate mental health services, unemployment, frustration, anxiety, low self-esteem and helplessness. Similar findings were reported by Veltman, Cameron, and Stewart (2002) in a study of the experience of providing care to relatives with chronic mental illness. The main theme of their findings was the stigma of mental illness. Stigma made caregivers feel unappreciated and misunderstood by the general public, and gave them a perception of being socially isolated from the rest of society.

Only a few studies have been conducted into the relationship between stigma and medication adherence. Rogers et al. (1998) found that individuals' awareness of the stigma of having schizophrenia influenced their views about medication and adherence. The findings also indicated that individuals perceived medication taking as a social contract to which they had to adhere in order to be tolerated by the community in which they lived. In a study on detection of non-adherent behaviour in early psychosis, a younger, recently diagnosed group of individuals reported that non-adherence was related to their feelings of embarrassment about taking medication (Hui, et al., 2006). Hofer et al. (2002) and Freudenreich et al. (2004) found that consumers who were employed had less positive feelings towards their antipsychotic medication and this may be influenced by their interactions with others. McCann, Boardman et al. (2008) had similar findings, with only 50% of respondents stating they would inform their employer that they had a mental illness or were taking

medication. The majority of consumers believed people would treat them differently if they knew they had a mental illness or were taking antipsychotic medication.

Stigma can have an adverse effect on consumers with schizophrenia and this in turn, may compromise their medication adherence (Lysaker, Davis, Warman, Strasburger, & Beattie, 2007). When consumers feel stigmatised, alienated and devalued, they are more likely to have positive symptoms, emotional distress and few social relationships (Lysaker, et al., 2007). It is important, therefore, for mental health clinicians to combat stigma and increase consumers' participation in society, and this may decrease medication non-adherence in this population (Williams, 2008).

3.5.4.4 Substance use

Substance use, including alcohol, licit and illicit drugs, has been shown to adversely affect medication adherence. Individuals with severe mental illness have an increased risk of developing a substance use disorder. The prevalence of co-existing mental illness and substance abuse has been reported to be between 10% and 65% (Mueser, Drake, & Miles, 1997). A study by Averill et al. (2002) on acute mental illness and comorbid substance abuse found that 38.6% of consumers acknowledged they engaged in substance use, and an additional 10% denied use, however their substance use was diagnosed by the psychiatrist.

Substance abuse has been identified as a strong predictor of medication non-adherence (Lambert, et al., 2010; Lang, et al., 2010; Olfson, et al., 2000; Olfson, et al., 1999; Patel, et al., 2008; Wilk, et al., 2006). In a study by Wilk et al. (2006), one-third (35.6%) of individuals with schizophrenia who were non-adherent to antipsychotic medication had a comorbid substance use disorder. Verdoux et al.

(2000) found that individuals with a first episode of psychosis (predominately schizophrenia) had a previous history of alcohol abuse. Persistent use after discharge was significantly related to poor adherence. Individuals also misused other substances, but results were less significant. In a similar study on first-episode schizophrenia, Coldham et al. (2002) found individuals with high levels of alcohol and cannabis use were non-adherent with their antipsychotic medication and this affected their ability to engage in treatment. This was confirmed in a study by Miller et al. (2009) on cannabis use in first-episode schizophrenia. At the beginning of treatment 44% of individuals were defined as cannabis dependent and 15–20% were using cannabis during their treatment period. Cannabis use led to an increase in non-adherence and drop-out from treatment. Lower rates of non-adherence were found in a study by McCann, Boardman et al. (2008), where 25% of illicit drug users on antipsychotic medication reported that their drug use compromised adherence.

Several studies have found no correlation between substance use and non-adherence with antipsychotic medication. Individuals recovering from a first episode of schizophrenia used marijuana (32%) but this was not associated with non-adherence (Perkins, et al., 2006). No association between substance use and adherence was found in a study by Mutsatsa et al. (2003) during early stages of treatment in schizophrenia. Similarly, Lindenmayer et al. (2009) examined the impact of substance abuse on treatment outcomes and found that a history of substance use did not predict non-adherence to antipsychotic medication.

In summary, there are multiple risk factors that have been presented which influence adherence in consumers with schizophrenia. Being male, young and unemployed will increase the risk of non-adherence. A person's attitude and perceived benefits of

treatment will influence how they feel about medication. Insight, improved clinical symptoms, and good support have all been identified as lowering the risk of non-adherence. Many individuals struggle with medication side effects and substance use; which both pose a risk to adherence. The following section describes interventions that may improve adherence to antipsychotic medication.

3.6 Interventions to Improve Adherence

There have been numerous studies examining interventions for improving medication adherence in individuals with schizophrenia. This section discusses these interventions, which include behavioural therapies, psychoeducation, use of depot antipsychotic medication and technology.

3.6.1 Behavioural therapies

Many behavioural therapies have been used to enhance adherence to antipsychotic medication in individuals with schizophrenia. The two principal therapies used by clinicians are adherence or compliance therapy⁴³ and cognitive behavioural therapy.

3.6.1.1 Adherence therapy

Adherence therapy is an intervention that uses a range of motivational and cognitive behavioural techniques to promote adherence (Ilott, 2005). The focus is on challenging the individual's beliefs and maladaptive behaviours regarding medication taking (McIntosh, Conlon, Lawrie, & Stanfield, 2006).

⁴³The term adherence and compliance therapy are used interchangeably in this section of the literature review as many authors use one or either of these terms.

Some studies have found that adherence therapy improves adherence in individuals with schizophrenia. Kemp, Hayward, Applewhaite, Everitt, and David (1996) compared compliance therapy and supportive counselling in inpatients with psychosis and found significant improvement in initial attitudes to drug treatment, insight and adherence in the intervention group. Adherence was maintained at the six-month follow-up period, with a 23% improvement in adherence compared with the control group. Adopting the same method as Kemp et al. (1996), but with an 18-month follow-up, Kemp, Kirov, Everitt, Hayward, and David (1998) found significant improvements in insight, drug attitude and adherence. In addition, the compliance therapy group were 2.2 times more likely to spend a longer time in the community before readmission to hospital occurred than the non-specific counselling group. Tay (2007) evaluated compliance therapy in consumers with schizophrenia or major depression in an inpatient unit. Compliance therapy was conducted in small groups or individually over 3–5 days. Consumers in individual and group sessions displayed improvement in their attitude to medication. Those with six or more previous hospital admissions had slightly less improvement than those with substance use or personality disorders.

Compliance therapy has not always been effective in improving adherence to medication. A Cochrane review by McIntosh et al. (2006) on compliance therapy was undertaken to assess the benefits of this therapy for consumers with schizophrenia and non-affective psychosis. In this review, compliance therapy was defined as an intervention based on motivational therapy. Participants were invited to review aspects of their treatment and consider the benefits and detriments of antipsychotic medication. Studies included all RCTs up until 2002. The authors concluded that there was little evidence that compliance therapy was helpful in adherence, or in improving

psychotic symptoms or quality of life. They did suggest, however, that it may reduce the amount of time consumers spent in hospital. Three other studies (Anderson, et al., 2010; Maneesakorn, Robson, Gournay, & Gray, 2007; Gray, et al., 2006) also found no difference in adherence. An RCT by Anderson et al. (2010) evaluated the effectiveness of adherence therapy for improving adherence and psychiatric symptoms in individuals attending an outpatient service. Participants in the intervention group received eight one-on-one sessions, while the control group received standard treatment. No differences were found between the intervention and control groups in adherence or symptoms of illness. In another RCT, Maneesakorn, et al. (2007) evaluated the effectiveness of adherence following an eight-week intervention based on adherence therapy and motivational interviewing.⁴⁴ Results indicated that there was a significant improvement in attitude and satisfaction with medication and overall psychotic symptoms. In comparing the effectiveness of adherence therapy and a health education program that included topics such as diet and healthy lifestyle, Gray et al. (2006) found there was no clear improvement in treatment adherence between the two interventions.

3.6.1.2 Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) is commonly used by mental health professionals when working collaboratively with individuals with schizophrenia to identify the cause of their distress and explore the behaviours they would like to change (Jolley & Garety, 2011). However, little research has investigated the use of CBT for changing adherence behaviour. Only one study has shown CBT to be

⁴⁴Motivational interviewing assists individuals by overcoming ambivalence that prevents them from making changes in their lives. The approach builds motivation and strengthens the commitment to change using specific strategies (Miller & Rollnick, 2002).

effective. Bechdolf et al. (2004) compared the effectiveness of CBT with psychoeducation. Patients were randomised into groups receiving either 16 sessions of CBT or 18 sessions of psychoeducation. The CBT group at six-month follow-up had a decrease in relapse rates and higher adherence to antipsychotic medication than the psychoeducation group. In contrast, an RCT by Barrowclough et al. (2001) combined motivational therapy, CBT and family intervention and compared this with routine care. Although the intervention had favourable outcomes for positive symptoms, relapse and decrease in substance use, there was no difference in adherence between the two groups. A large RCT is currently being undertaken by Velligan et al. (2009) using cognitive adaptive training through the use of environmental cues such as checklists, signs, and medication containers to improve medication adherence. Early pilot studies have shown significant improvements in positive symptoms.

3.6.2 Psychoeducation

Psychoeducation sessions provide information to individuals and families about medication and illness, with the aim of increasing understanding of the illness and promoting medication adherence (Gray, et al., 2002). Education can be individual or in a group setting and is considered part of routine therapy for individuals with schizophrenia (Bäumler, et al., 2007).

3.6.2.1 Consumer psychoeducation

Psychoeducation can have a positive effect on medication adherence in consumers with schizophrenia. An RCT by Aguglia, Pascolo-Fabrizi, Bertossi, and Bassi (2007) evaluated the effectiveness of long-term antipsychotic therapy and psychoeducation

on relapse rates over a 12-month period. The intervention group was treated with antipsychotic medication and traditional psychosocial support. In addition, eight psychoeducation meetings of 60–90 minutes' duration were provided to the consumers and their families. The control group received traditional psychosocial and drug intervention. The results indicated that consumers in the intervention group had improved adherence, increase awareness of their illness, and recognised the need for treatment. They also demonstrated an improvement in clinical symptoms, quality of life and relationships with staff in comparison to the control group. There was a reduction in relapse of their illness that resulted in 11 fewer hospital days. Their families also benefited from psychoeducation; learning to live with the consumer and the illness and seeing more positive qualities in the consumer (Aguglia, et al., 2007). Furthermore, a study by Hornung et al. (1998) assigned outpatients with schizophrenia into one of three treatment groups and a control group, and assessed how they managed their drug treatment. One treatment group received psychoeducation only, while the others received psychoeducation with either cognitive psychotherapy or psycho-educative counselling. The findings indicated that the participants of the three intervention groups displayed increased confidence in their medication and their doctor, and a reduced fear of side effects. In addition, the intervention and control groups showed no change in how they managed their medication following psychoeducation.

The effectiveness of a medication management model on knowledge and skills in three groups of consumers with schizophrenia was evaluated by Meder, Morawiec, and Sawicka (1998). They compared a behavioural group, an education class group, and control group with no education. The behavioural group had training in small groups using motivational training, practice and homework tasks. The education

group had the same topics and allowed discussion; however, no behavioural techniques such as role play or modelling were used. At post-training assessment, both intervention groups obtained new knowledge and skills in managing their medication, but the education group had higher levels of knowledge than the behavioural group. These results showed the importance of providing information that is relevant to the consumer (Meder, et al., 1998).

In contrast, other studies have found that psychoeducation has no effect on adherence to medication. In a Johanna Briggs Institute systematic review of the literature, Griffiths, Fernandez, Mostacchi, and Evans (2004) examined 21 RCTs that provided education to consumers with mental illness about their illness and medication adherence. Of these studies, only three focused on schizophrenia and adherence. These showed that psychoeducation made no difference to adherence in these individuals. Kavanagh et al. (2003) explored the effectiveness of medication education compared with standard care. Two information sessions were provided by the unit's pharmacist over a two-week period. Sessions included information on antipsychotic medication, including reasons for use, risks and benefits, side effects and precautions. The results showed that while consumers in the intervention group increased their insight over the course of the study, there was no effect on adherence or on attitudes or behavioural factors that affected adherence. A study by Macpherson, Jerrom, and Hughes (1996) provided consumers with an educational program using an information booklet which was based around their experience of illness and symptoms. Consumers were encouraged to give feedback and ask questions. There were three comparison groups: control, one education session, and three education sessions each lasting 25–30 minutes. The findings indicated that insight increased in

the three-session group; however, there was no change in medication adherence in the intervention or control groups.

3.6.2.2 Family psychoeducation

Having families involved in psychoeducation may improve adherence for some consumers. This may be delivered in conjunction with the consumer or family only. A psychoeducation family intervention program emphasising adherence and drug treatment was evaluated by Ran et al. (2003). Following participation in the program, medication adherence for consumers increased from 5.7% to 37.1%. However, despite the intervention 50% of families in the study continued to believe that the individuals did not have a mental illness. In many cases this was linked to their strong religious beliefs. In another study by Carra, Montomoli, Clerici, and Cazzullo (2007), an RCT was used to examine the effectiveness of multiple group family treatments. Families were randomly allocated to an information-based group that received weekly education related to schizophrenia for 24 sessions, or a group receiving additional support for 48 sessions. The additional support consisted of mutual support from other caregivers and social networking. These two groups were then compared with families with consumers receiving treatment as usual (control group). Clinical outcomes found that there were no differences between the three groups in terms of relapse or readmission. However, consumers' adherence was significantly greater at one-year follow-up in the two intervention groups compared with the control group (54% compared with 32%).

Not all studies have found that consumer and family psychoeducation improves medication adherence. A multicentre RCT study by Pitschel-Walz et al. (2006) evaluated whether psychoeducation groups for consumers and their families reduced

rehospitalisation and improved adherence. They found that one to two years after the intervention, consumers in the control group had poorer adherence and twice the number of readmissions and days in hospital than the psychoeducation group. Agarwal et al. (1998) found there was no difference in knowledge and attitudes between family members of non-adherent and adherent individuals, suggesting education for families was unlikely to be helpful.

3.6.3 Use of depot medication

Many consumers have to deal with poly-pharmacy and multiple doses of antipsychotics up to four times a day (Burton, 2005). Donohoe et al. (2001) highlighted that individuals with poor adherence had impaired recognition memory, and, therefore, complex medication regimes are particularly difficult for this group of consumers to implement. Individuals with lower insight are also less likely to be adherent and are therefore usually prescribed depot antipsychotic medication (Mahadun & Marshall, 2008).

In a recent systematic review of the literature on oral versus depot antipsychotic medication, Leucht et al. (2011) reported on 10 RCTs which found that depot antipsychotics significantly reduced relapse rates in individuals with schizophrenia (33.2% to 21.5%). However, in this review, only five studies reported non-adherence practices and no significant differences were found between depot and oral groups. In contrast, Patel et al. (2008) compared adherence and factors that influenced adherence in consumers prescribed oral and depot antipsychotics. They found that consumers taking depot had a higher rating of non-adherence compared with oral antipsychotics and this was influenced by their beliefs and concerns about the medication.

Other studies have found only short-term positive adherence outcomes using depot medication. A study by Weiden et al. (1995) found adherence improved at one-month post-discharge, when consumers were changed from an oral to depot antipsychotic; however, at six and 12 months' follow-up, there was no difference in adherence between oral and depot groups. Not surprisingly, Swartz, Swanson, Wagner, Burns, and Hiday (2001) in their study on the effects of involuntary outpatient status and depot antipsychotic treatment, found that administration of a depot, significantly improved adherence. In contrast to the study by Weiden et al. (1995), this was sustained for a period of six months.

3.6.4 Use of technology

In recent years, various technologies have increasingly been used in clinical and research areas to improve adherence. These have included computers, electronic cap monitoring, and telephone based interventions.

Computer technology has been used successfully to monitor adherence in consumers with schizophrenia. A study by Kurtz, Baker, Pearlson, and Astur (2007) used virtual reality to assess the management of antipsychotic medication. A virtual four-room apartment was developed, consisting of a living room, bedroom, kitchen and bathroom. An interactive television, clock and medicine cabinet were situated in the apartment. Consumers were presented with a scenario to see if they could manage their medication taking, and were compared with a healthy control group. The results indicated that consumers with schizophrenia made more errors in the number of tablets taken, they checked the clock less often, and did not take the medication at the correct time compared with the control group. Both groups made errors by taking the wrong medication. Bickmore, Puskar, Schlenk, Pfeifer, and Sereika (2010) evaluated

a computer-based medication adherence system that used a virtual reality agent called 'Laura'. Notebook computers were left with 16 consumers for 31 days and the agent interacted daily with consumers for 10 minutes over this period, tracking and reminding them about medication use, and promoting physical activity. Findings showed that consumers interacted with the computer on 65.8% of the available days for an average of 7.5 minutes each time. Three days prior to recruitment, consumers had missed on average two or more episodes of antipsychotic medication. One month after the intervention, consumers' self-reported adherence was 85-89%.

Another form of technology to manage adherence is the use of electronic cap monitoring. These caps are placed on medication bottles and electronically record the date and time of opening (Byerly, et al., 2005). Several studies have found that these caps are effective in monitoring adherence (Byerly, et al., 2005; Kozuki & Schepp, 2006; Nakonezny, Byerly, & Rush, 2008). Kozuki and Schepp (2006), for instance, found their monitoring cap was useful in determining whether visual feedback sessions improved adherence. Consumers were divided into a visual feedback group that focused on behaviour and psychodynamic therapies related to tablet taking and acceptance of medication, and a control group receiving supportive counselling. Data from the monitoring caps showed the visual feedback group steadily increased adherence over 12 weeks while the control group decreased adherence.

Two studies have examined a nurse-delivered telephone-based intervention for adherence (Montes, Maurino, Diez, & Saiz-Ruiz 2010; Beebe, et al., 2008). An RCT by Montes et al. (2010) evaluated whether three telephone calls to clinically stable consumers with schizophrenia over a three-month period improved medication adherence compared with routine care. The telephone call consisted of a brief semi-

structured assessment of adherence. If the nurse detected non-adherence, the consumer attended an appointment with the psychiatrist within seven days. Although this intervention was shown to be an effective strategy for identifying non-adherent consumers and improving adherence, it did not provide consumers with the necessary skills to prevent non-adherence in the future. Beebe et al. (2008) addressed this by adding problem-solving to a nurse initiated telephone-based intervention for consumers with schizophrenia. Nurses contacted consumers weekly by telephone and used the problem-solving approach to guide them through barriers that affected their adherence. As found in the study by Montes et al. (2010), higher adherence rates were found for the intervention group (80%) compared with the control group (60.1%). This intervention consisted of weekly telephone calls and used a problem-solving approach to discuss coping strategies and provide reminders.

3.7 Summary

The main interventions used to improve adherence to antipsychotic medication are adherence therapy and psychoeducation. Both interventions have obtained excellent results in decreasing hospital readmission rates for individuals with schizophrenia; however, mixed results have been reported about their effectiveness in improving adherence. CBT has shown promise in the treatment of schizophrenia; but, there is little evidence available to suggest it may improve adherence. Although family support is important, there is also little evidence to suggest that this improves adherence for consumers. The use of depot medication and technology has been shown to be helpful in assisting individuals manage their medication taking, but does not appear to improve long-term adherence.

Peer support is a novel and relatively untested approach as a means of improving medication adherence in individuals with schizophrenia and is discussed in the next chapter.

CHAPTER FOUR

PEER SUPPORT

4.1 Introduction

In this chapter, the literature on the topic of peer support is examined. The first section defines peer support and how it can be used as an intervention in health services. The next section specifically discusses peer support in the general health setting, including for mothers who are breastfeeding, individuals with heart disease or cancer, and those who have HIV-infection; and the use of telephone-based peer support. The final section examines peer support in the mental health setting, including non-government services, the use of consumer consultants, community and inpatient services, individuals with dual diagnosis, telephone-based peer support and individuals with schizophrenia. The current study used a peer support approach.

4.2 Peer Support

It is widely recognised that individuals who have experienced illness or adversity can offer support to those having a similar experience (Davidson, et al., 2006). This is commonly referred to as peer support. Simoni, Pantalone, Plummer, and Huang (2007) suggest it is an intervention that provides feasible and cost-effective support in the health care environment. Mohr, Burke, Beckner, and Merluzzi (2005) describe individuals offering peer support as usually having no formal training and typically having the same illness or condition as the person they are supporting. The support is usually voluntary (Dennis, Hodnett, & Gallop, 2002), however, it can be offered through a paid position (Middleton, Stanton, & Renouf, 2004). Delivery can be face-

to-face in a group or one-on-one arrangement, or can be via telephone or internet delivery (Pistrang, Jay, Gessler, & Barker, 2011).

The theoretical framework that underpins peer support is social support (Riegel & Carlson, 2004). Social support is provided by other people and may involve the provision of information, emotional support, and/or influence (Peterson, Bergström, Samuelsson, Åsberg, & Nygren, 2008). The vulnerability–stress model is a framework that can be used to understand and integrate knowledge about any disorder (Farhall, 2007). It is premised on the belief that all individuals are at risk of developing disorders such as schizophrenia and that these disorders can occur under certain circumstances. The degree to which a person is vulnerable will differ, depending on genetics, stress, environment, trauma or life events (Farhall, 2007). The vulnerability-stress model suggests that social support is a protective factor against the negative impact of stress. Stress can cause individuals' equilibrium to be disrupted and this may impact on their ability to cope (Farhall, 2007). Stress can be a precipitating factor for the onset of the symptoms of schizophrenia, and being aware of stress may help predict signs of relapse (Dawson, et al., 2010). A review of a peer support program in the US, by Wilson, Flanagan, and Rynders (1999) found that decreasing stress was found to be helpful in ensuring psychological well-being and reducing physical and emotional stress for individuals with psychiatric disabilities.

Peer support can be informal and can include having a friendship with someone else that is developed and maintained through the social roles the person occupies in work, leisure and family activities (Davidson, et al., 2004). Individuals with disabilities struggle to maintain these social connections and this may leave them feeling lonely and affect their recovery (Davidson, et al., 2004). Having informal support can lead to

increased friendships (Repper & Carter, 2011), enhanced social skills and social support, and, therefore better social functioning (Forchuk, Martin, Chan, & Jensen, 2005).

4.3 Peer Support in General Health

Several studies have examined the effectiveness of peer support in improving health outcomes in the general health environment. This type of support has been provided with health issues such as breastfeeding, heart disease, cancer, and HIV-infection.

4.3.1 Peer support with breastfeeding mothers

According to the World Health Organization, women should breastfeed exclusively for the first six months after giving birth (Curtis, Woodhill, & Stapleton, 2007). Previous interventions by health professionals have failed to increase the time women spend breastfeeding beyond two months (Curtis, et al., 2007; Raine, 2003).

Peer support has been used in several studies with the aim of improving breastfeeding rates. In a study located in a deprived socioeconomic area in the UK, Raine (2003) explored the relationship between peer support and breastfeeding. Semi-structured interviews, diaries and direct observation were analysed over a two-month period. Results indicated that peers made themselves available to the breastfeeding mothers at critical times, providing support and advice and demystifying breastfeeding practices. It was also clear that the women encountered social and cultural barriers to breastfeeding, experienced a lack of informal support, and were pressured into adopting “trusted” methods. A lack of public breastfeeding facilities in the community was also evident. Hoddinott, Chalmers, and Pill (2006) found that group-based peer support was preferable to individual peer support in coaching women to breastfeed in

the UK. They found that breastfeeding women enjoyed the social aspects of interaction and discovered it normalised breastfeeding in a safe and flexible environment. The group intervention increased breastfeeding rates two weeks post-birth from 34.3% to 41.1%. A study by Curtis et al. (2007) evaluated the Breastfriends Doncaster project in the UK. The project aimed to increase breastfeeding rates in a socially and economically deprived area by using peer support. Peers undertook 20 hours of classroom training prior to their role and focus groups were used to explore how the peers and health professionals negotiated the peer support project. Peers worked alongside breastfeeding women, supporting and encouraging them to breastfeed. The project found that peers experienced increased personal development, including greater social support and self-esteem. Additionally, the health professionals found that engaging peers helped them to decrease their workload. Outcomes for breastfeeding women were not reported.

Not all peer support initiatives produce positive results. An RCT in a multi-ethnic disadvantaged population in the UK (MacArthur, et al., 2009) used antenatal peer support to increase breastfeeding initiation in 2511 women. At the time of the study the UK rate of breastfeeding initiation following birth was 58%. Women received at least two face-to-face contacts from a peer at 24 and 36 weeks' gestation to provide advice and information on the benefits of breastfeeding. The findings indicated, however, that the peer support was ineffective in increasing the initiation rate of breastfeeding.

4.3.2 Peer support for individuals with heart disease

Peer support has shown promising results in studies with individuals with heart disease. An RCT by Riegel and Carlson (2004) evaluated the effectiveness of peer

support in improving health outcomes for individuals with chronic heart failure in the US. Nine peers and 60 patients participated. The peer interventions included home visits, telephone calls, joint outings, demonstrations and modelling. Peers maintained weekly contact with the participants in the first month post hospitalisation and monthly thereafter for the next three months. The control group received usual treatment. Results showed the intervention group had an improvement in self-care (ability to maintain health and manage symptoms) in the peers and the participants, and an increase in the use of acute care resources by participants. Another RCT by Parent and Fortin (2000) evaluating peer support for first-time cardiac patients recovering from coronary artery bypass surgery. Three peers and 56 patients participated in the study. Intervention and control groups received routine information on surgery and recovery. In addition, the intervention group had three supportive peer visits pre- and post-surgery, with the aim of reassuring, coaching towards physical activities, and reinforcing risk factor reduction. Results showed the intervention group had significantly reduced anxiety before and after surgery, improved self-efficacy and self activities, and accelerated recovery.

4.3.3 Peer support for individuals with cancer

Studies have shown that group peer support interventions can be effective for individuals with cancer (Steginga, Pinnock, Gardner, Gardiner, & Dunn, 2005; Tehrani, Farajzadegan, Rajabi, & Zamani, 2011). Steginga et al. (2005) evaluated 42 prostate cancer support groups across Australia. Most (71%) were led by a peer who had recovered from prostate cancer and the remainder by a health professional. Content included general discussion, education, telephone support and newsletters. Surveys were distributed to 1224 participants, with most men reporting satisfaction

with support groups; only 3% were dissatisfied. Overall, the men reported a good quality of life; however, they experienced sexual dysfunction and tiredness. Tehrani et al. (2011) conducted a non-randomised trial in Iran, with 68 women with breast cancer. Participants in the intervention group received twice-monthly meetings (six sessions) with a peer group leader. Participants shared their experiences and feelings about breast cancer. The control group had six educational sessions with an associate specialist. Both groups experienced significant improvements in various areas of functioning and health and the study found that although women could benefit from both interventions, there was no advantage in utilising a peer.

4.3.4 Peer support in individuals with HIV-infection

Adherence to antiviral medication is problematic in individuals with HIV-infection. To obtain maximum viral suppression, a 95% adherence rate must be achieved (Simoni, et al., 2007). Various interventions have attempted to address this issue; however, none has been successful. Simoni et al. (2007) examined the medical literature and found that increased social support led to improved adherence. Based on this information they developed an RCT using peer support, targeting antiretroviral medication adherence in HIV-infected women and men. They recruited 136 participants from a US outpatient service. HIV-infected individuals with high levels of adherence, who attended appointments regularly, and were socially skilled, were recruited as peers. A three-month intervention program was developed, comprising six twice-monthly one-hour group meetings facilitated by peers, and thrice-weekly telephone calls from peer to participant. The meetings aimed to identify barriers to adherence and used a problem-solving approach. Results found that there was drop in adherence levels; 78% at baseline, 80% at three months, and 72% at six months. The

authors identified that this result may have been the outcome of poor attendance by participants; on average participants attended only 2.1 meetings. *Post hoc* analysis of the intervention group, however, indicated that those who attended the majority of meetings had higher self-reported adherence, increased social support and fewer symptoms of depression. In contrast, a study by Deering et al. (2009) evaluated a peer intervention for HIV-infected female sex workers using illicit substances in Canada. Adherence was measured through self-report, pharmacy refill and viral load outcome. Women attended an average of 50 weekly one-hour peer support meetings. Adherence throughout the intervention was high (92%) and improvement was greatest in women who had housing instability and higher frequency of drug use.

4.3.5 Telephone-based peer support in general health

Interventions delivered by telephone are increasingly being used to provide peer support by healthcare organisations. The following section describes this support in the areas of breastfeeding, and for individuals with multiple sclerosis, cancer and diabetes.

Dennis et al. (2002) used an RCT to evaluate the effects of telephone-only peer support on breastfeeding duration for first-time mothers living in Canada. Peers provided telephone support and education over a 12-week period. Mothers who received the peer support intervention were 2.5 times more likely to continue breastfeeding at the follow-up time points (4, 8, and 12 weeks) than those receiving standard care.

Mohr et al. (2005) evaluated a telephone-administered peer support program in the US for multiple sclerosis patients. This was a pilot study with a small cohort and no

control. The program was conducted over an eight-week period and consisted of one 50-minute telephone call each week from a peer who had received 20 hours of training prior to the program and ongoing weekly supervision throughout the program. Participants include four peers and 16 patients with multiple sclerosis. A problem-solving approach was used; sessions were structured and included homework. Patients had a significant reduction in depressive symptoms and improvement in quality of life and well-being.

Telephone-based peer support groups for individuals with cancer have been found to be successful. Pistrang et al. (2011) examined the experience of the process and outcomes in a peer telephone support program for women with gynaecological cancer in the UK. Sixteen peers, who had completed their own cancer treatment and achieved physical and psychological recovery, received a two-hour orientation session. They contacted participants ($n=24$) by telephone once a week and after a period of three months the delivery was evaluated through semi-structured interviews. Two-thirds of the women responded to the program positively, identifying empathy, emotional bonds, reciprocity, talking openly, information and guidance, and humour as positive features. One-third reported no benefit, citing reasons such as not connecting with the peer, poor timing of support and already having support available.

Diabetes is a chronic illness that requires individuals to manage their own care, including maintenance of normal blood glucose levels and blood pressure. Telephone peer support has been used to assist patients to improve their self-care, with mixed results (Paul, Smith, Whitford, O'Kelly, & O'Dowd, 2007). An RCT by Heisler, Vijan, Makki, and Piette (2010) compared peer support to nurse care management. Peer support included weekly telephone calls and three group sessions. Nurse care

involved 1.5 hour education sessions and standard treatment. There were no differences in blood pressure, medication adherence or diabetes-related distress. The peer group, however, showed improved social support. A previous study by Heisler and Piette (2005) using the same intervention had positive outcomes for self management of diabetes. The majority of patients enjoyed talking to a peer and found it helpful in managing their diabetes; however, there was no comparison group.

A Cochrane review of seven RCTs by Dale, Caramlau, Lindenmeyer, and Wilson (2008) evaluated the effects of peer support via telephone intervention for individuals with physical, psychological or behavioural health outcomes. Overall, there were no significant differences between the intervention and control groups in three studies on post-myocardial infarction patients, diabetes and smoking cessation. However, peer support was found to increase mammography screening uptake in two studies, one study on postnatal depression found there were fewer major depressive symptoms in the peer group and one study on post-myocardial infarction found changes in diet following peer intervention (Dale, et al., 2008). Overall, the review found a limited number of studies with adequate design and believed there was a need for further well designed RCTs on telephone-delivered peer support (Dale, et al., 2008).

4.4 Peer Support in Mental Health

The following section will examine the effectiveness of peer support in improving outcomes for mental health consumers. This support has been evaluated in non-government consumer services and community mental health and inpatient services,

with consumer consultants,⁴⁵ consumers with dual diagnosis, and individuals with schizophrenia, and services offering telephone-based support.

4.4.1 Non-government consumer services

Consumer services are non-profit organisations that are run by and for individuals with serious psychiatric disabilities and can include drop-in centres, self-help agencies or mutual support groups, and consumer-run programs (Hardiman, 2007). In Victoria, Australia, support groups and consumer-run services include GROW,⁴⁶ Mental Illness Fellowship of Victoria (formerly Schizophrenia Fellowship), Association of Relative and Friends of the Emotionally Ill, and the Victorian Mental Illness Awareness Campaign (Middleton, et al., 2004). These groups differ in how they support consumers. Mutual support groups draw on empowerment and social support with voluntary peer interaction (Hardiman & Segal, 2003), whereas consumer-run services are not entirely mutual; peers are paid employees of the program and would not receive support from consumers in the program (Davidson, et al., 1999). Drop-in centres offer organised informal social and recreational activities and staff can help individuals with their daily living problems (Holter, Mowbray, Bellamy, MacFarlane, & Dukarski, 2004).

There is limited research on the effects of consumer-run services on mental health outcomes for individuals with schizophrenia. Chinman, Weingarten, Stayner, and Davidson (2001) evaluated the Welcome Basket Program in the US. This outreach

⁴⁵Consumer consultants are individuals with a mental illness who are employed by public mental health services to present a consumer perspective on delivery of care, drawing from their own experiences and leading to improvement in advocacy, service delivery, and planning (McCann, Clark, Baird, & Lu, 2008).

⁴⁶GROW is a consumer-run organisation which helps individuals with mental health problems. It was developed out of Alcoholics Anonymous in the 1950s (GROW).

program has been staffed and managed entirely by consumers since 1996. Staff initially visit consumers at home with a basket of items from local retailers, then engage them in various leisure activities. Staff also consult and advocate with mental health clinicians regarding adherence to treatment and encourage clinicians to view symptoms as barriers to community living. Program participants are involved in twice-weekly groups facilitated by a peer and a counsellor. Over a two-year period, the evaluation found that only 15% of participants in the Welcome Basket Program were readmitted to hospital, compared with 30% of outpatients from the local community mental health service. A state-wide peer service operating since 2006 in the US was evaluated by Dalgin, Maline, and Driscoll (2011). It offers after-hours telephone-based support called the “warm line” to consumers with mental illness from 5pm–8am, seven days a week. Trained peer specialists offer social support, advice on coping strategies, provide knowledge about their own illness and instil hope and strength. Overall, 78% of respondents felt that using the “warm line” reduced the need for further crisis service, 89.6% were satisfied with the service they received and 73% felt it increased their sense of well-being. Only 6.3% indicated that they were unlikely to use the service again.

Lucksted, et al. (2009) evaluated the National Alliance on Mental Illnesses, a structured peer-to-peer program across 13 states in the US. The program is led by a peer and focuses on relapse prevention and wellness. Participants ($n=138$) completed pre–post surveys and the results showed improvement in areas such as managing their illness, confidence, connectedness with others, and not feeling powerless. Consumer-run services across multiple sites in the US were evaluated by Corrigan (2006a). Results found that the services were positively associated with recovery and empowerment in 1824 participants. Both of the previous studies had no

randomisation, participants had a mixture of diagnoses and adherence was not evaluated.

In comparison, the evidence from 29 controlled studies on the effectiveness of consumer-led mental health services published from 1980–2008 was examined by Doughty and Tse (2011). Overall, traditional and consumer-led services showed equally positive outcomes in the areas of employment, living arrangements, decreased hospitalisation and the cost of services. Consumers had greater satisfaction and recovery with consumer-led services. A peer-led education intervention called BRIDGES (Building Recovery of Individual Dreams and Goals through Education and Support) across eight US communities was evaluated by Cook et al. (2012). Outpatient consumers with serious mental illness ($n=428$) were randomised into the BRIDGES intervention or usual care. In the intervention program participants received 2.5 hours of education per week for eight weeks, with four to thirteen participants in each group. Classes were interactive and included topics about recovery principles, problem-solving, communication, interpersonal relationships and information about mental illness, relapse and coping strategies. Follow-up evaluation was undertaken post-intervention and at six months. The findings indicated that consumers attended five sessions on average. Consumers had improved self-perceived recovery, were more confident, able to tolerate their symptoms and had an increase in hopefulness. Participants with severe depressive symptoms did not show improved outcomes. The program is now offered across 12 states throughout the US and Canada (Cook, et al., 2012).

4.4.2 Use of consumer consultants

In Australia over the last decade, mental health services have increasingly involved consumers in service development, planning and evaluation (Cleary, Walter, & Escott, 2006). Consumer consultancy emerged in the 1990s in Rozelle Hospital in Sydney, where advocacy groups were first established (Cleary, et al., 2006). This coincided with the first Australian National Mental Health Plan (NMHP) in 1992, which stated that consumers were to have input into mental health services, including the establishment of National and State Consumer Advisory Committees (Department of Health and Aging, 1992). In 1996, the Victorian Mental Illness Awareness Campaign strengthened the campaign for consumer input by advocating for the employment of consumer consultants in local area mental health services (Middleton, et al., 2004). Ensuing NMHPs in 2003 and 2009 (Victoria Government, (2009b) have further emphasised consumer input by increasing the levels of participation and ensuring that consumers receive the necessary training to undertake their positions. In the Victorian 2009–19 Mental Health Strategy Plan (Victoria Government, 2009b), consumer and carer issues continue to be considered an important part of mental health reform. Recommendations include development of consumer and carer roles in mental health services through peer worker roles, consumer and care consultancy programs, research, consumer-led recovery, training initiatives, greater representation at Mental Health Review Board⁴⁷ hearings and improved access to advocacy.

⁴⁷The Mental Health Review Board (MHRB) is a statutory tribunal under the Mental Health Act of Victoria 1986 that conducts reviews of, and hears appeals by, patients with psychiatric illness being treated involuntarily either as inpatients or on community treatment orders (MHRB, 2011).

Most mental health services in Australia employ permanent consumer consultants. Their role encompasses diverse areas such as advocacy, education and peer support, involvement in policy, service planning and development, committee membership, research and recruitment (Cleary, et al., 2006). However, there has been limited research undertaken on the effectiveness of consumer consultant services. Two studies to date have evaluated this role in Victoria public mental health services (McCann, Clark, Baird, et al., 2008; Middleton, et al., 2004). Middleton et al. (2004) recognised that the role had not been evaluated since its inception and undertook a qualitative study that explored the experiences of ten consumer consultants. At the time there were 60 consultants employed on a part- or full-time basis in Victoria. The major themes in the findings indicated that some services were more accepting than others of the role, and services either hindered or facilitated the work of consumer consultants. McCann, Clark, Baird et al. (2008) examined the attitudes of 47 mental health professionals towards consumer consultants in the acute and rehabilitation inpatient units in a large acute care hospital. The findings showed that female staff were more likely than their male counterparts to agree that consumers had a role in the management of services and should be involved in inpatient units. However, both sexes were undecided about whether consumer consultants should be involved in treatment-related matters for consumers. Staff with less experience showed greater support for the involvement of consumer consultants in treatment related matters than more experienced staff. Both Middleton et al. (2004) and McCann, Clark, Baird et al. (2008) highlighted the limitations of a small sample size and recognised the need for further research in this area.

Similar to the employment of consumer consultants in Australia, the Department of Veteran Affairs in the US recommends that peers should be employed in clinical

teams to provide support to others with serious mental illness. Peers are employed in paraprofessional roles and their duties range from orientating consumers, leading groups, intake and treatment planning, identifying housing needs, and taking consumers to community programs (Chinman, et al., 2008). Focus group interviews were undertaken to obtain feedback on the program, to provide support for peers and to help identify outlying services. Peers gave positive and negative feedback. When they first commenced the role they experienced poor access to workspaces and equipment, and several staff members had difficulties in accepting peers in the new role. Since then, however, the peers felt that teams had become more consumer centred, consumers were more empowered and motivated, and peers had a better understanding of services available and felt they were good role models (Chinman, et al., 2008).

4.4.3 Peer support in community mental health services

The following section examines the effectiveness of community mental health services or outpatient services in providing peer support.

Consumer-focused case management and advocacy was evaluated using an RCT by O'Donnell et al., (1999), for consumers with schizophrenia and bipolar disorder who were receiving outpatient service in Australia. Consumers ($n=119$) were randomly allocated to one of three groups for 12 months: standard case management, consumer-focused case management, or consumer-focused case management plus consumer advocacy. Consumer-focused case management involved case managers having a recovery focus, with an emphasis on meeting the consumer's goals. The consumer advocacy role included individuals who had recovered from mental illness, siblings, carers or someone with an interest in mental health. Advocates completed a three-day

course and were available for three hours a week. They provided role modelling, encouraged confidence and communication, and participated in recovery meetings with case managers and consumers. Results indicated no significant differences between groups in areas of functioning, disability, service satisfaction, quality of life and burden of care. However, consumers reported increased satisfaction when receiving consumer-focused management. Similarly, a study on peer-based case management for homeless persons with serious mental illness by Chinman, Rosenheck, Lam, and Davidson (2000) compared peer ($n=950$) with clinician-based case management ($n=1985$). Participants were recruited across six sites in the US, from a national program that provides outreach and intensive case management. The program employs peer case managers and health professional case managers to deliver mental health services. They found no significance differences between the two case management groups on any of the outcome measures (clinical, social and occupational functioning). Although this was a large study, the delivery by peer case managers did not use specific mutual support principles and this may have affected the results. Moreover, in a study in the US, across 14 community mental health services, the role of morale in consumer support and satisfaction with services was examined (Shahar, Kidd, Styron, & Davidson, 2006). Consumer participants were allocated randomly to a consumer partner, non-consumer partner or control group (no partner). Study outcomes found that consumer participants with high morale in the pre-study had reacted adversely when matched with a consumer partner, and this led to decreased satisfaction with the service. However, in the non-consumer and control group, high morale participants had increased satisfaction with services.

In contrast, two RCTs found peer support to be effective. Peer-assisted case management was compared with standard care in an RCT by Rivera, et al. (2007) in

the US. Participants ($n=203$) were randomly assigned to three groups: peer-assisted case management, standard care, and clinic-only based care. In the intervention group, peers facilitated social support with consumers through one-on-one and group activities, while case managers provided conventional services. The other two groups received no peer support. Over a 12-month evaluation period there was no differences in treatment outcome between the three groups. All showed improvements in symptoms, healthcare satisfaction, quality of life, and social networking behaviours. The other RCT by Davidson et al. (2004) was conducted in community mental health services across 14 towns in the US, and investigated whether engaging consumers in social and recreational activities with voluntary partners, would aid recovery. Participants were randomly assigned to three partnerships: peer partner with history of mental illness, person from general community, or not matched with a partner. Participants were matched to their partners depending on shared interests for two to four hours a week for nine months to engage in social and recreational activities. Functioning and self-esteem improved for all participants; the only differences in groups, were with the degree of contact. Participants in the non-consumer group improved in social functioning and self-esteem when they met with their partners, participants in the consumer group, however, only improved when they did not meet.

Peer support has made a difference in two Assertive Community Treatment (ACT) programs in the US. Clarke et al. (2000) conducted an RCT on the effects of ACT compared with standard care. The ACT program employs consumers and mental health clinicians who provide case management. Participants ($n=163$) had a diagnosis of severe mental disorder and were randomly allocated to three groups: ACT program staffed by peers, ACT program staffed by professionals, and standard care. No differences were found in rates of homelessness, arrests or emergency room visits in

all intervention groups. However, participants who received non-peer intervention were hospitalised earlier and had more hospitalisations and visits to emergency rooms.

In Canada, there is a requirement that, ideally, all consumers are employed in at least a part-time role as consumer service providers (White, Whelan, Derrick-Barnes, & Baskerville, 2003). A study by White et al. (2003) explored how peer support workers had integrated with assertive outreach teams in Canada. Surveys were mailed to 44 team leaders and community staff members, an average of six surveys were returned from each team. Results indicated that the peer support worker role was new to most teams, and on average had only been in place for four months. Twenty-two per cent of teams reported the positions were still not implemented. Authors found that peers were not working as primary clinicians, had inferior remuneration, and were not perceived as integral to the team. However, the role was seen as valuable, with peers reporting a sense of belonging, teamwork and high job satisfaction. The study did not report on what the peer support role was or the effect on consumer outcomes.

4.4.4 Peer support in inpatient services

Some studies have focused on peer support in inpatient mental health services. This has included group and individual peer support.

Meehan, Bergen, Coveney, and Thornton (2002) evaluated a peer support training program in Australia, that prepared former consumers to provide peer support in an inpatient setting. Ten former consumers participated in the 16-week training program, four weeks in a classroom setting and 12 weeks working alongside staff in the inpatient unit. Focus groups and questionnaires were used to evaluate the program

every four weeks. The peer trainees felt that their own experiences of the mental health system were of value to the current inpatients and exposure to acutely unwell consumers did not adversely affect them. The impact of the study on consumers within the inpatient unit was not assessed.

Many individuals with mental illness will relapse within one year of discharge. An RCT evaluated a transitional discharge model in an acute admission ward in the UK to assess whether this assisted consumers to adjust to community living and prevent early readmission (Reynolds, et al., 2004). The model included peer support and a period of time where inpatient and community mental health staff worked together to develop a relationship with the consumer prior to discharge. Peers provided friendship and understanding, and involved consumers in recreational and social activities. The results indicated that the intervention group participants were less likely to be readmitted, had fewer symptoms, better levels of functioning and quality of life. The sample size in the study ($n=19$) was small and lacked statistical power. No differences in outcomes were tested between peer and staff support. A similar study by Forchuk et al. (2005), but with a much larger sample size ($n=390$), assessed a transition discharge model in 26 wards in four psychiatric hospitals in Canada. Like the previous study, participants were randomised into a transitional discharge model intervention or control group (usual care). Participants in the intervention group received an overlap of inpatient and community staff support as well as peer support. The peer support included regular meeting with a peer for at least 12 months, with a focus on friendship, living skills and participation in community activities. Results indicated that the intervention group had improved social relations; however, no other outcomes were significant.

In contrast, Lawn, Smith, and Hunter (2008) evaluated a new peer support service in Australia with positive outcomes. This service provides early discharge and hospital avoidance support to adult mental health services. It consists of a project manager, peer coordinator, and eight peer support workers employed on an as-needed basis. Peers provided support prior to discharge for 8–12 hours over a one-to-two week period. The evaluation occurred within three months of opening, at which time the program had provided support packages to 49 individuals. Results showed that, following discharge, re-referrals decreased from 30% to 17%, resulting in a saving of 300 bed days and \$93,500. It is also recognised that consumers obtain peer support informally from other consumers in inpatient services.

Bouchard, Montreuil, and Gros (2010) explored the perceptions and experiences of consumers obtaining peer support informally in acute and long-term mental health units in Canada. The researcher interviewed ten consumers (maximum duration of 60 minutes) and observed non-verbal behaviour in the units. It was found that consumers observed, reflected, took action and evaluated the actions of their peers. They participated independently of staff and provided a range of services to their fellow consumers, including emotional support, sharing of personal belongings and information, and assisting in daily living activities. Consumers noticed that this support improved the emotional well-being and behaviour in their peers; however, this was not formally evaluated.

4.4.5 Peer support in consumers with dual diagnosis

Peer support has been evaluated in individuals with co-existing substance use and mental illness. An RCT was conducted in a public mental health service in the US to compare the effectiveness of two interventions in reducing alcohol, drug use and

criminality in 111 consumers with mental illness (Rowe, et al., 2007). One intervention used peer support combined with standard treatment and jail diversion, the other used standard treatment and jail diversion. Intervention participants were assigned a peer who worked with them each week for four months. Peers encouraged sobriety, friendship, social support, and advocacy. Results indicated that alcohol use by the intervention group had significantly decreased at six and 12 months. Drug use and criminality decreased in both groups; however, there were no significant differences between the groups.

The Friends Connection Program in the US (Min, Whitecraft, Rothbard, & Salzer, 2007) provides support to people with co-occurring mental health and substance use disorders. The goal of the program is to assist individuals to develop skills to live in the community and be drug or alcohol free. Each participant ($n=106$) was paired with a peer who had abstained from substances for three years. They interacted once a week for two to five hours and participated in community activities, shared experiences and coping strategies. Outcomes were compared against a comparison group ($n=328$) of consumers who did not receive the program. Evaluation of the program found that participants had significantly fewer hospitalisations over a three-year period (62% vs. 73%).

4.4.6 Telephone-based peer support in mental health

A few studies have evaluated telephone-based peer support intervention with consumers who have depression. Hunkeler et al. (2000) compared usual care ($n=123$), telephone care by a nurse ($n=117$), and telephone care by a nurse plus peer support ($n=62$) in a US primary health care setting for consumers with depression. Peer support was provided by telephone and face-to-face contact by individuals who had a

previous history of depression. Telephone care by nurses improved depression, mental functioning and treatment satisfaction in participants with or without peer support. Neither nurses' care nor peer support improved medication adherence. In a similar RCT by Ludeman et al. (2007) three different management programs were compared with usual care in a sample of 104 individuals with chronic depression in the US. Groups consisted of usual care, usual care plus telephone care by health professional, usual care plus telephone care by health professional and peer-led group program, and usual care plus telephone care by health professional and professional-led psychotherapy group. Health professionals contacted participants by telephone to assess depression, medication use and side effects. They provided education about medication adherence and management of side effects. The peer-led group program was a six-week workshop covering many topics, including goal setting, relaxation and medication management. Acceptance of treatment was high in all groups, with the intervention groups receiving adequate medication over a 12-month period. However, no significant differences were observed in clinical outcomes, probably because of the small numbers in each group.

In contrast, women at high risk of developing postpartum depression were evaluated in an RCT by Dennis (2003), comparing a peer telephone-based intervention to usual care. The study took place in Canada, with 42 participants. Women who had experienced postpartum depression telephoned participants over a period of eight weeks and provided social and emotional support and informal feedback. Findings showed that the control group had more major depressive symptoms than the intervention group. Most peers (87.5%) were satisfied with the experience and reported that they would undertake the role in the future. Furthermore, a telephone-based peer support was evaluated by Travis et al. (2010) for consumers with

depression in the US. Peers were provided a manual and attended a 90-minute training session. They telephoned consumers recruited from a Veterans' Affairs mental health service once a week for 12 weeks. Each call lasted approximately 26.8 minutes. Following the support, small but significant improvements occurred in depressive symptoms, functional disability, and overall psychological health and quality of life.

4.4.7 Peer support and schizophrenia

There is minimal evidence in the literature regarding the effect of peer support on individuals with schizophrenia. In one multicentre RCT in the Netherlands, Castelein et al. (2008) evaluated the effectiveness of a guided peer support group ($n=56$) compared with usual care ($n=50$). A group of ten consumers met bi-weekly for eight months and discussed their daily life experiences, supported by minimal involvement from a nurse. The intervention group had positive outcomes in social network and support. Those who attended more group sessions had increased self-efficacy and quality of life. The study was limited because it only included participants who were clinically stable and non-substance users, which does not closely reflect the mental health population. In a study in Germany, Rummel-Kluge, Stiegler-Kotzor, Schwarz, Hansen, and Kissling (2008) found that a peer counsellor was effective in answering questions related to illness in individuals with schizophrenia. A person who had been practising peer-to-peer psychoeducation for four years was recruited to provide peer counselling to 88 consumers. The peer counsellor offered one session lasting 20–30 minutes in an inpatient setting. Overall, most consumers indicated (85%) that their questions were fully or partially answered, 65% found the experience helpful, and 95% would recommend the session to other consumers.

4.5 Summary

Peer support is diverse in its role, function and delivery in general and mental health areas. It can vary in delivery from one-on-one, group, or telephone contact. Most peers have some form of preparatory training, and all have experience of the same illness as the individuals they are supporting. They provide general support, advice and information about the illness and share their experiences. In the mental health area, they are specifically involved in case management and have a paraprofessional role that includes consumer orientation, leading groups, and offering social and recreational activities. Other peers have a support role that provides friendship, advocacy and promotion of social activities.

There are mixed findings on the effectiveness of peer support, both in general and mental health areas. Positive outcomes include decreased hospitalisation, improvement in well-being and quality of life, better illness management and increased confidence about the illness. However, some RCTs failed to demonstrate a significant difference between usual care and peer support. Many of the studies highlight the need for more rigorous research in the area.

Overall, there is limited research on the effectiveness of peer support and adherence with medication in individuals with schizophrenia. The purpose of the present study was to determine if peer support would improve outcomes in medication adherence, mental state, quality of life, and satisfaction with medication in consumers with schizophrenia who have been non-adherent with their antipsychotic medication.

CHAPTER FIVE

DESIGN AND METHOD

5.1 Introduction

In this chapter, the design and methods of the study that evaluated the effectiveness of a problem-solving based peer support intervention program for enhancing oral antipsychotic medication adherence in consumers with schizophrenia are described. A mixed methods design, incorporating quantitative and qualitative methods, was used to evaluate the program. The program involved peers who provided support to consumers with a history of non-adherence to oral antipsychotic medication. The chapter begins by outlining the conceptual framework and design rationale. Next, the methods for the study are discussed, including the selection and recruitment process, and sample size. The procedure for delivering the peer support program, details of data collection and instruments used, study rigour, ethical considerations and data analysis finish the chapter.

5.2 Conceptual Framework for the Study

The conceptual framework for the study was based on the social problem-solving approach of D’Zurilla and Nezu (1999). This approach was conceived in the 1950s when the president of the American Psychological Association, Joy Guilford, believed the intellectual linking of problem-solving and creativity would have enormous significance in the future for addressing complex problems. At the same time, Alex Osborn, an advertising manager seeking specific training to enhance the creativity of employees in industrial areas, developed one of the first problem-solving training

programs using brainstorming techniques (D'Zurilla & Nezu, 1999). Participation in Osborn's early program improved participants' problem-solving abilities and assisted them to cope with everyday issues (D'Zurilla & Nezu, 1999). In the late 1960s and early 1970s, the problem-solving approach began to be adopted for use in clinical, counselling and health psychology services as a practical intervention and preventative approach; however, at this time, it focused mainly on negative events that occurred in an individual's life (Bell & D'Zurilla, 2009).

Richard Lazarus, a prominent psychologist and researcher in the 1970s and early 1980s (D'Zurilla & Nezu, 2007), found that there was an overlap between the relational model⁴⁸ he developed and the problem-solving approach. He found that negative cognitive appraisals and coping deficits led to an increase in the negative impact of stress, and therefore caused stress-related disorders (Bell & D'Zurilla, 2009). This led to the integration of Lazarus's relational model and problem-solving theory. Problem-solving became an effective therapy for individuals as a way to decrease, manage and cope with stress. By the 1980s, the approach was being used for treatment and prevention of stress-related disorders and for daily stress management (D'Zurilla & Nezu, 2007). The problem-solving approach became better known in clinical settings as 'social problem-solving' and was defined as 'a self-directed cognitive–affective–behavioural process by which an individual attempts to identify or discover solutions to specific problems encountered in everyday living' (D'Zurilla & Nezu, 2007, p.11). The term 'social' highlights that it occurs in a social context and can deal with a range of problems, including financial, relationship, and wider community and societal issues (D'Zurilla & Nezu, 2007). The process of

⁴⁸The Relational Model views stress as a person–environment relationship, where the demand of this relationship surpasses coping resources and well-being is threatened. How a person cognitively appraises and copes with this will determine the outcome of the stress (D'Zurilla & Nezu, 2007).

problem-solving assists individuals to deal with stress in a healthier way, leading to a decrease in emotional distress. Stress can occur because of major negative events (e.g., death of a loved one or divorce) or specific daily stressors (e.g., car problems, poor work performance) (Bell & D'Zurilla, 2009). Problems can occur when the stress cannot be responded to effectively or obstacles become apparent. This may have major implications for the individual's social environment (e.g., employment terminated, or worsening of illness). Solutions are the responses or outcomes of the problem-solving process. Effective solutions will address the problem effectively, decrease emotional distress and limit negative consequences (D'Zurilla & Nezu, 2007).

Within social problem-solving, two variables can affect an individual's problem-solving performance. One is problem orientation, or how individuals feel and think about problems and their ability to resolve them effectively. People react differently when faced with problems, and some view them as opportunities and are able to resolve them in a positive way, while others see problems as a threat to their well-being and will react in a negative way (Nezu, et al., 2007). The other variable is problem-solving style; the specific cognitive-behavioural activities that an individual uses to cope with stressful problems. This style can be adaptive, leading to a successful outcome, or dysfunctional, leading to psychological distress. When individuals have a dysfunctional style of problem-solving they may try and use avoidance, procrastination, dependence on others or develop physical or emotional ailments (Nezu, Nezu, Jain, et al., 2007).

D'Zurilla and Nezu's (1999) original social problem-solving process incorporated five steps: problem orientation, problem definition and formulation, generation of

alternative solutions, decision making, and solution implementation and verification. Nezu, Nezu and D’Zurilla (2007) modified the process and developed the ADAPT five-step self-help method to effective problem-solving. The model is written in plain language, and is straightforward to use. It is interactive, specific and relevant, enables practice of new skills, and is geared to minimise emotional distress (D’Zurilla & Nezu, 1999). The ADAPT acronym refers to the idea that through problem-solving a person can adapt or adjust more successfully to life’s stressors and strains (Figure 5.1).

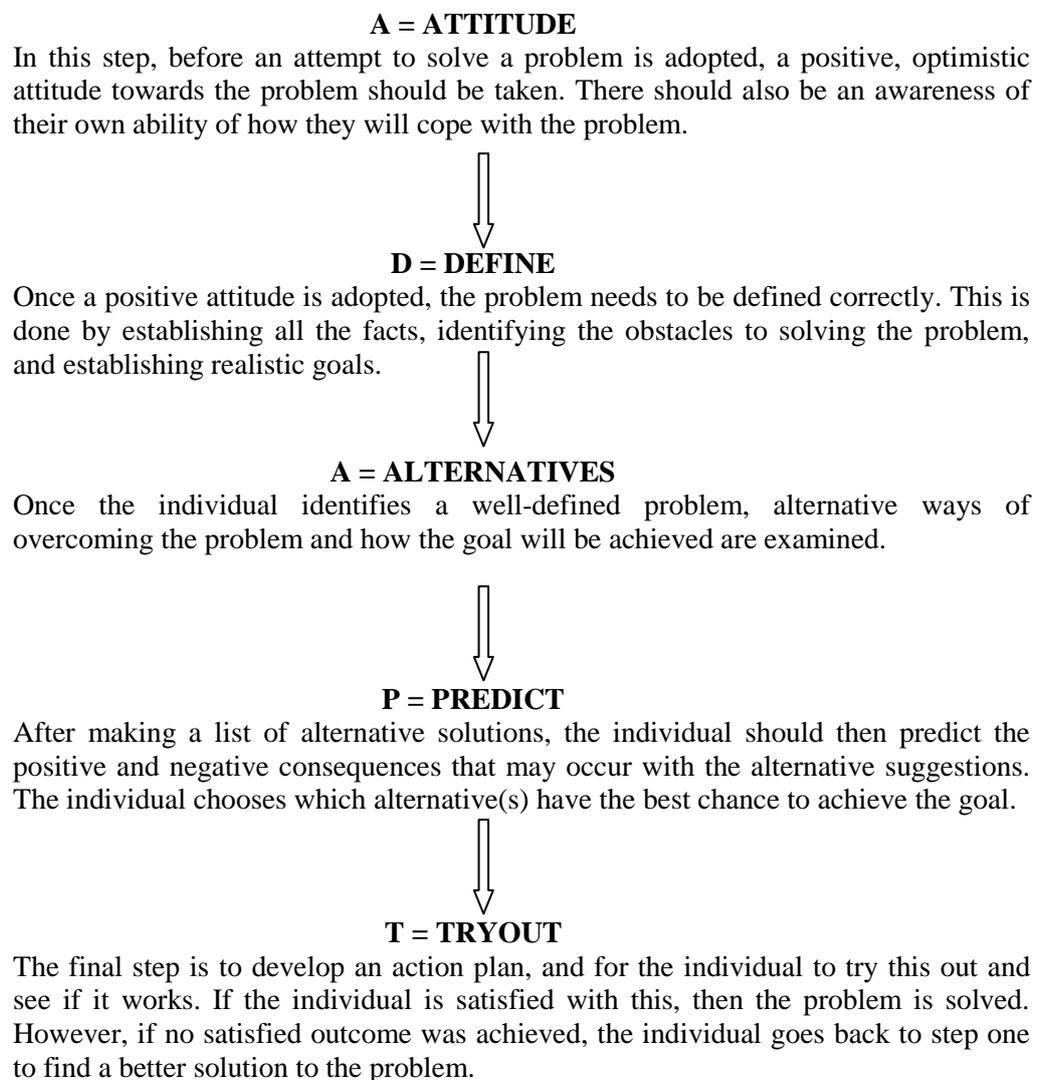


Figure 5.1 *The ADAPT 5-step method to effective problem-solving* (Nezu, Nezu, & D’Zurilla, 2007)

The problem-solving approach used in this present study was based on the ADAPT principle. It was designed to assist consumers with schizophrenia to identify and resolve medication adherence problems through the development of new skills. Individuals with schizophrenia typically exhibit varying levels of cognitive dysfunction (Sadock & Sadock, 2007) and impairment in occupational and educational performance, social functioning and independent living skills (Velligan & Gonzalez, 2007). Individuals may also have difficulties in recalling long-term memory of past autobiographical events as they advance into a chronic course of their illness and this may impact on their problem-solving abilities (Sponheim, et al., 2009).

The effectiveness of the problem-solving approach in individuals with schizophrenia has been examined in several studies, with mixed findings. Xia and Li (2007) in a Cochrane review evaluated problem-solving skills compared with routine care in individuals with schizophrenia. The authors concluded that there was insufficient evidence to evaluate the benefits of this therapy. There were no differences in mental state, behaviour, social skills and hospital admission between treatment groups. Quality of life and satisfaction with treatment were not tested. However, the small sample ($n=52$) from three RCTs limited the strength of the study findings. Falloon, Barbieri, Boggian, and Lamonaca (2007) reviewed four multi-centred pilot studies in Italy using a problem-solving training approach as a core strategy in the rehabilitation of individuals with schizophrenia. They found participants had improved functioning in clinical, social and neurocognitive effects and decreased hospital readmissions. A study by Üçok et al. (2006) evaluated the relationship between social problem-solving abilities, clinical features and cognitive function in 63 outpatients with schizophrenia who were randomised into a six-week problem-solving training group or a control

group. They found no correlation between cognitive measures and social problem-solving; nevertheless, individuals who received training demonstrated sustained attention and cognitive flexibility. However, one study by Beebe et al. (2008) found positive outcomes in adherence to antipsychotic medication. Outpatients with schizophrenia ($n=29$) were randomised into experimental and control groups. The authors evaluated a telephone intervention using a problem-solving approach that was delivered weekly by a nurse for three months. Nurses guided the consumer through the problem-solving process, identifying difficulties, generating solutions and following up effectiveness of the solution. After three months, consumers had significant improvement in medication adherence with their psychiatric medication.

The problem-solving approach was used in the current study to provide a conceptual framework for the peer support program. The approach is used in mental health clinical settings (Bell & D'Zurilla, 2009; Falloon, et al., 2007) and as previous research has shown, can be effective as an additional treatment in the management of individuals with schizophrenia.

5.3 Design Rationale

The current study used a mixed methods design with a combination of quantitative and qualitative approaches (Creswell & Plano Clark, 2007). The advantage of this design is that it provides a better understanding of the whole problem than one approach alone. Creswell and Plano Clark (2007) describe three ways in which quantitative and qualitative data can be mixed; merging the two data sets together (triangulation), connecting each set by having one build on the other (explanatory), or embedding one within the other to provide a supportive role (embedded). In the current study, an explanatory mixed methods design was used. This type of design

allowed the student researcher (hereafter, researcher) to explore further the quantitative results. This design was preferred because each set of data could be collected separately, and only one researcher was required (Creswell & Plano Clark, 2007).

5.3.1 Quantitative

In the current study, a time-series design was used to collect quantitative data using questionnaires. A time-series design requires multiple observations that occur before and after an intervention (England, 2005) and does not have a control group or random allocation (Polit, Beck, & Hungler, 2006). It is a type of quasi-experimental design commonly used in nursing research and includes non-equivalent control group before-and-after designs⁴⁹ and time-series designs (Polit, et al., 2006). Using this type of design, the researcher may observe changes in the data following the introduction of an intervention as a means of measuring the effect of the intervention on the dependent variable (Polgar & Thomas, 2008). This design enabled the researcher to evaluate systematically the effects of the peer support program on consumers' adherence, mental state, side effect profile, satisfaction with medication, and quality of life.

All participants received the same intervention and the effects were measured over multiple time points. This enabled the researcher to compare the rate of medication adherence before and after the intervention. A disadvantage of this design is that an outcome may not be due to the intervention, and could be caused by outside influences (Parahoo, 2006). Using multiple collection points strengthens the ability of

⁴⁹A non-equivalent control group before-and-after design involves an intervention, with two or more groups being observed before and after the intervention. No randomisation occurs; however, there is a comparison or control group (Polit, et al., 2006).

the researcher to attribute the changes to the intervention, indicating an effect has occurred (Polit, et al., 2006).

Other research designs, such as randomised controlled trials (RCTs), could have been used. Generally, RCTs require larger numbers to detect moderate differences, have an extended time frame, can utilise multiple sites and usually require significant funding (Liamputtong, 2010). In the current study, an RCT would have been unsuitable since there was only one PhD student collecting data in a limited time period. The population may have been difficult to recruit and retain, and this may have reduced the final sample size and the feasibility of having a treatment and control group. Additionally, funding was limited, and recruitment was from one clinical setting only.

Numerous adherence intervention studies have targeted individuals with schizophrenia (Bechdorf, et al., 2004; Maneesakorn, et al., 2007; Owen, et al., 2008; Puschner, et al., 2009), however, they have not recruited individuals who are specifically non-adherent with medication. This study was unique because it investigated whether peer support was effective in improving medication adherence in this population.

5.3.2 Qualitative

In the current study, semi-structured interviews were used to collect qualitative data. Peers were interviewed by the researcher, after the follow-up data was collected, regarding their perspectives about the usefulness of the peer support program. This was an important component of the program as it gave peers the opportunity to give their opinions and feedback, and to formally debrief about their experience. Semi-structured interviews allowed the researcher to elicit information using a prepared set

of questions, allowing time for the peer to elaborate and be spontaneous. This type of interview is commonly used in health and social sciences (Liamputtong, 2010).

5.4 Method of Study

In this section the methods used in the study are described. This includes the setting for the study, selection and recruitment of consumers and peers and sample size.

5.4.1 Setting for the study

The study was carried out at a large Area Mental Health Service in Melbourne. Three services participated, the Continuing Care Team (CCT),⁵⁰ Community Care Units (CCU)⁵¹ and the Mobile Support and Treatment Team (MSTT).⁵² These services provide mental health care and rehabilitation for individuals with serious mental illness.

5.4.2 Selection and recruitment of participants

5.4.2.1 Consumer selection criteria

Purposive sampling was used in the study to select consumer participants. The following inclusion and exclusion criteria were used:

Inclusion criteria:

- DSM-IV-TR (American Psychiatric Association, 2000) primary diagnosis of schizophrenia or schizoaffective disorder

⁵⁰Continuing Care Team provides assessment, treatment, continuing care, case management, and consultancy service in an outpatient setting.

⁵¹Community Care Unit provides treatment and rehabilitation in a residential inpatient setting with 24-hour support.

⁵²Mobile Support and Treatment Team provide long-term treatment, rehabilitation and support to consumers with severe mental illness who are living in community settings.

- Aged 18 years and over
- Receiving treatment for their mental disorder at mental health service
- Prescribed oral antipsychotic medications
- Self-reported history of partial or non-adherence (hereafter, non-adherence) to antipsychotic medication. In this study, non-adherence was defined as occurring when consumers had missed taking their prescribed oral antipsychotic medication on five or more occasions in the past four weeks
- Access to a telephone at home
- Ability to communicate conversational English.

Exclusion criteria:

- Cerebrovascular disease or other neurological disease
- Intellectual disability
- In an acute episode of the illness⁵³
- Receiving only depot antipsychotic medication.

5.4.2.2 Consumer recruitment procedure

Participants were not approached directly by the researcher to take part in the study. Instead, case managers were initially approached by the researcher and asked to identify consumers who met the inclusion criteria. The case managers then contacted the consumers and provided them with brief information about the study, including a copy of the Patient Information and Consent Form (Appendix 1).

When consumers expressed provisional interest in participating, and with their consent, the case manager forwarded their telephone contact details to the researcher.

The researcher then contacted the prospective consumer participants by telephone to

⁵³An acute episode is defined as: When a person who has previously been diagnosed with schizophrenia experiences at least two of the following symptoms, for at least one week, in an intense and active way that interferes with his/her ability to carry out the ordinary requirements of life: 'delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour, negative symptoms' (American Psychiatric Association, 2000, p. 298).

explain the study briefly and answer any questions. If they continued to agree to participate, the researcher arranged a time to meet each prospective participant at the Mental Health Service. At the meeting, the purpose, rationale, procedures, confidentiality, and conditions of consent related to the study were discussed. He or she was able to have their questions answered to their satisfaction. The consumer then signed the Consent Form for study participation and was given a copy of it. Each consumer's treating doctor and case manager were informed of the consumer's participation in the study. Consumers were reimbursed financially with \$25 for their time and inconvenience at the completion of the data collection period.

5.4.2.3 Peer selection

Mental health professionals employed at the Mental Health Service were asked by the researcher if they could recommend individuals who met the following criteria to be recruited as peers. The following inclusion and exclusion criteria were used:

Inclusion criteria:

- DSM-IV-TR (American Psychiatric Association, 2000) primary diagnosis of schizophrenia or schizoaffective disorder
- Aged 18 years and over
- Prescribed maintenance doses of oral antipsychotic medication
- Discharged from public outpatient mental health service
- Self-reported high level of medication adherence
- Self-reported attendance at regular appointments with a general practitioner or private psychiatrist
- Access to a telephone at home.

Exclusion criterion:

- An acute episode of the illness.

5.4.2.4 Peer recruitment procedure

Clinical staff at the Mental Health Service initially contacted individuals who met the inclusion criteria and gave them brief information about the study. For those who expressed interest in participating, their telephone contact details were forwarded, with their approval, to the researcher. They were then contacted directly by the researcher and a mutual meeting time was organised to discuss the study. At the meeting, the purpose, rationale, role, procedures, confidentiality, and conditions of consent related to the study were discussed. The researcher encouraged eligible participants to ask for further information or clarification about the study. Individuals then signed the Consent Form (Appendix 2) for study participation and were given their own copy. The peers informed their treating doctor that they would be participating in the study.

Peers were financially reimbursed approximately \$95 each for expenses incurred in their study participation, including transport costs and telephone calls. This amount varied slightly between peers and was dependent on the number and type of telephone calls conducted by each peer.

There are contrasting views about whether research participants should be paid for participation. Endorsement to compensate participants for their time and out-of-pocket expenses is evident in the literature (Fry, et al., 2005; Shields & Pearn, 2007; Festinger, Marlowe, Dugosh, Croft, & Arabia, 2008). In Australia, Fry et al. (2005) surveyed 84 key research organisations and found highly variable practices for reimbursement of participants. They found that ethics committees were largely involved in decision-making by providing advice about reimbursement and overall, there was a lack of written policies and guidelines on this subject. A study by

Festinger et al. (2008) investigated the impact of cash payments for participants in a substance abuse treatment program. They found there was no new drug use or perceived coercion when participants received reimbursement. According to the authors, payment produced higher follow-up rates and participants claimed to use reimbursement payments for essential and non-luxury purchases. In contrast, Russell, Moralejo, and Burgess (2000) interviewed unpaid research volunteers to find out their views on whether they should be paid for undertaking clinical research. The majority (66.2%) disagreed with being paid and felt that they should be recognised in a non-financial way for their time and effort in research.

5.4.3 Consumer and peer sample size

A power analysis for the study was carried out using the statistical software package G Power (Version 3) (Munroe, 2005). To achieve power of .80 using an estimated medium effect size ($F=0.25$), alpha of .05 (2-tailed), and three time-points, it was estimated that 28 consumers would be required.

The peer sample size was six, allowing for up to six consumers per peer for the duration of the study and potential attrition of peers. Peers supported a maximum of two consumers at any given time because the researcher did not want to overwhelm the peers. It was anticipated that the peer support program would take about 12 to 18 months to complete from commencement.

5.5 Procedure

In this section the procedures for the study are described. This includes the background, preparation of the peers, and procedures regarding the peer support program.

5.5.1 Background for the peer support program

The peer support program developed for the study was adapted from Hibbard et al. (2005a), who designed a mentoring partnership program for individuals and their families with traumatic brain injury. This program was selected because it had all the necessary components that could be adapted to the current study. Program evaluation by Hibbard et al. (2002) found that the intervention had a positive effect on participants, who gained increased knowledge of their disorder, enhanced quality of life, and increased ability to cope with depressive symptoms. The program created considerable interest in community-based programs in the US and has also been used in patients with spinal cord injury (Hibbard, et al., 2005b). There were five main components to the mentoring partnership (Hibbard, et al., 2005b): (1) recruitment and training of mentors, (2) recruitment of individuals and families requiring peer support, (3) formation of mentoring partnerships, (4) technical aid, and (5) evaluation of the program. The program involved peers contacting their allocated partners at least once a week by telephone to provide information about traumatic brain injury and resources available, offer emotional support and provide advocacy skills (Hibbard, et al., 2005a). The authors gave permission to the researcher of the current study to adapt the program to suit consumers and peers in a mental health setting.

5.5.2 Preparation of the peer

Following recruitment of the peers, a preparatory session was organised to inform and educate them about delivering the peer support program. The session was conducted by the researcher in a private training room at the Mental Health Service, and lasted approximately three hours. Subsequent one-on-one sessions were conducted when

new peers were recruited. The researcher ensured that education was provided using plain and concise language. It was an interactive session; peers discussed their own experiences and were encouraged to clarify any parts of the program they did not understand and to seek advice on an individual basis at a later stage, if required.

An information booklet, adapted from Hibbard et al. (2005a) and the ADAPT model of problem-solving (D'Zurilla & Nezu, 2007) was used to prepare the peers for the peer support program (Appendix 3). The peers were provided with a copy of the booklet during the preparatory session. The purpose of the booklet was to provide a reference for procedures related to the peer support program and it comprised the following six sections.

- (1) Overview of peer support, including definition and purpose of support, core elements of the program, characteristics and the role of a peer and responsibilities to a consumer.
- (2) Information on the problem-solving approach. A flow chart was included that identified the five steps to problem-solving. Peers were given information on using the problem-solving approach in improving medication taking.
- (3) Information on schizophrenia, including details about symptoms, causes and treatment (including antipsychotic medications and their side effects). Information was also provided on potential early warning signs and symptoms of relapse, and reasons why some individuals may be reluctant to take their antipsychotic medication.
- (4) Information about the communication skills that are required to undertake the peer role, including listening skills, communication enhancers and barriers. In addition, information was given about how to maintain a conversation with

a consumer and provide social support, through listening, sharing experiences, and finding common interests.

(5) Instructions on how to contact the consumer by telephone. Peers were given information on how to make the first call, continue contact after the first call and the final call.

(6) Emergency, crisis and researcher telephone numbers were provided. In addition, peers were informed about the importance of maintaining confidentiality.

5.5.3 Peer support program procedure

5.5.3.1 Peer support to consumer participant

The peers used the problem-solving approach to address identified problems with consumers about medication adherence. The researcher initially contacted the consumer and confirmed times for the peer to establish contact with them. The peer then contacted the consumer at a mutually agreeable time each week, for a period of approximately 20 minutes. They communicated weekly by telephone for a period of eight weeks. This was a flexible arrangement between the consumer and peer. During the weekly telephone call, peers were expected to develop a relationship with the consumer, provide mutual support, and spend a short time discussing the consumer's medication taking. The peers took personal notes of telephone conversations with consumers. This helped the peers to record and recall problems raised, suggested alternatives, decisions made, evaluation of strategies and what needed to be addressed in the next telephone call.

5.5.3.2 Researcher support to peer participants

The peers received a telephone call each week from the researcher. The purpose of the telephone call was to answer any questions that arose, to provide information, discuss any concerns or issues, and to enhance peer retention. The peers or researcher could request a face-to-face meeting with the consumer when a telephone call was considered insufficient to discuss any concerns or issues arising from the program. No peers asked to meet face-to-face during the program; however, a monthly group meeting with the researcher and peers took place at a cafe adjacent to the Mental Health Service. The meeting provided the peers with the opportunity to discuss any issues, give feedback on the program and to socialise with the other peers.

5.6 Data Collection

Two methods of collecting data were used, including questionnaires and peer interviews. Quantitative data were collected from consumer participants at baseline (Week 0), post-intervention (Week 8) and follow-up (Week 14). An evaluation of the program was completed by the consumer and peer participants post-intervention (Week 8) and qualitative interviews with the peers were conducted after the last consumer completed the peer support program.

5.6.1 Instruments

In this section, the instruments used in the study are described. Six instruments were used to gather data from consumers and one instrument and an individual interview collected information from peer participants.

5.6.1.1 Consumer instruments

1) The *demographic questionnaire* contained 21 items that included gender, age, marital status, living circumstances, education, and employment, information about mental health service, illness, medications, recreational substances, side effects related to medication and medication adherence (Appendix 4). All demographic information was obtained at baseline, and information regarding medication adherence was administered at all data collection points. The instrument was adapted from a previous study by Boardman et al. (2008) and allowed the researcher to obtain demographic information about consumers and information about current medication and adherence.

2) The *Brief Psychiatric Rating Scale-E (BPRS-E)* was developed by Overall and Gorham in 1962 (Dingemans, Linszen, Lenior, & Smeets, 1995) and measures the severity of specific psychiatric symptoms. The BPRS-E is an extended version of the original instrument, consisting of 24 items (Appendix 5) and has shown sufficient to good internal reliability (range: 0.64 to 0.76) (Dingemans, et al., 1995). It is based on a clinician's interview with the consumer following observation of the consumer's behaviour. Each item in the scale is rated for each symptom that ranges from '1' (not present) to '7' (extremely severe). A total score is then calculated and this can be compared with the score at other times. In this study, the instrument was administered by the consumers' case managers during their regular appointment time, which coincided with all data collection points. The scale has been used widely in research investigating medication adherence (Kelly, Feldman, Boggs, Gale, & Conley, 2010; Gray, et al., 2006; Maneesakorn, et al., 2007; Aguglia, et al., 2007). It was considered to be an appropriate scale to measure psychiatric symptoms in consumer participants

to determine if any changes occurred in symptom severity between the three data collection points.

3) The *Liverpool University Neuroleptic⁵⁴ Side Effects Rating Scale (LUNSERS)* (Day, Wood, Dewey, & Bentall, 1995) measures the experience of side effects from antipsychotic medications. The instrument was developed by Day et al. (1995) and was tested with a group of 50 consumers with schizophrenia. It contains 51 items rated on a five-point scale from '0' (not at all) to '4' (very much) (Appendix 6). The test-retest reliability was high ($r = 0.811$ $p < 0.001$) (Day, et al., 1995) and the scale has concurrent validity against the scale 'Udvalg for Kliniske Undersøgelser (UKU)', a 48-item scale for neuroleptic side effects. Total scores can range from 0 to 164, and scores above 20 indicate the presence of side effects. In the current study, the instrument was chosen because it has been used successfully in numerous studies to provide a structured framework to assess and manage side effects (Hwang, Jung, Ahn, Kim, & Kim, 2010; Kim & Kim, 2009; McCann, Clark, & Lu, 2009; Lambert, Cock, Alcock, Kelly, & Conley, 2003; Morrison, et al., 2000). It has the advantage of being a self-report measure and takes less time to administer than other side effect scales (Lambert, et al., 2003). The instrument was completed by consumers at each data collection point.

4) The *Satisfaction with Antipsychotic Medication Scale (SWAM)* (Rofail, Gray, & Gournay, 2005) measures consumer satisfaction with antipsychotic medication. The scale contains two sub-scales: treatment acceptability (Part A) and medication insight (Part B) (Appendix 7). Part A contains 15 items and Part B has 9 items, rated on a five-point scale from '1' (strongly disagree) to '5' (strongly agree). Scores in Part A

⁵⁴Neuroleptic or antipsychotic medications are drugs that are used to manage psychosis (Sadock & Sadock, 2007).

range from 15 to 75 and in Part B from 9 to 45. High scores in Part A indicate higher treatment acceptability and thus higher satisfaction levels. Higher scores in Part B indicate a lack of insight into the need for medication, and, therefore, lower satisfaction levels. The instrument was developed by Rofail et al. (2005) and was tested in a sample of 315 consumers with schizophrenia. Good reliability has been demonstrated for each sub-scale with high α coefficient scores (0.92 and 0.84 for sub-scales and 0.91 for total score). No factor analysis was undertaken; however, the authors used the accepted rule of 10 participants for every item on the scale (Rofail, et al., 2005). Two studies (Maneesakorn, et al., 2007; Gray, Bressington, Lathlean, & Mills, 2008) have used the instrument, obtaining positive outcomes in improving medication adherence. In the current study, the instrument was chosen because it gave information on consumers' attitude and satisfaction with their medication, which can influence medication adherence. The instrument was completed by consumers at each data collection point.

5) The *Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q-18)* (Ritsner, Kurs, Gibel, Ratner, & Endicott, 2005) is used to monitor quality of life outcomes in individuals with mood and psychotic disorders. It measures four quality of life domains: physical health, subjective feelings, leisure time, and social relationships, and also has an overall satisfaction with medication domain (Appendix 8). It contains 18 items and each domain is scored on a five-point Likert-type rating scale ranging from '1' (never) to '5' (all the time). Scores range from 18 to 90, with higher scores indicating better enjoyment and satisfaction with specific life domains. The instrument was found to have high reliability and validity with stable test-retest ratings ($r=0.86$, $p<0.001$) in a study of consumers with major psychoses (Ritsner, et al., 2005). The instrument was used in this study to determine whether consumer

participants had any change in their quality of life following participation in the peer support program. It was administered to consumers at each data collection point.

6) The *Consumer Intervention Evaluation Questionnaire (CIEQ)* was used to evaluate the consumers' views about the value of the peer support program (Appendix 9). It was designed by the researcher, using principles from the Lichstein, Riedel, and Grieve (1994) treatment and implementation model and the Hibbard et al. (2005a) mentoring model. The CIEQ contains 14 items, with a five-point scale from '1' (strongly disagree) to '5' (strongly agree). Items were designed to gain information about telephone calls, the peer support program, and medication taking. Examples of items included: 'Each telephone call was long enough;' 'It was easy to talk to peer about my medication.' The instrument has not been used in previous studies. It was reviewed by an expert panel that consisted of a clinical nurse, nurse academic and a consumer representative to assess face and content validity, including the clarity of and adequacy of questions. The instrument was completed by each consumer post-intervention (Week 8).

5.6.1.2 Peer evaluation

1) The *Peer Intervention Evaluation Questionnaire (PIEQ)* evaluated the peers' perspectives about the value of the peer support program (Appendix 10). It was adapted for use by the student researcher from the Lichstein et al. (1994) treatment and implementation model and Hibbard et al. (2005a) mentoring model. The PIEQ contains 14 items, with a five-point scale from '1' (strongly disagree) to '5' (strongly agree). Items were designed to gain information about the telephone calls, peer support program, medication taking, role of the peer and support received. Examples of items included: 'Telephone conversation was a convenient way to deliver the

program;’ ‘I had difficulty contacting consumer by telephone.’ The instrument was completed by the peer at the end of each consumer’s program.

2) *Peer Interview*: Following participation in the peer support program, peers were interviewed by the researcher about their experience. Semi-structured interviews were conducted at a convenient and private setting, with only the peer and researcher present. Interviews were digitally recorded and lasted approximately 30 minutes. Peers were asked a set of 12 questions (Appendix 11). Questions sought information about the peer support program, expectations, preparation, operation, support, and the overall peer experience.

5.7 Study Rigour

In this section the rigour of the study is discussed for the quantitative and qualitative data collection.

5.7.1 Quantitative

To ensure rigour, the findings of the study must be dependable and believable. Rigour in quantitative research can be assessed by critically analysing the trustworthiness of the findings; this includes the reliability and validity of the instruments (Holloway & Wheeler, 2004).

Reliability is the degree to which the instruments evaluated, measured, and predicted outcomes in the study and that the intended use was appropriate to what was being observed and could be replicated under similar conditions (Liamputtong, 2010). In the current study, the reliability of the instruments was considered prior to commencing the study. Four of the instruments (BPRS-E, SWAM, QLES-Q-18 & LUNSERS) had

been used in previous medication adherence studies (Dingemans, et al., 1995; Rofail, et al., 2005; Ritsner, Kurs, Kostizky, Ponizovsky, & Modai, 2002; Day, et al., 1995) and had good reliability. The two other instruments (PIEQ and CIEQ) were reviewed by three experienced clinicians and one consumer representative to test face and content validity, including the clarity and adequacy of questions, prior to the study commencing. Because cognitive deficits may occur in people who have schizophrenia (Tarrrier & Wykes, 2004), the PIEQ and CIEQ questionnaires were designed with simple questions to better suit this population.

Other influences that may impact on the reliability of an instrument include the method of data collection and maintenance of consistent recording procedures (Burns & Grove, 2001; England, 2005). To minimise factors that may have led to errors in measurement and researcher influence, the following data collection procedures were implemented. Each participant was given a copy of the instrument. The researcher slowly read each question out loud and then read the corresponding potential answers. At the same time, the researcher indicated the words she was saying by pointing to them on the participant's copy. This ensured that the participant could hear and read the questions and responses. Questions were asked at a pace determined by participants. Their answers were marked on the researcher's copy of the instrument. Parts of the instrument allowed participants to give verbal comments; the researcher recorded these comments in the spaces provided on the instrument. These responses were then read back to each participant to ensure correctness. The PIEQ and CIEQ were completed independently at the end of the program by the consumer and peer to ensure their answers were not influenced by the researcher. The researcher maintained a written record of all data collection time-points for each participant.

Time-series designs contain potential threats to internal validity (Schneider, Whitehead, Elliott, LoBiondo-Wood, & Haber, 2007). Internal validity refers to the degree to which it is possible to make an inference that the intervention (peer support) has a measurable effect on the dependent variable (consumer outcomes) (Polit, et al., 2006). The biggest threat is that, without a control group, it is not possible to know whether observed changes happened because of the intervention, or simply because of the passage of time. Another threat to internal validity can occur in the recruitment period when selecting participants and possibly creating a biased sample (Schneider, et al., 2007). To prevent this, participants were selected using clearly defined inclusion and exclusion criteria. Case managers were approached by the researcher and asked to identify consumers who met the criteria. This process ensured that consumers were only approached by the case manager if they specifically met all criteria. To further maintain internal and external validity of the study, all consumers continued to receive ongoing case management and had regular appointment times with their treating doctor. Any changes in a consumer's adherence or mental state would be identified at this time, and exclusion from the study would occur. To ensure that there was consistency in the peer support program, all peers were trained in the same manner by the researcher (an experienced Registered Psychiatric Nurse), who maintained weekly contact with them by telephone and monthly face-to-face meetings to provide advice and support. Any changes in a peers' adherence or mental state could be identified at this time, and exclusion from the study could be organised.

External influences can affect the observed results (Polit, et al., 2006). Multiple data collection points in a time-series design minimise the threats to the validity of the observations and, therefore, are considered to enhance reliability (Schneider, et al., 2007; England, 2005). In this study, three time-points were used to measure the

intervention; this is more rigorous than a pre–post test design and allowed the researcher to see if trends were maintained following the intervention (Polit, et al., 2006).

5.7.2 Qualitative

In determining whether qualitative research is rigorous, the researcher must ensure that the inquiry is a meaningful and true portrayal of the person's experience (Holloway & Wheeler, 2004). In determining validity, the purpose of the research must be relevant to the problem and the study must be capable of replication in similar settings. Threats to validity may include the collection of inaccurate or incomplete data, and researchers imposing their own ideas and preconceptions about the experience and not considering alternate reasons for the findings (Holloway & Wheeler, 2004). Finally, it is imperative that the information obtained is reliable, credible, dependable and confirmable (Holloway & Wheeler, 2004).

To ensure that the qualitative interviews were reliable, an interview schedule was developed by the researcher and checked for clarity by two supervisors. Questions were open-ended, in plain language and the researcher allowed time for the peers to complete their answers. Peers were interviewed separately by the researcher at a convenient location in a private setting following completion of the peer support program. Interviews were semi-structured and each peer was asked the same set of questions.

To ensure credibility and therefore, internal validity, information should be obtained from a trustworthy source and be accurate (Holloway & Wheeler, 2004). Participants are more likely to relate the truth if they trust the interviewer (Holloway & Wheeler,

2004). In the current study, the researcher worked with the peers for an extended period of time (14 months). During this period, peers were contacted by the researcher each week and they met as a group once a month. This should have eliminated any reactivity in answering the questions. There was also the potential for bias in the researcher's favour. To decrease this, peers were all interviewed in the same manner; peers seemed to be comfortable during the interview process and answered questions freely. To further ensure credibility, information obtained should be accurate (Holloway & Wheeler, 2004). In the current study interviews were recorded with a digital recorder and transcribed verbatim. The interviews were read and re-read by the researcher multiple times to gain an understanding of the interviews and the peers' experience. To demonstrate dependability and confirmability, an audit trail was undertaken to show how the themes were developed (Figure 5.2).

Data extract	Coded for	Theme
Probably to help other people, show other people that they're not alone. And basically people I knew were doing it as well, I just thought it was a good idea.	Desire to help others	Motivation to participate in study
I don't know. It's hard to earn. And you know I've met one, but like he's wrapped that I done the program. But now he's doing things with his life. But, yeah, just to have, because I'm nobody to them, and, yeah a few open up. It was good.	Developing trust	Rewards and challenges of peer experience

Figure 5.2 *Audit trail of the data extracted from peer interviews*

5.8 Ethical Considerations

Approval to carry out the research was obtained from Melbourne Health Mental Health Research and Ethics Committee, and Victoria University Human Research Ethics Committee (Appendices 12 and 13). There were five main ethical considerations in the study: ensuring informed consent; withdrawal; maintaining

privacy, confidentiality and anonymity; data storage, access and disposal; and minimising the risk of harm.

5.8.1 Informed consent

An important ethical principle for protecting research participants and informing them of risks and benefits of a study is to obtain informed consent (Polit, et al., 2006). Initially the Participant Information and Consent form was provided to participants before obtaining informed consent. The researcher was then guided by the case manager's advice about whether the consumer had the ability to provide informed consent. This was done prior to any contact with the consumer. Once the case manager advised the researcher of prospective participants, they were given a verbal and written explanation of the study. The purpose, procedures, confidentiality, rights as a participant, and the conditions of consent were included. The possible risks and benefits of the study were discussed. Potential participants were given the opportunity to ask questions about matters they did not understand, and have them answered to their satisfaction, prior to consent being obtained. The researcher, in consultation with the case manager, continually assessed the consumers' capacity to give consent and maintain participation throughout the study.

5.8.2 Withdrawal

If consumers decided not to take part in, or to withdraw from, the study, they were assured it would not affect their routine treatment at the Mental Health Service or their relationship with their case manager. In the event of a consumer withdrawing, the researcher would contact the consumer's case manager and inform him or her of the withdrawal.

The peers were informed fully about the study and could withdraw at any time, without penalty. In the event of a peer withdrawing from the study during the program, the consumer was advised that another peer could be appointed or he/she was free to also withdraw from the program. Six consumers and one peer withdrew from the study.

5.8.3 Privacy, confidentiality, and anonymity

Participant privacy, confidentiality, and anonymity were maintained. In order to identify and process individual data, names were replaced with unique identification numbers in the data file. Study findings were only reported as grouped data in this thesis and in professional conference presentations and scientific papers. Only the researcher and peers had access to the names and telephone numbers of the consumers. Any personal notes taken by the peers for purposes of record and recall of conversation with consumers were not identifiable. The researcher asked the consumer to destroy these notes after contact with each consumer was finished.

To ensure anonymity in the digital recording of peer interviews, names were withheld by the researcher. Recordings were sent for transcription to a reputable transcription company. No identifiable information was disclosed on the transcriptions, and each peer was given a unique identification number. Recordings from the digital recorder and any information stored on the password protected computer following transcription were deleted.

5.8.4 Data storage, access and disposal

Consent forms and a hard copy of the data were stored in a locked filing cabinet, in a locked office, within the School of Nursing and Midwifery, Victoria University. All

electronic data files were password protected. Only the researcher, Principal and Associate Supervisors had access to files. All data files, including questionnaires and consent forms, will be retained for five years. After this time questionnaires will be shredded and databases deleted from electronic files.

5.8.5 Minimise risk

5.8.5.1 Consumers

There were potential minor psychological risks (e.g., mild anxiety) for consumers who may, at times, have felt uncomfortable discussing their medication adherence with a peer. Strategies were introduced to minimise risks. Participants were informed fully about the design of the study. They were advised that participation was voluntary and could choose to withdraw at any time. Consumers continued to receive their standard medical and psychosocial treatment and outpatient appointments at the Mental Health Service. They were assessed for acute episodes at their regular appointments with their case managers.

In the event of a consumer participant showing symptoms of relapse, or presenting in an acute episode of schizophrenia, as identified by the peer or the researcher during the intervention or data collection, the researcher would immediately contact the Mental Health Service. Two consumers had a relapse of their illness during the study.

5.8.5.2 Peers

There were potential minor psychological risks for peers (e.g., mild anxiety) who may have experienced some psychological discomfort from study participation. Strategies were introduced to minimise risks. Peer participants were encouraged to attend their

regular scheduled appointments with their general practitioner or private psychiatrist. They received a telephone call each week from the researcher throughout the study period. They discussed any issues or discomfort arising from their involvement in the program and the researcher provided debriefing and ongoing support. If the researcher felt that extra support was needed, the researcher would then meet with the peer in person to discuss their concerns.

In the event of a peer becoming anxious or stressed as a result of involvement in the study, the researcher, as an experienced Registered Psychiatric Nurse with extensive counselling skills, would meet with the peer to provide further support at the Mental Health Service, or a mutually convenient location. At this meeting, the researcher would offer basic emotional support such as listening and empathising, allow the peer to decide whether he or she wanted to continue participation, without any coercion. If necessary, and with the peer's approval, the researcher would refer him or her to the most appropriate free health service or to their treating clinician.

In the event of the peer showing signs of relapse or presenting in an acute episode of schizophrenia, the researcher would immediately contact his or her treating doctor and organise either an appointment or referral to the nearest Mental Health Service. If peers believed a consumer was unwell and in need of medical attention, they were instructed to contact the researcher immediately, who would then notify the consumer's treating team. The peer would then be telephoned by the researcher to explain what processes were provided to the consumer, and provide support and debriefing to the peer.

In the event of any problems arising in the relationship between the researcher and peer, the researcher would organise a meeting with the peer to discuss what the issues

were and, if possible, resolve them. If it was not possible to resolve the issues, the peer was free to remain in or withdraw from the study. If necessary, counselling and support would be made available to the peer, in consultation with his or her doctor. The researcher was also able to notify the Principal Supervisor, who would liaise directly with the peer, if necessary. This did not occur during the study.

5.9 Data Analysis

5.9.1 Quantitative analysis

Data were analysed using SPSS (SPSS Version 18 Inc., Chicago, IL, 2009). Data screening was conducted prior to statistical analysis. The raw data were manually checked to ensure no errors. To ensure accuracy, 20% of the data were randomly selected for re-entry by another researcher and checked for inter-rater reliability. Descriptive statistics were used to assess for skewness and kurtosis. Stem-and-leaf plots were used to identify outliers.

Descriptive statistics were used to summarise demographic data, including frequencies, means, medians and standard deviations. Fischer's exact test compared completers and non-completers. The Friedman non-parametric test was used to measure outcomes for the three time-points. This test is used with the same sample of subjects when measuring differences in the median for three or more time-points (Pallant, 2001). If significant ($p < 0.05$) results were found by the Friedman's Test, then the Wilcoxon Signed Ranked Test was conducted for pair-wise comparisons between Baseline and Week 8; Week 8 and Week 14; and Baseline and Week 14. The Wilcoxon Signed Rank Test is the non-parametric alternative to using the t -test, and converts scores to ranks and then compares these ranks at the different time-points. If

the significance level [Asymp. Sig. (2-tailed)] is equal to or less than .05, then there is a statistically significant difference between the two scores (Pallant, 2001).

In the data analysis of the CIEQ and PIEQ evaluation questionnaires, the data is reported as numbers and percentages. The responses 'agree' and 'strongly agree' were collapsed, as were the responses 'disagree' and 'strongly disagree', because of the low number of returned questionnaires.

5.9.2 Qualitative analysis

Braun and Clarke's (2006) thematic analysis framework was used to analyse the qualitative data. Thematic analysis is a method used to identify, analyse and report themes across qualitative data. This method of analysis was used because it provided a rich and comprehensive description of the data (Graneheim & Lundman, 2004). It gave the researcher more flexibility than other types of qualitative analysis, it required minimal organisation of data, yet captured important themes in rich detail (Braun & Clarke, 2006). When undertaking the thematic analysis, the researcher identifies themes in the data, analyses these themes into subthemes and codes, and finally provides a detailed written report (Graneheim & Lundman, 2004).

Following the peer interviews, data were transcribed verbatim. There were six phases in the analytic process. In the first phase, the researcher became familiar with the data by reading and re-reading the transcribed interviews and identifying any early ideas. The second phase involved systematically identifying interesting features in the data, and from this, codes were generated. Once all codes were collated, the third phase began by searching for broader themes. In this process, codes were grouped into themes and subthemes, based on common relationships. Themes were then reviewed

and refined in the fourth phase to ensure that they suited the related codes. Once there was a defined thematic map, the fifth phase was to ensure that the themes were clear and named appropriately. The final phase was the production and writing of the thematic analysis (Braun & Clarke, 2006). See Table 7.12 for an example of codes from data.

5.10 Summary

In this study the effectiveness of a problem-solving based peer support intervention program for enhancing oral antipsychotic medication adherence in consumers with schizophrenia was evaluated. A mixed method design was used that incorporated quantitative and qualitative methods. A time-series design with three data collection measured adherence with antipsychotic medication, quality of life, satisfaction with medication, side effect profile and mental status in consumers with schizophrenia. Semi-structured interviews evaluated peers' perspectives of the program following completion of the research. Ethical matters were strictly adhered to throughout the study.

CHAPTER SIX

PEER SUPPORT PROGRAM OUTCOMES

6.1 Introduction

The overall aim of the study was to assess if non-adherent consumers with schizophrenia have improved adherence to their antipsychotic medication after participation in a problem-solving based peer support program. Secondary aims evaluated whether the peer support program improved consumers' mental state, side effect profile, attitude towards and satisfaction with antipsychotic medication, and quality of life following participation; and to evaluate consumers' and peers' perspectives about the usefulness of the peer support program.

In this chapter the quantitative results of the study are presented. Firstly, recruitment of consumers is described. This included information about consumers who did not consent to the study and consumers who consented but did not complete the peer support program. Secondly, the socio-demographic and treatment-related characteristics of the consumers are presented. Thirdly, outcomes from the peer support program are described. Finally, the evaluation of the peer support program by consumers and peers is described.

6.2 Recruitment of Consumers

A total of 58 individuals with schizophrenia were eligible to take part in the study; 28 agreed to participate (Figure 6.1). Individuals ($n=30$) expressed a range of reasons for declining to participate, including pending discharge ($n=5$, 16.7%), difficulty initiating telephone contact ($n=4$, 13.3%), too busy ($n=2$, 6.7%), unwell ($n=2$, 6.7%),

engaged in full-time employment ($n=1$, 3.3%), and pending birth ($n=1$, 3.3%). Fifteen (50%) gave no reason for non-participation.

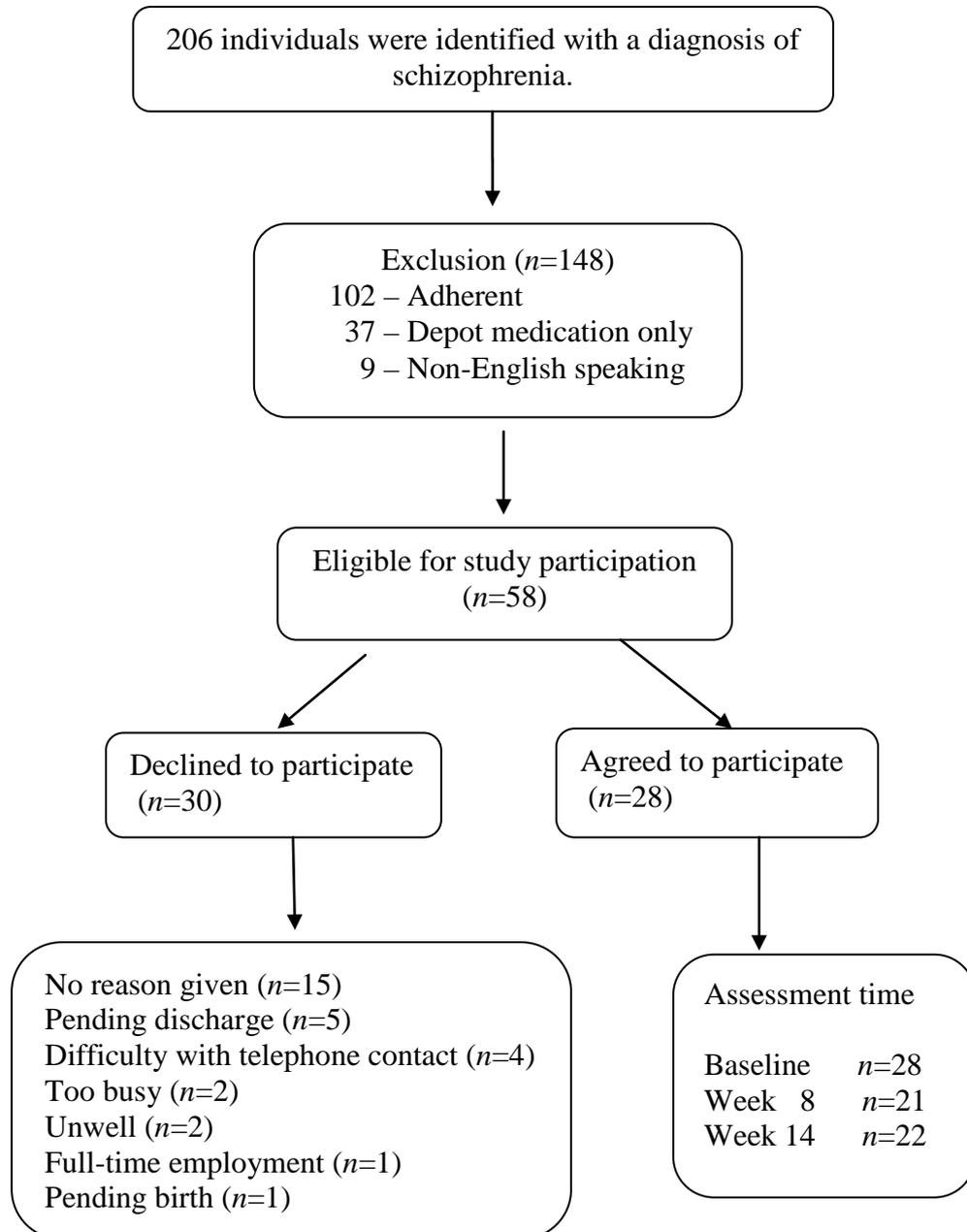


Figure 6.1 *Flow of consumers in the study*

Of the 28 consumers who agreed to participate, six withdrew prior to Week 8 of the study. Various reasons were offered for withdrawal: two did not want to continue the

intervention claiming they were too busy; two had a relapse of their mental illness resulting in hospital admission; one recommenced depot only medication; and one could not be contacted by telephone. Of the remaining consumers, 22 (78.5%) completed the intervention. One consumer was unable to complete the questionnaire in Week 8 because of illness; however, he completed data collection at Week 14.

6.3 Socio-demographic Characteristics

Socio-demographic information for all consumers is shown in Table 6.1. At baseline, the majority were male ($n=19$, 67.9%) and single ($n=23$, 82.1%). The mean age was 35.1 years (range 21–53 years, $SD=7.8$). Most had attended secondary education ($n=20$, 71.4%), had no paid employment ($n=20$, 85.7%), and resided with others ($n=23$, 82%). Most used recreational substances⁵⁵ ($n=23$, 82.1%), including nicotine ($n=21$, 75%) and alcohol ($n=13$, 46.4%). Approximately one-third of consumers ($n=9$, 32.2%) used illicit substances.

Socio-demographic characteristics of those who completed and did not complete the study were compared using the Fisher Exact Test (Table 6.1). No statistically significant differences were found between completers and non-completers for any demographic or recreational substance use measures.

Consumers were asked a series of questions about their illness, satisfaction and contact with mental health services. The mean duration of illness (schizophrenia) was 12.1 years, ranging from 2 to 30 years. The majority received treatment from a Continuing Care Team (CCT) ($n=24$, 85.7%) and 60.7% ($n=17$) had face-to-face contact with a case manager or medical staff on a fortnightly-to-monthly basis (Table

⁵⁵Recreational substances are used for recreation purposes and are usually addictive and might be illicit in nature.

6.2). Most consumers ($n=22$, 78.6%) were satisfied with the contact they received from the mental health service.

Table 6.1 Comparison of socio-demographic characteristics and recreational substance use between completers and non-completers at baseline.

Demographic Characteristics	Baseline Total cohort ($n=28$) n (%)	Completers ¹ ($n=22$) n (%)	Non-Completers ² ($n=6$) n (%)	p value ³
Gender				
Male	19 (67.9)	13 (59.1)	6 (100.0)	.136
Female	9 (32.1)	9 (49.9)	0	
Age (years)				
18–35	14 (50.0)	11 (50.0)	3 (50.0)	1.000
36–53	14 (50.0)	11 (50.0)	3 (50.0)	
Marital status				
Single	23 (82.1)	17 (77.3)	6 (100.0)	.553
Other	5 (17.9)	5 (22.7)	0	
Living circumstances				
Living with others ⁴	23 (82.1)	18 (81.8)	5 (83.3)	1.000
Living alone	5 (17.9)	4 (18.2)	1 (16.6)	
Highest Education				
Secondary	20 (71.4)	14 (63.6)	6 (100.0)	.141
Further	8 (28.6)	8 (36.4)	0	
Employment				
None	24 (85.7)	20 (90.9)	4 (66.6)	.191
Paid	4 (14.3)	2 (9.1)	2 (33.3)	
Recreational substance use ⁵				
Yes	23 (82.1)	19 (86.2)	4 (66.6)	.285
No	5 (17.9)	3 (13.6)	2 (33.3)	
Type of recreational substances				
Nicotine	21 (75.0)	17 (77.3)	4 (66.6)	.622
Alcohol	13 (46.4)	11 (50.0)	2 (33.3)	
Illicit substances ⁶	4 (14.3)	2 (9.1)	2 (33.3)	.191

Legend

¹Completers are consumers who completed the intervention

²Non-completers are consumers who did not complete the intervention.

³Fischer's Exact Test was used to test statistical significance ($p<0.5$) for differences between completers and non-completers.

⁴Living with others included parents, children, friends, siblings or sharing with peers.

⁵Consumers may have used one or a combination of recreational substances.

⁶Illicit substances included marijuana ($n=4$), heroin ($n=2$), amphetamines ($n=1$), cocaine ($n=1$) and ecstasy ($n=1$).

Table 6.2 *Consumer contact and satisfaction with mental health service at baseline (n=28).*

Variable	N	%
Mental Health Service (MHS)¹		
CCT	24	85.7
CCU	3	10.7
MSTT	1	3.6
Contact with MHS		
Fortnightly-to-monthly	17	60.7
Daily-to-weekly	11	39.2
Satisfaction with MHS contact		
Satisfied	22	78.6
Would like more contact	4	14.3
Would like less contact	2	7.1

Legend

¹Continuing Care Team (CCT), Community Care Unit (CCU), Mobile Support and Treatment Team (MSTT) are separate treatment services within the mental health service.

6.4 Treatment Characteristics

Consumers reported taking the following prescribed psychotropic medications⁵⁶ at baseline: antipsychotics, antidepressants, mood stabilisers, and anxiolytics (Table 6.3). The mean number of medications consumed per day was 2.7 (range 1–8). The majority took their medication in the morning ($n=20$, 71.4%) and at bedtime ($n=20$, 71.4%).

Antipsychotic medications were separated into two groups: typical and atypical. All consumers were prescribed an oral antipsychotic medication (Table 6.3). The majority ($n=27$, 96.4%) were prescribed an oral atypical antipsychotic as their primary medication: one (3.6%) was prescribed an oral typical antipsychotic and two (7.1%) were prescribed both. Six (21.5%) were prescribed an oral antipsychotic combined with a depot antipsychotic medication. Olanzapine was the most frequently prescribed oral atypical antipsychotic medication ($n=13$, 46.4%), followed by Clozapine ($n=8$, 28.6%). Over one-third were prescribed an antidepressant ($n=11$, 39.3%) and four

⁵⁶Psychotropic medications are used to treat a range of mental illnesses and affect mood, affect and behaviour of individuals (Usher, et al., 2009).

(14.3%) were prescribed non-psychiatric medication for reflux and hypertension, or methadone for heroin addiction. Some also reported using self-prescribed over-the-counter medication ($n=9$, 32.1%): including vitamins, fish oil, paracetamol, and aspirin.

Table 6.3 Medication characteristics for consumers at baseline ($N=28$).

	<i>N</i>	%
Types of medication¹		
<i>Atypical antipsychotic</i>	27	96.4
Olanzapine	13	46.4
Clozapine	8	28.6
Risperidone consta depot	5	17.9
Paliperidone	4	14.3
Ziprasidone	2	7.1
Risperidone	2	7.1
Aripiprazole	1	3.6
<i>Typical antipsychotic</i>	3	10.8
Chlorpromazine	1	3.6
Pimozide	1	3.6
Flupenthixol depot	1	3.6
<i>Other psychotropic medication</i>		
Mood stabilisers	8	28.5
SSRI ² antidepressants	11	39.3
Anxiolytics	2	7.1
<i>Other medication</i>		
Over-the-counter medication	9	32.1
Non-psychiatric prescribed medication	4	14.3
Time of medication taking³		
Morning	20	71.4
Bedtime	20	71.4
Evening meal	8	28.6
Lunch	2	7.1

Legend

¹Consumers used one or a combination of medications.

²SSRI: selective serotonin reuptake inhibitors.

³This included all medications consumed by consumers.

6.5 Peer Support Program Outcomes

The following section describes the consumer outcomes from participating in the peer support program. These include adherence, mental state, side effect profile, satisfaction with antipsychotic medication, and quality of life characteristics.

6.5.1 Adherence

In this study, non-adherence was defined as when a consumer had missed taking prescribed oral antipsychotic medication on five or more occasions in the past four weeks. Data for missed medication was skewed: outliers were present at baseline and Week 14. At baseline, one consumer missed 21 doses. Another consumer missed 30 doses in the previous four weeks. One consumer missed 11 doses in Week 14. The study inclusion criteria specifically targeted individuals who were non-adherent; therefore, these data were retained.

At baseline, consumers self-reported missing a mean of 7.8 doses of their prescribed antipsychotic medication in the previous four weeks (Table 6.4), ranging from five to 30 doses. The rate of missed medication reported by consumers declined to a mean of 1.3 doses at Week 8, and a mean of 1.1 doses by Week 14. Over the three study time-points there was a statistically significant reduction in the rate of missed medication as indicated by the Friedman Test ($\chi^2(2)=31.59, p<.001$). Wilcoxon Signed Rank Tests were conducted for pair-wise comparisons between each time-point. A statistically significant reduction in missed medication was found between baseline and Week 8 ($Z = -4.03, p<.001$) and baseline and Week 14 ($Z = -3.97, p<.001$). However, there was no statistically significant reduction in the rate of missed antipsychotic medication between Weeks 8 and 14 ($Z = -.944, p=.345$).

Consumers were asked why they missed their antipsychotic medication (Table 6.5). The main reason offered for non-adherence was forgetfulness (baseline, $n=23, 82.1\%$; Week 8, $n=9, 75\%$; Week 14, $n =6, 85.7\%$). Six consumers (21.4%) reported at baseline that they were feeling 'okay' and did not need to take their medication. Only

one reported that side effects of the medication caused doses to be missed in Week 8 and Week 14.

Table 6.4 Rates of medication adherence at all time-points.

	<i>n</i>	M	SD	Min	Max	<i>p</i> ⁴		
						B-W8	B-W14	W8-W14
B ¹	28	7.8	5.5	5	30			
W8 ²	21	1.3	1.4	0	4	<0.001		.345
W14 ³	22	1.1	2.5	0	11		<0.001	

Legend

¹B=Baseline.

²W8=Week 8.

³W14=Week 14.

⁴*p* value is derived from Wilcoxon Signed Rank Test and pair-wise comparisons between B-W8; B-W14; W8-W14.

Table 6.5 Reasons for non-adherence at each time-point.

Reasons ⁵	B ¹	% ⁴	W8 ²	%	W14 ³	%
	(<i>n</i> =28)		(<i>n</i> =12)		(<i>n</i> =7)	
Forgetfulness	23	82.1	9	75.0	6	85.7
Feeling okay\don't need them	6	21.4	0	0	0	0
Not doing me any good	2	7.1	0	0	0	0
No medication left	0	0	2	16.7	0	0
I decreased dose	0	0	2	16.7	1	14.0
Side effects	0	0	1	8.3	1	14.0
Not at home to take	0	0	1	8.3	0	0
Made me feel worse	1	3.6	0	0	0	0
Used illicit substances instead	1	3.6	0	0	0	0
Didn't want to go to bed	1	3.6	0	0	0	0

Legend

¹B=Baseline.

²W8=Week 8.

³W14=Week 14.

⁴Percentage calculated on the number of consumers who missed medication at each time-point.

⁵Reasons for non-adherence are not exclusive. Consumers could report more than one reason for non-adherence.

6.5.2 Mental state

The Brief Psychiatric Rating Scale-Expanded BPRS-E⁵⁷ (hereafter, BPRS) was used to measure consumers' mental state at each time-point. BPRS scores can range from 24 (having no symptoms present) to 168 (extremely severe symptoms of mental illness).

⁵⁷See Chapter 5.6.1.1

At baseline, consumers' total mean BPRS was 36.0 and this indicated very mild symptoms of mental illness (Table 6.6). The BPRS mean score declined at Week 8 (32.0), and remained stable at Week 14 (32.2). There was a statistically significant difference in the total mean BPRS score across the three study time-points, as indicated by the Friedman Test ($\chi^2(2)=11.73, p=.003$). Wilcoxon Signed Rank Tests were conducted for pair-wise comparisons between each study time-point. Consumers' mental state improved following involvement in the peer support program, with statistically significant reductions in total mean scores between baseline and Week 8 ($Z = -2.93, p=.003$) and baseline and Week 14 ($Z = -2.68, p=.007$). No statistical difference was found between Week 8 and Week 14 ($Z = -.665, p=.506$).

BPRS scores were further categorised into positive, negative and depressive symptoms (Table 6.6).⁵⁸ At baseline, consumers' positive symptom mean score was 10.3 and this decreased slightly to 9.3 (mean) in Week 8 and to 9.2 (mean) in Week 14. The Friedman Test indicated that there was no statistically significant reduction in positive symptoms ($\chi^2(2)=4.51, p=.105$) across the three study time-points. Wilcoxon Signed Rank Tests were not conducted for pair-wise comparisons between each study time-point because no statistical significance was found with the Friedman Test.

At baseline, consumers' negative symptom mean score was 8.4 and this decreased to 6.9 (mean) in Week 8 and then slightly increased to 7.2 (mean) in Week 14. The Friedman Test indicated that there was a statistically significant difference in negative symptoms ($\chi^2(2)=7.18, p=.028$) across the three time-points. Wilcoxon Signed Rank Tests were conducted for pair-wise comparisons of negative symptoms between each

⁵⁸See Chapter 2.4 for definition of positive, negative and depressive symptoms.

time-point. A statistically significant reduction in negative symptoms was found between baseline and Week 8 ($Z = -2.8, p=.005$) and baseline and Week 14 ($Z = -2.48, p=.013$), but not between Week 8 and Week 14 ($Z=.499, p=.618$).

Consumers had a mean score of 10.4 for depressive symptoms at baseline and this decreased only slightly to 9.3 (mean) in Week 8 and remained stable at 9.3 (mean) in Week 14 (Table 6.8). The Friedman Test indicated there were no statistically significant reduction in depressive symptoms ($\chi^2(2)=1.97, p=.373$) across the three study time-points. Wilcoxon Signed Rank Tests were not conducted for pair-wise comparisons between each study time-point because no statistical significance was found with the Friedman Test.

Table 6.6 *Psychopathology⁴ symptoms, including positive, negative and depressive symptoms, measured over three time-points.*

	N	Total Score		Positive Symptoms		Negative Symptoms		Depressive Symptoms	
		M	SD	M	SD	M	SD	M	SD
B¹	28	36.0	8.8	10.3	4.0	8.4	2.5	10.4	3.8
W8²	21	32.0	7.7	9.3	3.8	6.9	2.1	9.3	3.2
W14³	22	32.2	6.8	9.2	3.3	7.2	2.4	9.3	2.3

Legend

¹B=Baseline.

²W8=Week 8.

³W14=Week 14.

⁴Total scores range from 24 (not present) to 168 (extremely severe); positive symptoms (7 to 42); negative symptoms (5 to 35); depressive symptoms (6 to 42).

6.5.3 Side effect profile

Unpleasant side effects of antipsychotic medication may affect adherence to medication. At baseline, approximately half of the consumers ($n=15, 53.6\%$) self-reported annoying side effects from their medication.

The Liverpool University Neuroleptic Side Effects Rating Scale (LUNSER) scale⁵⁹ was used to measure the rate of side effects from medication at each study time-point. A LUNSER score above 20 indicates a high level of side effects (Day, et al., 1995). At each time-point the mean LUNSER score exceeded 20, indicating that consumers experienced a high level of side effects (Table 6.7). At baseline, consumers' mean LUNSER score was 39.1, ranging from 12 to 97. At Week 8, the mean score increased to 43.8, indicating a slight increase in side effects following the intervention. By Week 14, self-reported side effects decreased to a mean score of 39.7. However, there were no statistically significant differences in LUNSER scores across the three study time-points as indicated by the Friedman Test ($\chi^2(2)=.914$, $p=.633$). Wilcoxon Signed Rank Tests were not conducted for pair-wise comparisons between each study time-point because no statistical significance was found with the Friedman Test.

Table 6.7 Overall side effect profiles at each time-point.

	<i>n</i>	<i>M</i> ⁴	<i>SD</i>	<i>Min</i>	<i>Max</i>
B ¹	28	39.1	19.5	12	97
W8 ²	21	43.8	22.2	9	88
W14 ³	22	39.7	18.9	5	82

Legend

¹B=Baseline.

²W8=Week 8.

³W14=Week 14.

⁴LUNSER scores range from 0 to 164 with scores >20 indicative of high side effects.

6.5.4 Attitudes towards and satisfaction with medication

The Satisfaction with Antipsychotic Medication Scale (SWAM) scale⁶⁰ was used to measure consumers' attitude and satisfaction with their antipsychotic medication. The scale is divided into two sections: treatment acceptability and medication insight.

⁵⁹ See Chapter 5.6.1.1

⁶⁰ See Chapter 5.6.1.1.

6.5.4.1 Treatment acceptability

Consumers were asked at each study time-point about acceptability of treatment for their mental illness and how this related to their antipsychotic medication. SWAM scores for treatment acceptability can range from 15 to 75, with higher mean scores indicating greater treatment acceptability. Rofail et al. (2005) suggest this would indicate high satisfaction with or positive orientation towards antipsychotic medication.

Consumers scored in the 'mid-range' which indicated that they showed a moderate acceptance of treatment. At baseline, the mean score was 56.9 and following the intervention the mean score decreased to 55.4 at Week 8 and increased to 57.8 by Week 14 (Table 6.8). This indicated that consumers had slightly higher treatment acceptability at Week 14 compared with previous time-points. However, there were no statistically significant differences in treatment acceptability during the study period, as indicated by the Friedman Test ($\chi^2(2)=2.51, p=.285$). Wilcoxon Signed Rank Tests were not conducted for pair-wise comparisons between each time-point because no statistical significance was found with the Friedman Test.

6.5.4.2 Medication insight

Consumers were asked about their medication insight at each study time-point. This included knowledge and understanding of antipsychotic medication and how this affected them. Scores for medication insight can range from 9 to 45; higher mean scores indicate lack of medication insight. Rofail et al. (2005) suggest that a lack of medication insight may lead to decreased satisfaction with antipsychotic medication.

Consumers scored in the ‘mid-range’ which suggested that they had moderate insight towards their medication. At baseline, the mean score was 18.4 and this increased only slightly to 18.8 at Week 8 and then decreased to 18.2 by Week 14 (Table 6.8). The Friedman Test ($\chi^2(2)=1.79, p=.409$) indicated that medication insight did not alter significantly during the study period. Wilcoxon Signed Rank Tests were not conducted for pair-wise comparisons between each study time-point because no statistical significance was found with the Friedman Test. This indicated that the intervention had no effect on consumers’ medication insight.

Table 6.8 Comparison of satisfaction with antipsychotic medication subscales at each time-point.

	<i>n</i>	Treatment acceptability ⁴		Medication insight ⁵	
		M	SD	M	SD
B¹	28	56.9	5.2	18.4	4.1
W8²	21	55.4	10.4	18.8	5.6
W14³	22	57.8	8.1	18.2	4.3

Legend:

¹B=Baseline.

²W8=Week 8.

³W14=Week 14.

⁴Treatment acceptability scores can range from 15–75.

⁵Medication insight scores can range from 9–45.

6.5.5 Quality of life

The Quality of Life Enjoyment and Satisfaction Questionnaire QLES-Q⁶¹ was used to measure quality of life in the previous week at study each study time-point. Five domains were assessed including physical health, subjective feelings, leisure time, social relationships, and satisfaction with medication.

Consumers’ quality of life scores for each domain are presented in Table 6.9. At baseline, the mean physical health score was 12.9 and this decreased slightly to 11.9 at Week 8 and returned to 12.9 by Week 14. These scores indicate that consumers

⁶¹See Chapter 5.6.1.1

'sometimes' felt in good physical health in the previous week. The Friedman Test indicated that there was no statistically significant difference in physical health across the three study time-points ($\chi^2(2)=.720, p=.698$).

Subjective feelings increased over the three study time-points. At baseline the mean score was 17.7 and this increased to 18.1 at Week 8 and 18.6 in Week 14. The Friedman Test indicated that there was a statistically significant difference, with subjective feelings increasing over the three study time-points ($\chi^2(2)=6.54, p=.04$). Wilcoxon Signed Rank Tests were conducted for pair-wise comparisons. No statistically significant differences were found between each of the study time-points; baseline and Week 8 ($Z = -.810, p=.418$), baseline and Week 14 ($Z = -1.333, p=.185$), and Week 8 and Week 14 ($Z = -1.286, p=.199$).

The quality of consumers' leisure time activities remained stable over the study three time-points. At baseline the mean score was 10.1 and this increased slightly to 10.7 in Week 8 and 10.5 by Week 14. These scores indicate that consumers only 'sometimes' enjoyed leisure time activities. The Friedman Test indicated that there was no statistically significant difference in this domain over the three study time-points ($\chi^2(2)=184, p=.912$).

Social relationship domain scores increased over the three study time-points. At baseline the mean score was 15.6 and this increased to 16.6 at Week 8 and further increased to 17.3 in Week 14. Although the scores increased, they still indicated that consumers only 'sometimes' enjoyed their social relationships. The Friedman Test indicated that there was no statistically significant difference in social relationships across the three study time-points ($\chi^2(2)=2.622, p=.270$).

Consumers were asked how satisfied they were with their antipsychotic medication in the previous week. At baseline the mean score was 3.9 and this increased to 4.1 at Week 8 and 4.2 in Week 14. These scores remained in the ‘satisfied most of the time’ category (Table 6.9). The Friedman Test indicated that there was no statistically significant change in level of satisfaction over the three study time-points ($\chi^2(2)=1.78$, $p=.410$).

Table 6.9 Comparison of QLES domains and satisfaction with antipsychotic medication over three time-points

	n	Physical health		Subjective feelings		Leisure time		Social relationships		Medication satisfaction	
		M	SD	M	SD	M	SD	M	SD	M	SD
B¹	28	12.9	3.0	17.7	3.9	10.1	2.7	15.6	3.8	3.9	0.8
W8²	21	11.9	3.5	18.1	3.2	10.7	3.3	16.6	4.3	4.1	0.9
W14³	22	12.9	3.0	18.6	3.6	10.5	2.5	17.3	3.7	4.2	0.9

Legend:

¹B=Baseline.

²W8=Week.

³W14=Week 14.

Higher mean scores indicate better enjoyment and satisfaction with each specific life domain.

Physical health: never (4), rarely (8), sometimes (12), most of the time (16), all of the time (20).

Subjective feelings/social relationships: never (5), rarely (10), sometimes (15), most of the time (20), all of the time (25).

Leisure time: never (3), rarely (6), sometimes (9) most of the time (12), all of the time (15).

Medication satisfaction: never (1), rarely, (2), sometimes (3), most of the time (4), all of the time (5).

6.6 Consumer Experience of Peer Support

This section describes the consumers’ perspectives regarding the peer support program. Consumers completed an evaluation questionnaire following participation in the peer support program in Week 8 ($n=22$). Questions related to feedback in three areas: telephone delivery, opinions about the peer support program and medication taking.

The majority of consumers ($n=19$, 86.4%) felt that telephone delivery was a convenient way to deliver the peer support program, the duration of telephone calls ($n=19$, 86.4%) was long enough and receiving calls once a week ($n=18$, 81.9%) was adequate (Table 6.10).

Table 6.10 Consumers' opinion about the peer support program (n=22).

	Disagree ¹		Neutral		Agree	
	n	%	n	%	n	%
Telephone delivery						
Each call was long enough	2	9.0	1	4.5	19	86.4
Space between calls long enough	1	4.5	3	13.6	18	81.9
Telephone conversation was a convenient way to deliver the program	1	4.5	2	9.1	19	86.4
Opinions about program						
Length of program was about right	3	13.6	2	9.1	17	77.3
Satisfied with content of program	1	4.5	2	9.1	19	86.4
Program made a positive difference to my life	3	13.6	3	13.6	16	72.8
Program was supportive	1	4.5	0	0.0	21	95.5
Would like to continue with a peer support program in the future	3	13.6	8	36.4	11	50.0
Medication taking						
Program provided helpful information on improving medication taking	5	22.7	4	18.2	13	59.1
Program did not help improve my medication taking	9	40.9	9	40.9	4	18.2
Program helped me resolve problems with my medication taking	2	9.1	9	40.9	11	50.0
Program made a positive difference to how I felt about taking my medication	5	22.7	4	18.2	13	59.1
It was easy to talk to the peer about my medication	1	4.5	2	9.1	19	86.4
Program has helped me talk about my medication issues with my case manager	4	18.2	7	31.8	11	50.0

Legend:

¹Scales were collapsed into three categories: 'strongly disagree' and 'disagree' were combined into the 'disagree' category. 'Strongly agree' and 'agree' were combined into the 'agree' category.

Feedback about the program was mostly positive. Consumers (n=21, 95.5%) found the peer support program supportive and felt it made a positive difference to their lives (n=15, 72.8%). The majority (n=19, 86.4%) were satisfied with the content and length (n=17, 77.3%); and half (n=11, 50%) reported a desire to continue with a peer support program in the future.

Overall, the majority of consumers (n=19, 86.4%) found it easy to talk to a peer about their medication taking; and half (50.0%) found this helped them to discuss medication concerns with their case manager. Over half of the consumers found the program provided helpful information on improving medication taking (n=13, 59.1%), made a positive difference to how they felt about taking their medication

($n=13$, 59.1%), and assisted in resolving problems with their medication taking ($n=11$, 50%). Nine consumers (40.9%) reported that the program improved their adherence with their medication regime, only four felt it had no effect.

6.7 Peer Experience of Delivering Peer Support

This section describes the peers' perspectives on the peer support program. Peers completed an evaluation questionnaire after each consumer concluded the peer support program in Week 8. Questions related to the following: telephone delivery, opinions about the peer support program and medication taking (Table 6.11). Only 12 questionnaires were returned to the researcher. Two peers completed four evaluations and two completed one each. One peer did not complete the evaluation due to medical issues following the completion of her involvement in the study.

Peers were given a formal education session following their recruitment to provide them with information on the peer support program. The majority ($n=11$, 91.7%) found this preparation satisfactory and felt they were given enough information to carry out the role (Table 6.11). Throughout the delivery of the program, peers received weekly telephone and monthly face-to-face support from the researcher. The majority ($n=11$, 91.7%) felt that this was adequate. Peers were asked about their opinions of the program. Five (41.7%) reported that for some consumers the length of program was not right; however, most were satisfied with the content of the program ($n=8$, 66.7%). For three consumers, peers (25%) thought the program could have been more structured.

Seven peers (58.3%) regarded telephone calls as a convenient medium for delivering the program to consumers. Approximately 50% ($n=6$) felt that the duration of and

time between the calls was adequate. Contacting consumers by telephone, however, was sometimes difficult, with 50% ($n=6$) of peers reporting problems.

Peers gave their perspectives on how the program might have improved consumers' medication taking. Ten (83.3%) thought it provided useful information to them; however, five (41.7%) found it difficult to talk to consumers about their medication.

Being involved in peer support was perceived by the majority of peers as a worthwhile experience ($n=11$, 91.7%) and the majority ($n=11$, 91.7%) indicated they would like to be involved in future peer support programs.

Table 6.11 Peer evaluation of the peer support program ($n=12$).

	Disagree ¹		Neutral		Agree	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Telephone delivery						
Each call was long enough	2	16.7	4	33.3	6	50.0
Space between calls long enough	2	16.7	3	25.0	7	58.3
Telephone conversation was a convenient way to deliver program	0	0.0	5	41.7	7	58.3
I had difficulty contacting consumer by telephone	3	25.0	3	25.0	6	50.0
Opinions about program						
The preparation for the peer role was satisfactory	0	0.0	1	8.3	11	91.7
I was given enough information to carry out the role of peer support	0	0.0	1	8.3	11	91.7
Length of program was about right	5	41.7	3	25.0	4	33.3
Satisfied with content of program	0	0.0	4	33.3	8	66.7
Program could have been more structured	4	33.3	5	41.7	3	25.0
I received adequate support from the researcher	0	0.0	1	8.3	11	91.7
It was a worthwhile experience being a peer	0	0.0	2	16.7	10	83.3
I would like to continue with peer support in the future	1	8.3	0	0.0	11	91.7
Medication taking						
Program provided helpful information on improving consumer's medication taking	1	8.3	1	8.3	10	83.3
I found it difficult to talk to consumer about their medication	3	25.0	4	33.3	5	41.7

Legend

¹Scales were collapsed into three categories: 'strongly disagree' and 'disagree' were combined into the 'disagree' category. 'Strongly agree' and 'agree' were combined into the 'agree' category.

6.8 Summary

Twenty-eight consumers participated in the peer support program; however, six withdrew for various reasons following recruitment. Most of the consumer participants were male and single. Atypical antipsychotics were the most common medication prescribed and over one third of consumers were concurrently prescribed an antidepressant.

Prior to commencing the peer support program, consumers missed approximately 7.8 doses of the prescribed antipsychotic medication. This non-adherence to antipsychotic medication decreased during the study period and the main reason for missing doses for the majority of consumers was forgetfulness. Consumers had an improvement in mental state, especially in negative symptoms and this was statistically significant.

Approximately half of the consumers reported experiencing annoying side effects at baseline. The rate of side effects did not change significantly throughout the study period. In addition, there were no changes in consumer satisfaction, attitude towards antipsychotic medication, or quality of life during the study period.

Feedback from the consumers and peers about the program was mostly positive. The consumers felt it made a positive difference to their lives and felt it was easy to discuss their medication with the peers. The views of peers about the peer support program were also obtained; most felt that telephone was a convenient medium for delivering the program; however, they found that accessing consumers by telephone was at times problematic. Most reported it was a worthwhile experience and would like to be involved again in the future.

CHAPTER SEVEN

PEER INTERVIEW OUTCOMES

7.1 Introduction

A secondary aim of the study was to evaluate the peer perspectives about the usefulness of the peer support program. In this chapter, these perspectives will be presented. Originally six peers were recruited to participate in the study. One withdrew from the study after completing peer support with one consumer; therefore, her experience of the peer support program was not obtained. Five were interviewed and their perspectives on the peer support program are explored in this chapter. Three themes were highlighted: motivation to participate in the study, experience of peer support program, and rewards and challenges of peer experience (see Table 7.1).

Table 7.1 *Summary of themes, subthemes and codes.*

Themes	Subthemes	Codes
Motivation to participate in the study	• Previous life experiences	Personal understanding of mental illness Previous involvement with peer support
	• Altruism	Belief in peer support Desire to help others
Experience of peer support program	• Preparation for role	Training for the role Helpful information about the role
	• Operational experience	Amount of prior information about consumers Telephone delivery experience Note taking Using the problem-solving approach
	• Research experience	Constraints of research participation Challenges working within professional boundaries Student researcher support Peer-to-peer support
Rewards and challenges of peer experience	• Personal rewards	Increasing in confidence Improving well-being Making a difference to others Managing time effectively
	• Personal challenges	Developing trust Confronting own experience of mental illness

7.2 Motivation to Participate in the Study

In this theme the description of peers' motivation to participate in the peer support program is explored. Peers described their willingness to participate in the peer support based on two subthemes: their previous life experiences and altruism.

7.2.1 Previous life experiences

In this subtheme, peers recalled how their previous life experiences had impacted on their motivation to participate in the study. This included their own experience of being unwell and, therefore, having a personal understanding of mental illness, and their previous involvement as a recipient and provider of peer support.

Peers reflected on their own experience of being unwell with a mental illness and found that the possibility of helping another person experiencing something comparable was an important motivator. They saw the peer support role as an important addition to current treatment offered by health professionals. They felt their personal understanding of mental illness could facilitate consumers in their recovery, because they related to the consumers' current situation and believed they had the practical knowledge and experience to provide peer support.

When you can help somebody else who's been through, or is going through, something similar to what you are, or have been going through, is an amazing thing, no matter what the illness. But with mental health, it's such a specific thing. It can be so debilitating at times that to have somebody on the other end of the phone, even if the main motivation is just to talk about medication, but talking about medication with somebody who knows. Doctors know the technical stuff; we know the practical living and everyday stuff. (P4)

Furthermore, one peer acknowledged the ramifications of not seeking support and treatment from anyone, especially health professionals, and felt that her recovery may have been different if she had had someone to talk to.

Well, I was hoping that nobody would 'go down the road' [not seek treatment or support from others] that I did. In other words, 'keep things to myself.' I wanted to encourage people to speak out and by speaking out, that's the best way, so the medical field can help them [consumers] better. (P2)

In addition to peers' experience with mental illness, prior experience with peer support was an important factor in their decision to become involved in the program. One had personal experience as a recipient of peer support with a non-government mental health program and claimed the peer support aspect of the program was helpful in her recovery.

I was one of the naive people in regards to mental health until I became ill, and then I realised that the support that I was getting [with a non-government program], I know that this was helping me along ... If they'd been through the same thing that I'd been through they would actually understand it better. (P2)

Another was employed in a youth mental health organisation as a peer support worker and had observed the direct benefits of peer support in assisting individuals to recover from an acute episode of mental illness. This peer wanted to be involved in the present program because it was research based, and was confident the findings would show positive outcomes for peer support, which in turn would generate interest from the mental health services.

I had previous experience with peer support in the past. I worked at another mental health organisation as a peer and saw the direct benefit of that. It was something I believed in and wanted to get more involved in more research and documentation [future publication] about it. (P1)

7.2.2 Altruism

In this second subtheme peers described an altruistic motivation to participate in the peer support program. Peers articulated a belief in peer support and a desire to help others with mental health problems. When asked initially whether they would like to be involved in the study, all had no hesitation in accepting the role and they acknowledged that providing support to others with a mental illness was what attracted them to participate in the study.

The idea of peer support was the biggest thing [to be involved in a peer support program]. (P4)

When you first approached me about the program I was interested because it was dealing with consumers and, hopefully, doing stuff like this I really believe in. Because you're helping people and you're giving your honest opinion about the program. (P3)

Apart from their belief about the value of peer support, most recalled that they also enrolled in the study because they had a desire to help other mental health consumers. Peers identified with the consumers' experiences and wanted to support them through what they saw as a difficult period in their lives. It also was important to one peer that this support helped consumers understand that they were not the only one with a mental illness: "I wanted to help other people, show them that they are not alone." (P5)

7.3 Experience of Peer Support Program

In this theme the peers described the practical aspects of the program and how this impacted on their ability to perform the role. It encompassed a range of experiences that included three subthemes: preparation for role, operational experience and research experience.

7.3.1 Preparation for role

In this first subtheme, peers described their preparation to undertake the role of peer support. Prior to their involvement in the program, peers were given one half-day preparatory session about the program with the researcher. This included information about schizophrenia, communication skills, the peer support program, and their responsibilities as peers.

Peers felt that having a preparatory session was important in their preparation for the role of peer support. Most agreed that adequate information was provided by the researcher and this helped them to understand and prepare for the role. There was recognition that they were able to combine this session with their own experience and knowledge of mental illness and medication, and this was enough to feel prepared for the role.

For me, the only things that were needed were prerequisites to understanding the program and research, but we understand medication and our medication to a certain degree. But also that we can get on the phone [to consumer] and we have empathy and a passion to bring our experience and our knowledge and our listening ear, and I think those are probably the strongest things that we could have to be prepared. (P4)

Although the preparatory session assisted peers initially in understanding the operational functions of the program, they were also given a booklet to take home that contained information from the preparatory session and essential telephone numbers.⁶²

⁶²See Appendix 2

Peers could refer to it at any time, especially when they were uncertain about an aspect of the peer support program: “You got to keep the booklet and you could refer to it, which I did quite a few times at the beginning. You sort of think, ‘am I doing this wrong?’ So you refer back [To booklet].” (P2)

7.3.2 Operational experience

In this second subtheme peers’ opinions of the functional aspects of the program were explored. These included the amount of prior information they were given about consumers, telephone delivery experience, using the problem-solving approach and note taking.

Prior to making the first telephone call, peers were given basic information about consumers.⁶³ Most felt they were given enough information by the researcher to initiate contact. Having minimal information allowed the peer and consumer to get to know each other without any preconceived ideas.

The best part was actually you speaking to the consumer first, and then you’d speak to me. I didn’t know anything about the consumer, which ‘left the door open’ [allow the possibility for open communication] for questions from my side, so they [consumer] felt comfortable. (P2)

In contrast, one peer struggled to make a connection with one of the consumers she was supporting, and felt that having more information beforehand may have assisted her to develop a stronger relationship with him. She found this consumer difficult to contact by telephone, and when in contact, he provided mainly monosyllabic verbal responses.

⁶³Peers were aware that participants had schizophrenia and were on oral antipsychotic medication.

It could have been helpful to have a bit more information about the person you were about to connect with. It might have been a good starting point just so that you didn't go into the initial contact completely blank. So, just knowing a name, if you had a bit of background even a few interests might be a starting point and again that was presented to the consumer as well, that they might feel a bit less stuck when that first phone call arrives. (P1)

Another important operational experience was the telephone delivery aspect of the program. Peers found it a convenient form of communication, although some had difficulty contacting consumers and keeping to the prescribed time limit of the telephone contact. They also found that communicating over the telephone was a good method of providing support to consumers. They felt that telephone delivery was convenient, because they could make the telephone calls from home, at a time suitable to them and the consumer. However, most also felt that face-to-face contact might have been worthwhile and expressed a desire to meet with the consumer either during or after the completion of the program. One peer felt that it would have been worthwhile to have one face-to-face contact a few weeks into the program to "show people that you are real." (P5) He felt that this would be beneficial to the peer and consumer as they could see the face they were talking to over the telephone.

In contrast, another reported a preference for telephone delivery only. This peer felt that this form of contact was less invasive, and that when someone has a mental illness it can be difficult to undertake routine tasks. She also found that having this type of illness caused her to become isolated from others and felt that having a telephone call from someone who understands would be beneficial. "[The] telephone part is excellent. One-on-one wouldn't be any good ... It's hard to go outside the door; some days it is hard to get up to dry a dish." (P2)

Initially, peers recalled that they thought that telephone contact with consumers would be straightforward. However, at times, contact was problematic for some of the peers who found that consumers were not always at home when they telephoned, despite previous arrangements. They found this frustrating and at times became concerned about why consumers were not answering their telephone.

It was difficult getting hold of them. You leave messages and messages and sometimes they just don't get back to you. It can be a bit frustrating. (P5)

I would make arrangements to ring on a certain time and they weren't home. Or they weren't answering and in the back of your mind, especially if they had a problem taking medication, you're thinking, "is he okay?" (P3)

Although peers found that communicating over the telephone was a good method of providing support to consumers, they also remarked on how useful it was for them to take brief handwritten notes. These were made immediately after each telephone call as a record of the conversation. Although this was not discussed in the preparatory session, peers adopted this approach after subsequent discussion with the researcher. They found it beneficial to take notes and this assisted them to remember what was discussed in the previous telephone call.

Taking notes was a good thing, because when I looked at the notes, I also recalled what she [consumer] was saying and how she was saying it. If there was a problem, I could go back and highlight it in my mind, and be able to think about it and talk with the consumer about it. (P4)

Another operational area that peers experienced was the problem-solving approach (D'Zurilla & Nezu, 1999). This was used by peers to assist consumers to improve their medication adherence. In their preparatory session they were given information on how to incorporate the approach. This was a novel approach for peers and, at

times, consumers did not feel like discussing difficulties about their medication or illness, and discussions were of a more social nature. One peer found that it was not possible to jump straight into the problem-solving approach, and did not recognise that social discussion was a valuable ice-breaker that was helpful in initially building a relationship and establishing trust.

There was a lot of general discussion about football, work and things like that, and I'm not sure if they were problem-solved or more general chat. I don't think that they would have helped cure my young person very much. (P1)

Most peers, however, found the problem-solving approach useful and were able to discuss difficulties with medication adherence with the consumers. They were able to relate their own experience with medication taking and provide useful guidance to consumers about the importance of adherence.

I had a thing about medication over the years myself and it's been a hell of a lot of difference when you're on the other end trying to explain to these guys that haven't met you and you're speaking over the phone that it's a good thing to have medication, and I did that in the end. (P3)

7.3.3 Research experience

In this third subtheme, the peers explored their experience of participating in the research project. This included the constraints of research participation, challenges working within professional boundaries, support received from researcher and peer-to-peer support.

Working within the confines of a research project meant that peers were required to have only telephone contact with the consumer, once a week for 20 minutes. There were mixed views about whether 20 minutes was adequate. One peer found that some

consumers wanted more telephone contact and consequently, this affected adversely their ability to perform their peer support role. “When you finally get them [consumers] to open up, the 20 minutes isn’t long enough and they want to talk to you for half an hour, 40 minutes, but the program wasn’t set up for it.” (P5) In contrast, one peer recalled that a consumer wanted to talk for less: “The discussions would go for definitely less than the allocated twenty minutes.” (P1)

On several occasions during the program, peers would ask the researcher about the possibility of having face-to-face contact with consumers or increasing telephone contact frequency. When this happened, the researcher instructed them to maintain weekly telephone contact only, explaining that it was important to stay within the bounds of the research project. One peer requested additional telephone contact; this arose from concern about a consumer’s mental state and belief that extra telephone calls would provide further support. “There were a couple of times there I rang you [researcher] and I asked for guidance on which way I should go and you were always there to help me.” (P3) When this occurred, the researcher contacted the consumer’s case manager to inform them of the peer’s concerns.⁶⁴

In addition to staying within the confines of the research project, there was a need for peers to maintain a professional boundary between themselves and the consumers. This is important in the development of a therapeutic relationship. A professional boundary allowed the relationship to have a structure where consumers felt safe and, as a result, discussed their thoughts and feelings. It was also imperative that the relationship was goal directed, and the main focus of conversation remained on the

⁶⁴This provision was approved by the ethics committee to allow the researcher to follow up any concerns about consumers with their allocated case manager.

consumers' medication taking (Stein-Parbury, 2009). These boundaries were tested by consumers and peers during and after completion of the program.

During the eight-week program, one peer found that a consumer and a relative wanted more personal contact: "I had a couple of people wanting to take me out for dinner, but that wasn't part of the research. I think talking on the phone was all right, but I think more of them wanted more." (P5) This peer was able to inform the consumer and relative that he was unable to agree to this request. In his opinion, this had minimal impact on his working relationship with the consumer.

Following the conclusion of the research project, two of the peers made further contact with consumers. One visited a consumer in hospital who had become unwell after the consumer's family alerted her.

I went to the hospital and visited her and she was unwell. I asked permission from her and her family. When she heard my voice, and she knew who I was, and she was expecting a visitor she quite enjoyed that; it really picked her up, and we were able to talk face-to-face. It was really good. (P4)

The other peer made further telephone contact with the consumers on conclusion of the research project. "I would ring them out of the blue [unexpectedly], just to see how they're going. And to hear it in their voices, 'oh, she hasn't forgotten me,' it helps me with my illness too." (P2) The researcher was unaware that these two peers contacted consumers until the qualitative evaluation at the conclusion of the peer support program.

In addition to the constraints of research participation and challenges of working within professional boundaries, peers experienced professional support from the researcher and personal support from other peers. Having regular contact with the

researcher was important to the peers. Each week the researcher would contact them by telephone to discuss any peer, consumer and research related concerns, and to provide support. One peer found that being able to discuss and debrief about their telephone calls was helpful.

I had been through some past traumas, which encroached on my mental health well-being. And it was sometimes quite difficult to come in and go [spontaneous discussion with consumer]; I needed to unwind. It was good to talk [with the researcher] about things, and to unwind, and then get on the phone [with the consumer] and be able to leave those behind and to worry about somebody else. (P4)

Peers also had the researcher's telephone number and they were able to contact her if required. Knowing that there was someone who could be contacted with any concerns about the peer support role was important to the peers. Some of the peers contacted the researcher by text message when they were concerned or if they had difficulties establishing contact with a consumer. The researcher would return their telephone call immediately; however, this only happened on a few occasions. The researcher contacted the consumer's case manager to discuss peer concerns on two occasions during the study. One peer had concerns about a consumer's mental state and another peer was unable to contact a consumer. Both were resolved; the first consumer required follow-up from the case manager and was admitted to hospital for a short period and excluded from the study because of illness; the second recommenced telephone calls with the peer after replacing a lost telephone.

There were a couple of times I rang you and asked for guidance on which way I should go and you were always there to help me ... You were always there for all of us and as I said if we had a problem we used to ring you and you used to get back, you used to ring us at weekends to see how things are going.

I don't think you could have done any more unless you were on call 24 hours.
(P3)

Peers and the researcher also met face-to-face as a group once a month at a local coffee shop. This was perceived to be important by the peers because it enabled them to discuss their experiences, share difficulties and interact within a social environment.

It was just nice for all of us to be together, and have that little bit of debrief, and have that socialising time, and to just feel like a group, rather than just people who are dispersed [working separately in the role], and to feel like a group and to feel, dare I say it, loved. It was nice, because we learned from one another, and we listened, and the hot chocolate [drink] was good too. I was able to get to know others who were peer support people better, so, I guess, I gained friends there. (P4)

Three of the peers also contacted each other informally for advice and support. They would contact each other by telephone and occasionally meet informally, following a consumer forum meeting at the local community mental health service.

There were only three of us [peers] at the beginning. We would ring each other just to get others' viewpoint. We never talked about the consumers. It helped because I didn't know them before that and that helped a lot [with the program]. (P2)

7.4 Rewards and Challenges of Peer Experience

In this theme, the rewards and challenges experienced by the peers in undertaking the role of peer support are explored. Providing peer support over the telephone was a new experience for all of the peers. Although they recognised that the program had a positive impact on their lives, there were also some challenges. This is highlighted in two subthemes: personal rewards and personal challenges.

7.4.1 Personal rewards

In this subtheme peers described the personal rewards they obtained in undertaking the peer support role, including their increased confidence and well-being, and making a difference to others.

Providing peer support to current mental health increased self-confidence for some peers. Prior to participating in the research project, peers were not involved in peer support participation. All were receiving treatment for their mental illness and were involved in different activities related to their own mental health care.

It made me feel worthy again, definitely, and [it] builds the confidence up. Because you're hearing something good is going on with the consumer and you know it's because you've been working with this consumer ... I'm not the only one with problems, there's someone out there that are going through a lot worse than I am; I'm the lucky one. (P2)

You asking me to do the program was good; you didn't offer the role to just anyone, you actually wanted someone with a bit of responsibility. (P5)

There was the acknowledgement that involvement in peer support was beneficial to the well-being of the peer and consumer.

Whenever you help somebody else, you learn. And you don't just learn, your heart grows, and you develop life skills, speaking to other people, communicating. And also learning about yourself, and being able to teach others, in a way, being a good example. And when you do a service for somebody else, it puts a smile on your face and makes your day better. (P4)

In addition to increased peer confidence and well-being, they also felt encouraged by the changes they believed consumers were making. They believed their involvement in the peer support role was creating a positive change for the consumer. "When you

start hearing good things coming back, you realise they were taking it in [what was discussed].” (P2) Another peer described the positive change in two consumers: “I got one of them out of his house [consumer spent a lot of time isolated at home] and the other one built up enough confidence and moved out of home.” (P5)

7.4.2 Personal challenges

In this subtheme peers described the personal challenges they encountered while delivering the program. These included managing time effectively, developing trust with consumers and confronting their own experience with mental illness. Involvement was an added responsibility to their regular day-to-day activities and, on occasion, was personally challenging.

Managing their own time effectively was not difficult for most peers; however, occasionally one peer found this problematic. Unlike the other peers, he had an added responsibility of working part-time and was rostered on early morning shifts commencing at 5am. As a result, he found at times that it was difficult to manage his telephone calls. He would plan to telephone a consumer on a certain night, however because of tiredness would fall asleep and would then telephone the consumer the following day.

Thursday night I have to ring, but I have to take my tablets an hour earlier so I can get up in the morning, sometimes I would fall asleep or there were times because I've set the day and they look forward to me ringing them on the set date and I've slept through. You're ringing on Friday and Friday was not good for them. (P5)

Developing trust over the telephone was difficult at times for peers. Just because a peer also had a mental illness did not mean that the consumer would communicate

immediately. One peer recognised that trust played an integral part in the development of any relationship. This peer took it for granted that the consumer would accept him automatically and speak with him over the telephone. He recognised subsequently that he needed to earn the consumer's trust and felt he did this by taking time to recontact consumers if they were not available and therefore was able to consistently talk with them each week on the telephone.

I thought I would just have to ring them once a week, 20 minutes, done, but I found that sometimes you can't get hold of them every week. I also found that I thought it would be easy to talk to them, but first you got to earn their trust and it was hard doing that ... I found it good that they eventually opened up to me, whereas it can take a long time for most people to do that ... But to have this [happen] because I'm a nobody to them and yeah, it was good. (P5)

Two peers found that their participation in the peer support program was personally confronting because it reminded them of their own mental illness experience. Although it brought back unsettling emotions, they were able to reflect positively on their own experiences with schizophrenia.

I might have been like that years ago and I don't know, it's hard to look back, it's hard to look at your life, but when you meet some people, like that, you see where they are going [course of their illness]. (P5)

Another could identify with what the consumer was going through and remembered what it was like for her: "There were a couple of times [interactions with consumer] that stirred up things from the past. There was a woman who'd actually gone through something similar; it brought it all forward." (P2) Consequently, peers would contact the researcher and would debrief with her about these issues. Although peers found this confronting, they were able to recognise that they were now doing well and the experience with peer support was worthwhile.

7.5 Summary

Peers were motivated to participate in the peer support program because of their previous experiences with mental illness and peer support. They had a strong desire to help other mental health consumers and believed that the program would be beneficial. Hence, they had no hesitation in agreeing to participate.

Most peers found telephone contact a good method of contacting consumers. They found it convenient to be able to contact consumers from their home, at a time suitable for them and the consumer. However, some would have preferred face-to-face contact, and had a desire to meet the consumers. Overall, interactions with the consumers were constructive, although at times they did not answer their telephone in the first instance. Peers found this frustrating and occasionally they were concerned about the consumer's welfare. Mixed views were evident about the duration of the short telephone call.

Although there were some difficulties with contact, most peers had a positive experience with the peer support role. They found it gratifying that a consumer could communicate openly with them and were surprised by the trust that was gained. Participating in the program also increased their own confidence and made them feel worthwhile. They felt well supported by the researcher and developed new friendships with other peers.

While peers faced some challenges, they were able to work within the bounds of the research project and their professional relationship with consumers. At times, peers were confronted with dilemmas regarding their consumer or experienced discomfort reflecting on their own past difficulties with mental illness. However, having regular

contact with the researcher and being able to debrief was important as it helped with difficulties and provided support.

CHAPTER EIGHT

DISCUSSION

8.1 Introduction

The primary aim of the study was to assess if non-adherent consumers with schizophrenia, have improved adherence to their antipsychotic medication after participation in a problem-solving based peer support program. This was a unique study that involved peers, who provided a program delivered by telephone to consumers with a history of non-adherence to oral antipsychotic medication.

In this chapter, the findings of study are discussed. The chapter begins with a discussion of the findings related to the socio-demographic and treatment characteristics; then an examination of the outcomes of the problem-solving based peer support program is provided. This is followed by a discussion of the consumers' and peers' experiences of the program. An overall discussion of the findings is then given. Next, the strengths and limitations of the study are considered. Finally, the clinical and research implications of the findings and conclusion are presented.

8.2 Socio-demographic and Treatment Characteristics

In this section the socio-demographic and treatment characteristics of consumer participants, including gender, age, living circumstances, substance use, and prescribed medication, are described. The majority of consumer participants were male. Males have a 30% to 40% higher lifetime risk of developing schizophrenia and tend to develop the illness earlier than females (Messias, et al., 2007). Non-adherence to antipsychotic medication occurs more frequently in male consumers (Dassa, et al.,

2010; Velligan, et al., 2010b). When comparing symptomatology and treatment outcomes, men tend to have more severe illness, have poorer psychosocial outcomes, and higher comorbid health issues, such as substance use; and require higher doses of antipsychotic medication than females (Rossler, 2011). In comparison to males, females usually pay greater attention to their well-being and engage in help-seeking treatment, including regular use of mental health services (Nadelson & Dickstein, 2002) and increased visits to general practitioner, and consequently fewer hospital admissions (Morgan, et al., 2008). The consumer participants in the current study reflected the general population of individuals with schizophrenia; this was evident in that there were more male participants. The consumers who withdrew from the study ($n=6$) were male. Other telephone-based studies have incurred a similar attrition rate (Byrne & Dean, 2011; Pistrang, et al., 2011; Travis, et al., 2010). While another telephone-based adherence study had a significantly lower rate of attrition (Montes, et al., 2010). However, the gender of participants who withdrew from these studies was not specified.

The average age of participants in the current study was 35.1 years, ranging from 21 to 53 years. This finding is similar to several studies on non-adherence, indicating that consumers under 40 years are more likely to be non-adherent (Dassa, et al., 2010; Lacro, et al., 2002; Novick, et al., 2010). Consumers in the present study were predominately single and unemployed. Onset of schizophrenia usually occurs in early adulthood (Messias, et al., 2007); these are the years when individuals are more likely to form relationships and obtain employment (Messias, et al., 2007). In the current study, the majority of consumers lived with others and regularly attended outpatient appointments on a fortnightly-to-monthly basis. The level of support a consumer receives can influence medication adherence. The CATIE (Clinical Antipsychotic

Trials of Intervention Effectiveness) trial (Glick, et al., 2011) found that the presence of available and supportive families assisted consumers to remain in treatment and improved long-term adherence to antipsychotic medication.

It is not uncommon for up to one-third of consumers with schizophrenia to have a comorbid substance use disorder (Wilk, et al., 2006). In the current study, while most used recreational substances ($n=23$, 82.1%), only a small proportion used illicit substances ($n=4$, 14.3%). This low use of illicit substances may be related to the age group of participants. In Australia, substance use is commonly found in those aged 15 to 19 years and over 40 years, with risky alcohol and recent cannabis use placing major demand on health services (Fischer, Cavarino, & Najman, 2012). The majority of consumers in the current study smoked cigarettes (75%). This is consistent with the current literature where nicotine use is highly prevalent in consumers with schizophrenia (45% to 85%) compared with the general population (20%) (Wing, Wass, Soh, & George, 2012). Although there is extensive research into the positive relationship between substance use and non-adherence (Lang, et al., 2010; Lambert, et al., 2010; Olfson, et al., 2000; Olfson, et al., 1999; Patel, et al., 2008; Wilk, et al., 2006), there is limited information available related to nicotine use and adherence. Research in this area focuses mainly on improving abstinence and the interaction of nicotine with antipsychotic medications and mental state (Matthews, Wilson, & Mitchell, 2011; Wing, et al., 2012). In reviewing the role of antipsychotics in smoking and smoking cessation, Matthews et al. (2011) found that consumers self-medicated with cigarettes to relieve negative symptoms and side effects of medication. In addition, these consumers displayed an improvement in attention and visuospatial⁶⁵

⁶⁵Visuospatial is the ability to understand visual representations and their spatial relationships. It allows a person to estimate depth and distances in their surroundings (Harris, et al., 2010).

working memory. The link between adherence and nicotine use was not examined in the current study.

Olanzapine, an atypical oral antipsychotic, was the most commonly prescribed medication in this study, followed by Clozapine. This is consistent with the current trend to prescribe atypical antipsychotics for the treatment of schizophrenia, with advantages in greater efficacy and a lower risk of developing side effects (Buchanan, et al., 2010; Sherin & Marder, 2011). Two large trials, CATIE and CUtLASS (Cost Utility of the Latest Antipsychotics in Schizophrenia), suggest that typical and atypical antipsychotics are equally effective in treating individuals with schizophrenia (Foussias & Remington, 2010). Olanzapine has been found to be superior in efficacy and remission of symptoms; however, increased weight gain and adverse metabolic effects are problematic. In treatment-resistant schizophrenia, Clozapine is the most effective antipsychotic compared with all other atypicals for better outcomes (Foussias & Remington, 2010; Levine, et al., 2011); nevertheless, Olanzapine is still considered more acceptable to consumers because of the close monitoring requirements for Clozapine prescription⁶⁶ (Usher, et al., 2009).

Consumers in the current study were prescribed an average 2.7 medications per day; generally to be taken in the morning or at night. Polypharmacy is a common practice in psychiatry, with 10% to 50% of individuals with schizophrenia being prescribed more than one antipsychotic (Barnes & Paton, 2011; Essock, et al., 2011). The current Royal Australian and New Zealand College of Psychiatry (2005) treatment guidelines recommend that multiple antipsychotic medications, especially a combination of typicals and atypicals, should not be prescribed, except when someone is switching to

⁶⁶Individuals on Clozapine require regular monitoring, including blood and cardiac tests, because of the risk of developing neutropenia, myocarditis and cardiomyopathy (Castle et al., 2006).

another antipsychotic. In a study by Pfeiffer, Ganoczy, and Valenstein (2008), multiple dosing caused a moderate decrease in adherence compared with a once-daily dosage regime. However, an RCT by Essock et al. (2011) examined the risks in changing from antipsychotic polypharmacy to monotherapy. They found that non-adherence was higher in monotherapy (31%) than polypharmacy (14%). Furthermore, consumers who remained on polypharmacy were more satisfied and less inclined to change their treatment regime than those on monotherapy. In the current study, consumers were, on average, prescribed multiple types of medications and this may have contributed to their initial non-adherence at baseline.

One-third of consumers in the current study were prescribed a Selective Serotonin Reuptake Inhibitor antidepressant medication. Antidepressants are used to treat other mental health conditions such as depression, anxiety and insomnia that may co-occur in consumers with schizophrenia (Chakos, et al., 2011). Antidepressants have also been used to treat negative symptoms. A Cochrane review by Rummel-Kluge, Kissling, and Leucht (2006) evaluated the use of antidepressants in the treatment of negative symptoms of schizophrenia. They found that there was positive improvement in illness and negative symptom severity. However, the CATIE trial found that 14.6% of consumers with schizophrenia who were prescribed an antidepressant were mainly white females, with a prior diagnosis or symptoms of depression at baseline (Chakos, et al., 2011). Antidepressants have also been associated with non-adherence. A study by Lang et al. (2010) assessed the rates of adherence in consumers treated with oral and depot antipsychotic medication in an inpatient unit. They found prescribing of antidepressants was high, with 61% of consumers taking antidepressants, and this was found to be a predictor for non-adherence. In the current study, the demographic and

treatment characteristics may assist to identify non-adherence in single, male participants who were taking concomitant psychotropic medication.

8.3 Peer Support Program Outcomes

In this section, the findings from consumer participation in the problem-based peer support program are explained. These include medication adherence, mental state, side effect profile, attitudes towards and satisfaction with antipsychotic medication, and quality of life.

8.3.1 Medication adherence

The primary aim of the study was to assess whether non-adherent consumers with schizophrenia had improved adherence to their antipsychotic medication after participation in a problem-solving based peer support program. The first finding of the study was that there was significant improvement in self-reported adherence following participation in the program. These improvements were apparent from baseline to post-intervention (Week 8) and baseline to follow-up (Week 14), but not Week 8 to Week 14.

Most of the adherence research to date has focused on the factors that influence antipsychotic medication adherence (Beck, Cavelti, Wirtz, Kossowsky, & Vauth, 2011; Bodén, et al., 2011; McCann, Boardman, et al., 2008; Novick, et al., 2010; Rabinovitch, et al., 2009) and interventions by health professionals to improve adherence behaviour in consumers with schizophrenia (Gray, White, Schulz, & Abderhalden, 2010; Lee, Kane, Sereika, Cho, & Jolley, 2011; Staring, et al., 2010; Valenstein, et al., 2011). There is limited literature available providing evidence for the use of peer support as an effective intervention for improving adherence. A review

of the Schizophrenia (PORT) recommendations by Dixon et al. (2010), indicated that there was little evidence to substantiate treatment recommendations in the area of peer support or peer-led services, or specific interventions promoting adherence to antipsychotic medication. An Australian study by O'Donnell et al. (1999) evaluated an RCT of consumers with schizophrenia and bipolar disorder who were allocated to three case management groups, with one involving consumer advocacy. The advocacy consisted of peers encouraging consumers in self-confidence, role modelling, and improving communication with their case managers. In their study, medication adherence was measured at baseline and 12-month follow-up. Although consumers reported increased satisfaction with the consumer advocacy, there were no differences in adherence or other outcomes. A study by Druss et al. (2010) explored a peer-led intervention to improve medical self-management for consumers with serious mental illness. Peer leaders delivered a six-session manual-based intervention in a Health and Recover Program (HARP). At six-month follow-up, consumers demonstrated an improved ability to manage their illness and health behaviours; however, like the previous study by O'Donnell et al. (1999), no difference in medication adherence was observed.

In contrast to previous studies, the results of the current study indicate that peer support may be effective in increasing self-reported adherence to medications in non-adherent consumers with schizophrenia. Although there is limited evidence in the mental health literature to confirm that peer support is effective for increasing medication adherence, there is evidence of successful outcomes in individuals with HIV-infection taking antiretroviral medication. Similar to individuals with schizophrenia, HIV-infected individuals have difficulties adhering to medication (Simoni, et al., 2007). Studies by Deering et al. (2009) and Simoni et al. (2007) using

a peer approach have had some success in improving adherence to prescribed medication. Furthermore, the use of telephone-based interventions has also been reported to be useful in improving adherence for individuals with schizophrenia (Beebe, et al., 2008; Montes, et al., 2010); however, these interventions were delivered by health professionals.

The current study has also shown that a problem-solving peer support program delivered by telephone can be an effective adjunct treatment to routine care. It can be inferred that the problem-solving approach was a useful technique that assisted consumers to work through difficulties with their medication taking. Consumers in the study cited forgetfulness as the main reason for their medication non-adherence. The findings of the 2000 UK National Psychiatric Morbidity survey (Cooper, et al., 2007) and the Hudson et al. (2004) study showed that forgetfulness was one of the main causes of non-adherence to oral psychotropic medication. Other studies have found that memory impairment may also result in poor adherence (Donohoe, 2006; Kim, et al., 2006). Peers were able to discuss their own experiences of medication taking and this provided useful information to consumers about their medication adherence. Having this regular contact with a peer each week may have assisted in providing consumers with the necessary skills to overcome forgetfulness in relation to their oral antipsychotic medication.

8.3.2 *Mental state*

The second main finding of the present study was the improvement in consumers' mental state between baseline to Week 8 and baseline to Week 14. This indicates that, overall, the peer support intervention had a significant positive effect on the

consumers' mental state. In particular, there was a decrease in negative symptoms across all study time-points.⁶⁷

Other studies have found that negative symptoms can be a factor in decreased adherence to antipsychotic medication. Consumers with greater symptom severity are more likely to be non-adherent (Tattan & Creed, 2001) and are usually less responsive to treatment (Stauffer, et al., 2012). These symptoms are associated with attention deficits and may lead to increased psychological and social dysfunction (Tsai, Lysaker, & Vohs, 2010). Stauffer et al. (2012), in an analysis of changes in consumers' symptom severity, found that those with prominent negative symptoms responded positively to atypical antipsychotic treatment, with a decrease in severity of symptoms. In a significant number of consumers with persistent negative symptoms, antipsychotic medication has been found to be ineffective, with subsequent poor outcomes (Buchanan, et al., 2010).

The use of alternative interventions has shown promise in improving negative symptoms. Repper and Carter (2011) report that social functioning improved following engagement with peer support. Moreover, consumers who engaged in peer support had reduced admission rates and spent more time residing in the community (Repper & Carter, 2011). They were also more likely to use crisis stabilisation services and less likely to be admitted to hospital (Landers & Zhou, 2011).

It could be inferred that in the current study, consumers' initial medication non-adherence may have been related to their negative symptoms and forgetfulness. After peer support, improvement in negative symptoms may have led to an overall

⁶⁷ See Chapter 6, Section 6.5.2: Results of BPRS instrument.

improvement in mental state and medication adherence. No attempt was made to measure correlation between negative symptoms and adherence.

8.3.3 Side effect profile

In the present study, 56% of consumers self-reported at baseline that they had experienced annoying side effects from their antipsychotic medication. Additionally, at each study time-point they reported experiencing side effects and these increased slightly from baseline to Week 14;⁶⁸ however, the difference was not statistically significant.

The impact of side effects on adherence to antipsychotic medication has been well documented in numerous studies (Chabungbam, et al., 2007; Gray, et al., 2005; Kikkert, et al., 2006; Lambert, et al., 2004; McCann, Boardman, et al., 2008). However, other studies have found no relationship between side effects and adherence (Mutsatsa, et al., 2003; Perkins, et al., 2006; Rettenbacher, et al., 2004).⁶⁹ One study reported that despite experiencing side effects, consumers continued to take their medication, recognising clear benefits of the medication (Tranulis, et al., 2011). In a Johanna Briggs Institute systematic review by Ling, et al. (2011), the impact of side effects on consumers' attitudes towards medication was evaluated. Seven out of 13 studies reviewed found a positive correlation between side effects and negative attitudes towards medication, and this affected adherence. This is consistent with other studies (Gray, et al., 2005; Rofail, Heelis, & Gournay, 2009) which have found that most consumers were satisfied with their medication; however, when

⁶⁸See Chapter 6, Section 6.5.3: Results of LUNSER instrument.

⁶⁹These differences in outcomes for side effects and adherence may be related to the methodological differences, sample size, type of intervention and the definition of adherence.

dissatisfaction occurred, it was related to the experience of side effects from medication.

Although there is conflicting evidence in the literature about the impact of side effects, participants in the current study may be at risk for future non-adherence because of the increase in side effects observed in this study. This is an important finding because health professionals need to be mindful of consumers' attitudes and the consequences of side effects on adherence.

8.3.4 Attitudes towards and satisfaction with medication

Consumers in the current study had a moderately favourable attitude towards, and level of satisfaction with, treatment acceptability and medication insight⁷⁰ at each study time-point. These findings suggest that consumers' medication non-adherence and the peer support intervention did not influence or change consumers' attitude towards, or satisfaction with, antipsychotic medication. Other studies have found that following an intervention directed at adherence, consumers' attitudes improved and subsequently adherence increased, because of the intervention (Montes, et al., 2010; Tay, 2007). However, in the current study consumers' attitudes towards their medication remained constant, despite having initial non-adherence and receiving peer support intervention. This was similar to an RCT of the effect of compliance therapy on adherence by O'Donnell et al. (2003). They found no changes in attitudes or adherence following therapy. Furthermore, a Cochrane review by McIntosh et al. (2006), which evaluated compliance therapy for individuals with schizophrenia, found that there was no evidence that it improved consumers' attitudes towards their treatment. In contrast, an RCT by Hornung et al. (1998) evaluated psycho-educational

⁷⁰See Chapter 6, Section 6.5.4: Results of SWAM instrument.

training for medication management for individuals receiving outpatient services. They found that consumer attitudes towards medication did improve following the intervention; however, there was no change in the level of adherence between the intervention and control groups.

Having a positive attitude is associated with consumers having improved insight into their illness (Schennach-Wolff, et al., 2009) and this enables them to make competent decisions about their medication and need for treatment (Baloush-Kleinman, et al., 2011). A self-efficacy model proposed by McCann, Clark, and Lu (2008) suggests that individuals are more likely to be adherent if they are confident that their behaviour will produce positive outcomes. Likewise, external influences, such as personal issues, medication side effects and social stigma, affect how individuals think, feel and behave about medication. Having strong self-efficacy can help individuals maintain medication adherence (McCann, Clark, & Lu, 2008).

In the current study, medication insight remained at a moderate level, and despite this, adherence improved. There is conflicting evidence in the literature regarding the effect of insight and adherence. Similar to the current study, other research has found that insight has no influence over medication adherence in consumers with schizophrenia (Garavan, et al., 1998; Kavanagh, et al., 2003; Puschner, et al., 2009). In contrast, other studies report that impaired insight is linked to non-adherence and poorer treatment outcomes (Dassa, et al., 2010; Gray, et al., 2008; Kao & Liu, 2010; Lysaker, et al., 2002; Olfson, et al., 2006).^{71,72}

⁷¹This difference in research outcomes for insight and adherence may be related to the methodological differences, sample size, type of intervention and how adherence is defined in the different studies.

⁷²See Chapter 3, Section 3.1 for discussion on the different ways of assessing adherence.

8.3.5 Quality Of life

In the current study, consumers' quality of life scores⁷³ did not vary from baseline to Week 14. These findings may indicate that their medication non-adherence was not related to their quality of life. However, other studies have found a positive correlation between adherence and quality of life. Coldham et al. (2002), in a study of first-episode psychosis, found that consumers who were non-adherent experienced a poorer quality of life. This was also evident in a study of consumer satisfaction with psychotropic medication by Gasquet, Tcherny-Lessenot, Lepine, and Falissard (2006). They found that consumers' quality of life improved with increasing levels of adherence. Clinical status also influenced consumers' satisfaction with medication and, to a lesser degree, quality of life. However, two studies (Puschner, et al., 2006; Puschner, et al., 2009) found no direct correlation between quality of life and increased adherence.

Peer support in the current study also made no difference to consumers' quality of life. There is conflicting evidence as to whether peer support has improved quality of life. Three studies found no changes to quality of life in people with breast cancer, multiple sclerosis, or HIV-infection (Molassiotis, et al., 2002; Schwartz, 1999; Uccelli, Mohr, Battaglia, Zagami, & Mohr, 2004). Another study by Salzer et al. (2010) of an internet-based peer support group for women diagnosed with breast cancer found that quality of life worsened following the intervention and caused women psychological distress. In contrast, two studies (Castelein, et al., 2008 & Bouchard, et al., 2008) found a positive difference in the quality of life of mental health consumers. Consumers with psychosis who frequently attended a peer support

⁷³See Chapter 6, Section 6.5 for results of QLES instrument.

group had better quality of life outcomes than those who attended less frequently (Castelein, et al., 2008). Additionally, Bouchard et al. (2010) found that consumers in an inpatient unit who gave peer support informally to each other also had positive outcomes. These included improved mental health and quality of life, in the form of positive changes in behaviour, thinking and mood.

Although telephone-based peer support did not improve consumers' quality of life in the current study, it has shown promise in two other studies. Mohr et al. (2005) evaluated an eight-week intervention for individuals with multiple sclerosis. Individuals were contacted weekly by a peer for 50 minutes over eight weeks. Following the intervention, significant improvements were found in depressive symptoms and overall quality of life, but not in the sub-areas of physical or mental health. The other study by Travis et al. (2010) evaluated a 12-week intervention for individuals with depression or bipolar disorder attending a Veteran Affairs medical centre. Peers contacted veterans weekly for an average of 27 minutes by telephone. Like the Mohr et al. (2005) study, they found positive changes in depressive symptoms and overall health and quality of life.

In the current study, quality of life may have remained unchanged because of the relatively short duration of the intervention and telephone calls. Increasing the duration of the intervention may produce a different result that could be measured in future studies.

8.4 Consumer Experience of Peer Support

In the current study, consumers gave their perspectives of the program following participation.⁷⁴ Overall, they found that telephone delivery was convenient and supportive, and made a positive difference to their lives. Most of the consumers reported that it was easy to converse with their respective peer about medication taking. Furthermore, one-half found that the information provided about medication was useful, and some felt that the information enhanced their medication taking. These findings are consistent with studies by Travis et al. (2010) and Dennis (2003), who have found that telephone-based peer support was helpful for consumers with depression. They reported that consumers were very satisfied with telephone contact, and that peers provided useful information about the disorder and were supportive. Furthermore, a Cochrane review by Dale et al. (2008) found that telephone-based peer support was an effective intervention in studies of individuals with postpartum depression, breastfeeding, post myocarditis, and mammogram screening.

The intervention used in the current study was novel because peers delivered the program using a problem-solving approach to address non-adherence. Problem-solving has been used as an intervention for adherence in an RCT by Beebe et al. (2008). They used a telephone-based intervention for 29 outpatients with schizophrenia. Adherence was measured with pill counts and case note reviews over a three-month period. Findings showed a significant difference in adherence in the intervention group across the whole study time period when compared with the control group (usual treatment). However, in their study, the intervention was delivered by a health professional. In a study by Dennis (2003), peers were required to

⁷⁴See Chapter 6.6 results of CIEQ questionnaire

have knowledge of problem-solving skills to deliver telephone support to post-partum depressed women. The majority of women found that peers listened to their concerns, set realistic goals, assisted them to respond better to stressful situations, gave feedback on how they were making progress, and assisted them to solve their problems or concerns. Other studies have found improvement in cognitive function and clinical features of schizophrenia using problem solving, but have not measured adherence (Barbieri, Boggian, Falloon, & Lamonaca, 2006; Üçok, et al., 2006). While consumers in the current study expressed satisfaction with the peer support program, the problem-solving approach was not formally evaluated. Therefore, it can only be suggested that this approach may improve adherence for consumers, and merits further study.

8.5 Peer Experience of Delivering Peer Support

In the current study, peers gave their perspectives on the program following each intervention with the consumer,⁷⁵ and when the study was completed, participated in a semi-structured interview.

In the current study, peers were not involved in the development of the research project and had no input into the structure or process of the peer support program. Involving peers or consumers in the research process can bring development and improvement in the quality of the research and have an impact on future policy and practice (Delman, 2012). Ideally, there should be full collaboration and participation, from developing the research question to involvement in all aspects of the study (Horsfall, Cleary, & Hunt, 2011). Oliver et al. (2001) reviewed a needs-led health research program in the UK which included consumers in all stages of the research.

⁷⁵See Chapter 6.7 results of PIEQ questionnaire.

Consumers found that technical terminology and acronyms impeded effective communication with health professionals. They believed that health professionals were wary of them; however, despite this, they felt they were able to make helpful and timely contributions. In their study, although consumers appreciated the initial induction day, however it was identified that there was a further need for ongoing support in the form of mentorship and training. Another study by Delman (2012) engaged young adults with psychiatric disabilities as research assistants. He found that it was important to match strengths and interests, to ensure there was a clear job description, provide support through mentorship with the experienced researcher and engage vocational support services to provide additional resources and training.

Peers indicated that their preparation in the current study was satisfactory and they had enough information to perform the role effectively. They were given an initial three-hour introductory session that covered all aspects of the program. This is consistent with other telephone-based peer support programs where the duration of training is between 90 minutes and four hours (Dennis, 2003; Pistrang, et al., 2011; Travis, et al., 2010).

Helping others was an important motivator for peers in agreeing to participate in the current study. Helping others has been a common theme in other peer-related research (Marino, et al., 2007; Salzer & Shear, 2002), where peers recognised it was important for them to give back their time to others, helping them to recover and thus receiving personal rewards in return. While undertaking their role, peers felt that telephone delivery was a convenient way to deliver the peer support program in the current study. However, at times it was difficult to contact consumers by telephone and this would cause them to feel frustrated. Despite these difficulties, peers recognised that

being involved in the program increased their confidence and made them feel worthwhile. These findings are similar to a study that analysed peers' experiences of providing peer support (Salzer & Shear, 2002). Peers were interviewed about their role and the benefits they obtained from providing peer support in a consumer-run community mental health organisation, 'Friends Connection,' in the US. All peers reported benefits from helping others and this facilitated consumers' recovery. Most felt appreciated and this increased their confidence and self-esteem. This was similar to the experience of peers in a breastfeeding project in the UK (Curtis, et al., 2007). Peers reported having improved self-esteem, personal development, feeling appreciated and having greater assertiveness and increased social contact as the rewards of providing support to other breastfeeding women. A study by Mowbray, Moxley, and Collins (1998) interviewed 11 peer support specialists following termination of their employment from a three-year integrated case management project. They found that peer employment increased assertiveness, personal growth and self-esteem in peers. However, some peers felt they had too much responsibility, lack of support from their supervisors and limited resources to fulfil the role properly.

In the current study, peers gave their perspectives on how the program might have improved consumers' adherence to medication. The majority thought it provided useful information to them; while some found it difficult to talk to consumers about their medication most peers were able to relate their own experiences with medication taking and guide consumers about the importance of good adherence. There is limited research available on peer perspectives about peer support and adherence. In a qualitative study in Ethiopia and Uganda (Gusdal, et al., 2011) peer counsellors felt they played an important role in improving medication adherence in individuals with HIV-infection. They believed that their role modelling raised awareness and visibility

in the community improved antiretroviral medication adherence. However, adherence data were collected from the peers rather than the participants and hence, may not be reliable. Furthermore, in a study by Marino et al. (2007) peers reported their perspectives of a peer-led social support in individuals with HIV-infection on antiretroviral therapy. They found they were more assertive with their own treatment; however, there was no improvement in medication adherence from the intervention. Peers acknowledged that they received reciprocal support by helping others, increased their own personal growth and were able to develop more confidence. However, they did encounter challenges. Some of their HIV-infected partners were resistant to the peer support and they found this frustrating at times.

One of the challenges that peers had in the current study was the duration of the peer support program. They found it difficult to remain within the specified 20-minute timeframe of the telephone call; some consumers desired more time, while others less. On average, peer support telephone calls in other studies ranged from 26.8 to 39 minutes (Dennis, 2003; Pistrang, et al., 2011; Travis, et al., 2010). It has been suggested that it is the quality of the interaction and relationship that is positively associated with improved health outcomes, not the quantity (Dennis, et al., 2002). Peers in the current study found it challenging when consumers wanted more telephone time or face-to-face contact. They often needed to seek reassurance from the researcher to dispel their concerns or to debrief about their experiences. Mowbray et al. (1998), when interviewing peers following the termination of their role, found that for some peers friendships formed after the peer support role ended, while others were aware of maintaining clear professional relationship roles. They believed that having a mutual understanding of mental illness would allow peers to develop rapport through empathy, but for some this may lead to the development of friendships with

blurred boundaries (Mowbray, et al., 1998). In the current study two peers contacted consumers after the study was completed, mainly out of concern for them. However, unlike the Mowbray et al. (1998) study, the contact did not continue and friendships were not formed.

In the current study, peers were provided with regular contact with the researcher from the outset of the study. This was in the form of weekly contact by telephone and monthly face-to-face group meetings at a local cafe. Peers found this arrangement satisfactory. They found it beneficial to be able to debrief about their telephone contacts with consumers. Having the opportunity to meet with other peers on a monthly basis was also rewarding. Peers formed strong bonds with each other and continued to meet after the study was completed. Other studies (Lawn, et al., 2008; Rivera, et al., 2007) have found that supervision can vary depending on the nature of peer support delivery. Evaluation of two peer support programs found that face-to-face contact between consumer and peers required more regular intensive supervision, whereas telephone-based peer contact was less frequent and often supervision occurred over the telephone (Dennis, 2003; Travis, et al., 2010). In a review of peer involvement in mental health services, Simpson and House (2008) found that peer employees required more supervision to carry out their duties than health professional employees. They reported that peers spent more time with face-to-face contacts, doing outreach work, and spent less time on telephone and office duties than health professional employees. In the current study, peers were able to contact the researcher by telephone at any time, and did so on two occasions when they had concerns about a consumer. They preferred to utilise text messaging, as this was a cost-effective way to communicate with the researcher, who, in turn, telephoned them promptly.

8.6 Discussion of Overall Findings

The current study found that problem-solving based peer support was an effective intervention in promoting adherence to oral antipsychotic medication, improving consumers' mental state and reducing negative symptoms.

There was a significant improvement in consumers' self-reported medication adherence following participation in the peer support program. This was apparent from baseline to Week 8 and was maintained at Week 14 follow-up. Consumers cited forgetfulness as the main reason for non-adherence at baseline. There is limited research available on the outcome of peer support and adherence in mental health. Elsewhere, there has been some success in improving adherence to antiretroviral medication using peer support in individuals with HIV-infection (Deering, et al., 2009; Simoni, et al., 2007).

In the present study, there was significant improvement in consumers' overall mental state, and the decrease of negative symptoms was particularly significant. Negative symptoms play a major role in the ability of an individual to recovery from schizophrenia. These symptoms impact on consumers' memory and their ability to concentrate, pay attention to and complete tasks (Minzenberg, et al., 2008). Having a decrease in negative symptoms may assist consumers to form productive interpersonal relationships and potentially gain meaningful employment (American Psychiatric Association, 2000). Furthermore, negative symptoms have been associated with non-adherence to antipsychotic medication in individuals with schizophrenia (Rettenbacher, et al., 2004). It could be inferred in the current study that improvement of negative symptoms led to an increase in adherence for consumer participants following the intervention.

The present study is the first to use a problem-solving based peer support program to address non-adherence to oral antipsychotic medication in individuals with schizophrenia. The findings show that this approach is an important adjunct to interventions to improve adherence and mental state. The study used the problem-solving approach of Nezu, Nezu and D’Zurilla (2007), which is based on the ADAPT 5-step method. It could be inferred that the approach enhanced the consumers’ abilities to recognise obstacles and find alternative strategies to improve adherence. This assisted them to identify and resolve their medication adherence problems. Three studies have measured the effect of problem-solving based interventions in consumers with schizophrenia (Barbieri, et al., 2006; Beebe, et al., 2008; Üçok, et al., 2006). In particular, the study by Beebe et al. (2008) used a weekly telephone intervention delivered by a nurse over a period of three months. Similar to the present study, they found that medication adherence improved throughout the intervention. To date, only two studies have measured the effect of peer support on individuals with schizophrenia (Castelein, et al., 2008; Rummel-Kluge, et al., 2008). Neither of these studies reported the effect on adherence to antipsychotic medication or used a problem-solving approach, as adopted in the current study.

The use of peer support within mental health is an emerging practice. Peer support can be delivered in different formats, including self-help and consumer run agencies, consumer consultancy, intensive peer case management, peer-assisted care, and general peer support in the form of friendship, one-on-one support, telephone and internet based, and peer-led groups. Most formalised peer support relationships are established intentionally and occur in clinical settings (Davidson, et al., 2006). However, the role of a peer is quite different to a professional clinical role. First, peers have a history of a serious mental illness and share their own personal experiences

with consumers. In contrast to clinical staff, peers are often viewed by consumers as ‘friends’ and this is enhanced when their meetings occur within a casual community setting (Min, et al., 2007). Second, peers are often employed to assist and support consumers in their recovery. This includes providing role modelling, instilling hope and giving practical advice on many areas related to their mental health (Davidson, et al., 2006).

There are inconsistencies in the delivery of peer support within mental health services. The Victorian state government has developed an action plan to ensure mental health services actively involve consumers in service delivery (Victoria Government, 2009a). The plan does not go into specific detail about the role of consumers in peer support; however, it does state that peer support is a formal and informal medium for mentoring and recognises the importance of debriefing consumers about their experiences. However, in practice, mental health staff are often resistant and hesitant about embracing peer involvement (McCann, Clark, Baird, et al., 2008), and are concerned about boundaries between the consumer and peer (Cleary, et al., 2006). For instance, consumer consultants⁷⁶ have experienced paternalistic attitudes together with hostility, disrespect and suspicion from clinical staff, and often struggle with health professionals’ jargon and attending what they believe are unnecessary meetings (Middleton, et al., 2004). Despite these challenges, peers claim that they find their role worthwhile. Compared with mental health staff they report greater satisfaction with their peer support work, and a sense of belonging and teamwork (White, et al., 2003). They feel appreciated and benefit from helping others by facilitating consumers’ recovery; this, in turn, increases their confidence and self-esteem (Salzer & Shear, 2002).

⁷⁶See Chapter 4.4.2 regarding consumer consultants’ role.

In the current study, peers found the experience of problem-solving based peer support convenient and believed it made a positive difference to their well-being. They were motivated to participate based on their previous personal experiences with mental illness and peer support. Peers were motivated by a strong desire to help others and believed that the program would be beneficial to consumers; they had no hesitation in agreeing to participate. They claimed that their confidence increased throughout the program and it made them feel worthwhile. They acknowledged that they encountered some difficulties and were frustrated when consumers did not answer their telephone, and, at times, this caused them to be concerned about consumers' welfare. Peers found it helpful to have the researcher available to assist them to carry out their role. This included telephone contact outside regular meeting and contact times. This gave them the opportunity to regularly debrief about their experiences and have questions and concerns answered. They especially enjoyed the social contact with each other when they met for group supervision each month. They saw the peer support role as an important adjunct to current treatment offered by health professionals, and were reassured that consumers continued to receive ongoing case management.

8.7 Strengths and Limitations

8.7.1 Strengths

There were four strengths to the current study. The first strength was the inclusion criterion of non-adherence. Consumers who were non-adherent with their oral antipsychotic medication were purposefully recruited. Numerous adherence intervention studies have not specifically targeted individuals who have non-

adherence issues, but instead used a general sample of the population that may have included adherent consumers (Anderson, et al., 2010; Beebe, 2011; Gutiérrez-Casares, Cañas, Rodríguez-Morales, Hidalgo-Borrajo, & Alonso-Escolano, 2010; Montes, et al., 2010; Tranulis, et al., 2011). Other studies have targeted non-adherent consumers and used a variety of methods to measure non-adherence, including mental health service engagement, history given by consumer and family, outpatient attendance, and use of an adherence rating scale (Byrne & Deane, 2011; Staring, et al., 2010; Tay, 2007). This study was unique because it specifically targeted only non-adherent consumers.

The second strength was the moderate attrition rate of consumers ($n=6$) which compared favourably with other telephone peer support studies that had similar rates of attrition (Pistrang, et al., 2011; Travis, et al., 2010). In the current study, the rate of attrition may have been related to the support that consumers received from peers as an adjunct to their regular care and treatment from the mental health service. Furthermore, peers directly contacted consumers by telephone at prearranged times that were suitable to both parties. Both expressed that they found telephone contact convenient and this may have contributed to the retention rate.

The third strength was the peer participant retention. Only two peers left the study; one decided it was too stressful and another became unwell. In future studies it would be important to have stringent criteria for peer selection, to reduce the likelihood of this occurring. The remaining four peers, however, were retained for the duration of the study. This may have been because the researcher built rapport and maintained a professional relationship with peers throughout the study. In addition, the researcher contacted each peer weekly by telephone, met with them face-to-face as a group each

month and had additional *ad hoc* contact when needed. The regular contact allowed the peers to debrief about any concerns or problems with consumers, answer and discuss any issues related to the peer support program, and provide mutual support. The monthly meeting allowed the peers to interact with each other and provided peer-to-peer support and socialisation. This contact may have positively contributed towards the retention of consumers and peers in the study.

The fourth strength was the ADAPT model of problem-solving (D'Zurilla & Nezu, 2007). Use of this approach provided peers with a formal structure that was designed to assist consumers to identify and resolve medication adherence problems through the development of new skills. Peers reported that the information session and booklet they were given about the model was important for their preparation and both contained adequate information to enable them to understand and prepare for the role.

8.7.2 Limitations

There were six limitations to the current study. The first limitation was the methodology of the study. There was no control group or randomisation. Furthermore, the researcher was unable to recruit 28 consumers, which was the desired sample size based on the power analysis. Only 22 consumers completed the three data collection points; therefore, the study was under powered. However, resources were limited to one PhD student researcher, with limited funding available, recruitment was from only one clinical service and the sample was specific to non-adherent consumers. In future studies, an RCT would be more desirable, with increased funding and the addition of several clinical sites allowing recruitment of a larger sample.

The second limitation was the method of recruitment and data collection. To minimise the likelihood of bias or influence by the researcher in recruiting consumers, case managers of the mental health service first identified consumers who met the selection criteria. They gave consumers brief information about the peer support program and obtained initial verbal consent prior to the researcher having initial contact. Case managers may have inadvertently given the researcher 'favourable' non-adherent consumers and this may have biased the sample. Consumers who elected to participate may have also been more motivated to improve their medication adherence. An RCT study design may help confirm the positive findings of this study. The study also had a moderate proportion of eligible participants that declined to participate. In a future study it would be worthwhile to consider how to successfully encourage non-adherent consumers.

All data were collected by the researcher and during data collection consumers may have felt influenced or pressured to answer the questionnaire. To minimise this, the researcher gave each consumer a copy of the questionnaire, each question was read aloud slowly and answers were marked on the researcher's copy. In any future studies, it is preferable that an independent person collects data. Any potential participants should be screened and there should be a longer timeframe for recruitment.

The third limitation was the self-reporting of medication adherence by consumers. Identification of non-adherence was initially through the case manager, then confirmed by the consumer. At Week 8 and Week 14 data collection points consumers self-reported the number of missed doses in the previous four weeks. Velligan et al. (2010a) found that self-report is the most commonly used and easiest

method of measuring adherence in the usual clinical setting. Self-report is a subjective measure for determining adherence, and can be inaccurate. Furthermore, the consumers might have responded positively to please the researcher. A more objective assessment could have been made with the use of pill counts, blood analysis, electronic monitoring (Velligan, et al., 2010a) or adherence scales (Byrne & Deane, 2011). Because of the limited scope of a PhD study and limited resources, self-report was the most appropriate measure in this current study and has been used in other studies (Velligan, et al., 2010a).

The fourth limitation was the length of the telephone calls. Peers contacted consumers for 20 minutes. Peers found the duration of the telephone calls restrictive, with some consumers wanting more time, while others less. Other telephone intervention studies have had 26-minute (Mohr, et al., 2005) and 50-minute duration calls (Travis, et al., 2010) with positive results. In future studies, being less prescriptive about the duration of telephone calls and perhaps having peers record the duration of their telephone calls may be beneficial.

The fifth limitation is in the delivery of the peer support program. The study did not test the competence of the peers to deliver the intervention, nor was peers' adherence to medication evaluated throughout the study. There was no systematic process of supervision to monitor or observe telephone communication between the consumer and peer. In future studies this could be overcome by fidelity checking in the form of direct observation, or recording of telephone calls. The addition of an adherence questionnaire for peers would also be worthwhile.

The final limitation is in the findings of the study. Improvements in the consumer outcomes may have been due to factors other than peer support. In future studies, the

addition of a control group and using an RCT, may strengthen the validity of the findings. In addition, there is a need to evaluate whether the effect of peer support is sustainable. Future studies could use longer time frames. Furthermore, the addition of a problem-solving instrument may enhance the overall findings.

8.8 Implications of the findings

8.8.1 Clinical implications

The study findings suggest that a problem-solving based peer support program could be used as an adjunct intervention by mental health nurses and other mental health professionals to promote medication adherence in individuals with schizophrenia. The problem-solving approach can equip consumers to develop new skills to address their adherence difficulties. Furthermore, the use of a telephone-based intervention could be adapted for other mental health conditions. It is easily accessible (most consumers have either home or mobile telephones) and can be straightforward to implement.

The findings also have implications for healthcare services to provide peers with regular monitoring, debriefing, supervision and peer-to-peer interaction (Mowbray, et al., 1998). Ongoing training and quality improvement is also necessary (Chinman, et al., 2008). Peers can face barriers of stigma and discrimination, and lack of recognition and accountability while working within the medical model (Middleton, et al., 2004). Previous research has found that health professionals can also be resistant and ambivalent about the role peers have in delivering services to consumers (Chinman, et al., 2008; McCann, Clark, Baird, et al., 2008). All these factors may impact on a peer's ability to carry out the role successfully. Careful selection of peers is also necessary. In the current study, one peer found the program stressful and others

reported frustration when unable to contact consumers. However, they found that having regular support and debriefing assisted them in their peer support role.

8.8.2 Research implications

The findings of the current study provide justification for further larger scale research into problem-based peer support and adherence interventions. Follow-up research should use an RCT comparing a problem-solving based peer support program for medication adherence with standard treatment. There could be a larger group of participants and a longer follow-up period (6 and 12 months) than could be obtained within the constraints of PhD candidature. Recruitment could include the general population of consumers with schizophrenia or specifically those with non-adherence. There is limited research available on whether peer support is cost effective. This could be evaluated in future studies. Lastly, obtaining the consumer, peer, carer and mental health staff perspectives of the program may be worthwhile. While this study did not use a rigorous RCT, it has demonstrated that peer support is a viable intervention that can be delivered successfully in most mental health settings.

8.9 Conclusion

There is evidence that antipsychotic medication may be effective in treating individuals with schizophrenia. Unfortunately, many individuals are non-adherent with their medication, and this can result in a relapse.

In this thesis I have established that problem-based peer support may be an effective adjunct intervention for the promotion of adherence in individuals with schizophrenia. The findings offer a unique insight into the distinctive role peers can provide in addressing medication taking issues and providing mutual support. Furthermore, peer-

to-consumer relationships share some similarities with the healthcare professional-to-consumer relationship. There is still a need to build trust and create a therapeutic relationship. For peers, the relationship is also founded on their personal experiences with mental illness and their desire to help others.

The study also gives insight into the complex issue of adherence to antipsychotic medication. Adherence does not exist in a vacuum; it can be influenced by a range of factors including mental state, side effects, perceived efficacy, insight, attitudes, quality of life and support by others. Mental health service delivery may be enhanced with the addition of a problem-solving based peer support intervention, with consumers obtaining enhanced problem-solving skills and additional support.

In this thesis I have shown that the addition of peer support may be effective in improving adherence with antipsychotic oral medication, consumers' overall mental state and reduction of negative symptoms. Incorporating peer support into clinical service delivery may significantly improve mental health outcomes for consumers with mental illness.

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PARTICIPANT INFORMATION AND CONSENT FORM (PICF)

(Consumer Version)

Version1, Dated August 19th, 2008

Site: Mid West AMHS

Full Project Title: A peer support intervention program for enhancing medication adherence in consumers with schizophrenia.

Principal Researcher: Professor Terence McCann

Associate Researcher: Ms Debra Kerr

Student Researcher: Ms Gayelene Boardman

1. Introduction

My name is Gayelene Boardman, I am a PhD research student at Victoria University and I would like to invite you to take part in the following research project.

The aim of the project is to find out if taking part in a peer support program will

- result in you being more likely to take antipsychotic medication following participating in the study;
- have an improvement in your quality of life following participation;
- have less symptoms of your illness by taking medication regularly and;
- evaluate whether the program was useful for you.

This Participant Information and Consent Form explains to you about the research project. It details what is involved to help you decide if you want to take part.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your case manager.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you may be asked to sign the consent section. By signing it you are telling us that you:

- understand what you have read;
- consent to take part in the research project;
- consent to be involved in the procedures described;
- consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research project?

The purpose of this study is to examine the effectiveness of peer support in consumers with schizophrenia who do not take their oral antipsychotic medication on a regular basis.

Approximately 34 consumers and 6 peers will be invited to take part in this study. This project will be conducted by researchers from the School of Nursing & Midwifery, Victoria University.

The results of this research will be used by the researcher *Gayelene Boardman* to obtain a PhD degree.

3. What does participation in this research project involve?

- Procedures

A peer support person will be allocated to you. You will receive a 20-minute telephone call each week from this person. The purpose of the telephone call will be to provide support and to discuss your medication taking using a problem solving approach.

You will be asked to complete questionnaires before the start of the program (Week 0), at the end of the program (Week 8) and at follow up (Week 14). The questionnaires will take about 20 minutes to complete.

- Reimbursement

You will not be paid for your participation in this research, but you will be reimbursed for expenses incurred as a result of participating in the project.

You will receive an amount of \$25 for the inconvenience in participating and completing questionnaires.

4. What are the possible benefits?

While there may be no direct benefits to you by participating in the study, you may find it helpful talking to a peer about your medication taking. As a result of taking part in the study, you may discover different approaches to aid in your medication taking and this may improve your quality of life.

5. What are the possible risks?

There is a low risk for taking part in this study. In the unlikely event that you become upset or distressed as a result of your participation in the research, the researcher will contact your case manager or treating doctor who will arrange to see you. You may also contact your case manager and doctor and arrange an appointment to see them.

Your treating doctor will also be informed of your participation in the study.

6. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at a later stage.

Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with the researchers. You will continue to attend

appointments at Mid West Area Mental Health Service. This includes continuing to have direct access to your case manager.

7. How will I be informed of the final results of this research project?

Please let me know if you would like a written summary of the results of the study and I will send this to you on completion of the study.

8. What will happen to information about me?

During the project, the computer records will be stored in a locked office at the School of Nursing and Midwifery, Victoria University. Only Professor Terence McCann, Gayelene Boardman and Debra Kerr will have access to the computer records. At the completion of the study, an electronic copy of the data will be securely stored in the School of Nursing and Midwifery, and will be destroyed after seven years (hard copies will be shredded and electronic data will be deleted from computer drives).

Any information obtained in connection with this research project that can identify you will remain confidential and will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law.

In any thesis publication and/or presentation, information will be provided in such a way that you cannot be identified.

9. Can I access research information kept about me?

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you. Please contact one of the researchers named at the end of this document if you would like to access your information.

In addition, in accordance with regulatory guidelines, the information collected in this research project will be kept for at least 7 years. You must be aware that the information collected about you may at some point not be able to be identified once the identifying information has been removed (about 3 month after the information is collected]. Access to information about you after this point will not be possible.

10. Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Victoria University and Melbourne Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

11. Consent

I have read, or have had this document read to me in a language that I understand, and I understand the purposes, procedures and risks of this research project as described within it.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project, as described.

I understand that I will be given a signed copy of this document to keep.

I am age 18 years of over.

Participant's name (printed)

Signature

Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's name (printed)

Signature

Date

Witness to above signatures:

Witness's name (printed).....

Signature

Date

Note: All parties signing the consent section must date their own signature.

12. Who can I contact?

The person you may need to contact will depend on the nature of your query. Therefore, please note the following:

For further information or appointments:

If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project (for example, feelings of distress), you can contact the principal researcher Professor Terence McCann, on: (03) 9919 2325, after hours 0403 209 453

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Name: *Ms. Michelle Clemson*

Position: *Manager, Mental Health Research & Ethics Committee*

Telephone: *(03) 9342 - 7215*

OR

The Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001. Telephone (03) 9919 4781

PARTICIPANT INFORMATION AND CONSENT FORM (PICF)

(Peer Version)

Version1, Dated August 19th, 2008

Site: Mid West AMHS

Full Project Title: A peer support intervention program for enhancing medication adherence in consumers with schizophrenia.

Principal Researcher: Professor Terence McCann

Associate Researcher: Ms Debra Kerr

Student Researcher: Ms Gayelene Boardman

1. Introduction

My name is Gayelene Boardman, I am a PhD research student at Victoria University and I would like to invite you to take part in the following research project.

The aim of the project is to find out if consumers who take part in a peer support program will

- be more likely to take antipsychotic medication following participating in the study;
- have an improvement in their quality of life following participation;
- have less symptoms of their illness by taking medication regularly and;
- evaluate whether the program was useful to them.

This Participant Information and Consent Form explains to you about the research project. It details what is involved to help you decide if you want to take part.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you may be asked to sign the consent section. By signing it you are telling us that you:

- understand what you have read;
- consent to take part in the research project;
- consent to be involved in the procedures described;
- consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research project?

The purpose of this study is to examine the effectiveness of peer support in consumers with schizophrenia who do not take their oral antipsychotic medication on a regular basis.

Approximately 34 consumers and 6 peers will be invited to take part in this study. This project will be conducted by researchers from the School of Nursing & Midwifery, Victoria University.

The results of this research will be used by the researcher *Gayelene Boardman* to obtain a PhD degree.

3. What does participation in this research project involve?

- Procedures

You will be asked to meet with the researcher prior to the beginning of the program to:

- Obtain information about the program and expectations of your role;
- Obtain information about the problem solving approach and how to incorporate this with peer support;
- Discuss communication skills and qualities of helpful peer support;
- Discuss the importance of confidentiality;
- Clarify questions and concerns.
- Discuss the initial contact with the consumer
 - making the first telephone call
 - telephone instructions
 - taking brief notes about your conversation
- Discuss continuing contact with the consumer
 - frequency of contact, length of call
 - identifying changes in mental state
 - how to respond to a crisis

You will communicate weekly with the consumer via a 20-minute telephone call for a period of 8 weeks.

You will receive a telephone call each week from the researcher. This is to answer any questions that you may have, to provide support and information and discuss any concerns or issues.

You will be asked to complete a questionnaire about the peer support program at the end of the program.

- Reimbursement

You will not be paid for your participation in this research, but you will be reimbursed for expenses incurred as a result of participating in the project.

This includes:

All telephone calls to the consumer - \$25 (this amount will be increased if mobile phones are involved).

Travelling costs, if you are required to travel to meet with the researcher - \$25.

Other expenses that you may incur in participating in the research - \$40.

The total amount that you will receive will be \$90.

4. What are the possible benefits?

While there may be no direct benefits to you by participating in the study, you may find it rewarding using the problem solving approach to assist consumers with their medication taking and providing them with social support.

5. What are the possible risks?

There is a low risk for taking part in this study. In the unlikely event that you become upset or distressed as a result of your participation in the research, the researcher will: (a) offer basic emotional support such as listening and empathising; (b) allow you to decide whether to continue with the study (c) if necessary, and with your approval, refer you to the most appropriate free health service or to your treating doctor.

6. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any time.

Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with the mental health service. You will continue to receive your standard medical treatment and attend appointments with your doctor.

7. How will I be informed of the final results of this research project?

Please let me know if you would like a written summary of the results of the study and I will send this to you on completion of the study.

8. What will happen to information about me?

During the project, the computer records will be stored at the School of Nursing and Midwifery, Victoria University. Only Professor Terence McCann, Gayelene Boardman and Debra Kerr will have access to the computer records. At the completion of the study, an electronic copy of the data will be securely stored in the School of Nursing and Midwifery, and will be destroyed after seven years (hard copies will be shredded and electronic data will be deleted from computer drives).

Any information obtained in connection with this research project that can identify you will remain confidential and will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law.

In any thesis publication and/or presentation, information will be provided in such a way that you cannot be identified.

9. Can I access research information kept about me?

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you. Please contact one of the researchers named at the end of this document if you would like to access your information.

In addition, in accordance with regulatory guidelines, the information collected in this research project will be kept for at least 7 years. You must be aware that the information collected about you may at some point not be able to be identified once the identifying information has been removed (about 3 month after the information is collected]. Access to information about you after this point will not be possible.

10. Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Victoria University and Melbourne Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

11. Consent

I have read, or have had this document read to me in a language that I understand, and I understand the purposes, procedures and risks of this research project as described within it.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project, as described.

I understand that I will be given a signed copy of this document to keep.

I am age 18 years of over.

Participant's name (printed)

Signature

Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's name (printed)

Signature

Date

Witness to above signatures:

Witness's name (printed).....

Signature

Date

Note: All parties signing the consent section must date their own signature.

12. Who can I contact?

The person you may need to contact will depend on the nature of your query. Therefore, please note the following:

For further information or appointments:

If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project (for example, feelings of distress), you can contact the principal researcher Professor Terence McCann, on: (03) 9919 2325, after hours 0403 209 453

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Name: *Ms. Michelle Clemson*

Position: *Manager, Mental Health Research & Ethics Committee*

Telephone: *(03) 9342 - 7215*

OR

The Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001. Telephone (03) 9919 4781.

PEER SUPPORT PROGRAM TRAINING

WORKBOOK



**Supporting consumers with schizophrenia who
are reluctant to take their antipsychotic medication**

Adapted from:

Mentoring Individuals with Brain Injury and Their Families

Research and Training Center on Community Integration of Individuals with
Traumatic Brain Injury, Mount Sinai School of Medicine, New York, NY
Mary R Hibbard, PhD, Joshua Cantor, PhD, Nancy Gundersen, BA, Heather Charatz,
MA, Teresa Ashman, PhD, Wayne A Gordon, PhD, Margaret Brown, PhD
Brain Injury Association of New York State, Albany, NY
Judith Avner, JD, Lynne Ireland Knight, BA
National Self-Help Clearinghouse, New York, NY
Audrey Gartner, MA

Modifications to the Workbook Made in Collaboration with:

Brain Injury Association of New Jersey, Edison, NJ
Jane Lowenstein, MSW, LSW, Wendy Berk, MSW, LCSW, Susan Quick, BA, Judi
Weinberger, Med, CRC
February 2005

And

Reaching out: Supporting a family member or friend with first episode psychosis: A
self help guide

Terence Mcann, Dan Lubman, John Gleeson, Kingsley Crisp, Eileen Clark, Sai Lu
and Judith McCann

2008 School of Nursing & Midwifery, Victoria University, ORYGEN Research
Centre, University of Melbourne, & ORYGEN Youth Health.

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INTRODUCTION

Purpose of the manual

This manual has been developed to help you with your role in the peer support program for enhancing medication taking in consumers with schizophrenia.

The program utilizes social support, combined with a basic problem solving approach that is delivered through telephone contact to a consumer over an eight week period.

For the purpose of the program, the consumer will be referred to as your partner.

The manual contains information that will help you in your role as a peer. The manual is divided into five different sections, with a contents page to help you find the information you need. The first section gives an overview of the program and explains the role and characteristics of a peer. You will be utilizing the problem solving approach to assist your partner in managing their medication taking; the next section will give you the steps needed to help your partner through this process. The next part is information about schizophrenia; this includes an overview of treatment, medication, side effects, and early warning signs of relapse. In this section there is information on why individuals are reluctant to take their medication and gives helpful tips on how to manage this. To assist you in communicating with your partner there is a section about communication skills. The final section gives information about the telephone contact you will have with your partner.

This manual provides a reference for you to utilize throughout the program.

A. OVERVIEW OF PEER SUPPORT

Definition of Peer Support

Peer support occurs within a one-to-one relationship between an individual who has recovered from his or her illness and a consumer with schizophrenia.

Peer support involves a give and take, building on the strengths of both the peer and his/her partner.

Peer support means providing a confidential and consistent commitment to someone in need.

The rewards a peer receives are the benefits of helping someone else and feeling good about helping.

Purpose of Peer Support

Assist consumers to identify and resolve adherence problems through the development of new skills

It is a chance to provide social and emotional support, reduce isolation and offer hope to others for the future.

It is a chance to provide information to a consumer about medication taking.

It is a chance to help consumers gain the skills and the confidence to be responsible for their own medication.

Core Elements of the Program

The peer is

- committed to contact a consumer for a period of 8 weeks
- will contact these consumers via telephone call once a week for the 8 week partnership
- provided with continuing support from the researcher through telephone calls each week and face-face contact if required
- asked to keep contact logs of telephone calls and to fill out an evaluation form following each partnership to assist in the evaluation of the peer support program

Peer Characteristics

A peer is someone who...

Acknowledges	Shares	Affirms
Respects	Educates	Facilitates
Supports	Guides	Inspires
Understands	Listens	Models
Nurtures	Enables	Has an insider's view
Knows the ropes	Tells it like it is	

A peer is also someone who is...

Enthusiastic	Insightful	Loyal
Sincere	Confidential	Interested
Patient	Caring	Sensitive
Flexible	Dependable	An Ally

The Roles of a Peer

A PEER IS NOT:

A Professional Counsellor: psychologist, psychiatrist, social worker, case manager, counsellor

An Expert on Issues: rehabilitation, medical, legal, benefits

A Provider of Direct Family Support: babysitting, housekeeping, shopping, driving, etc.

A PEER DOES:

- Facilitate trust, openness and empathy
- Accept people as they are
- Listen, clarify, help people see alternatives for decision-making
- Give advice and offer multiple solutions
- Give support and encouragement to take positive action
- Validate people without being phoney
- Respect confidentiality
- Realize that not all problems can be “fixed” and not all people want to be “helped”

A PEER DOES NOT:

- Dominate or preach
- Judge people or try to change them
- Tell people what to do
- Impose his/her own solution (i.e., “what worked for me”)
- “Rescue”, that is, do for a person what he/she can do independently
- Put people down
- Gossip about what was said in confidence by a partner
- Expect all problems to be “fixed” quickly and easily

Peer Agreement

As a peer, you will play an important part in providing emotional support and guidance to a person who is experiencing schizophrenia who is not taking their antipsychotic medication regularly.

A Peer's Responsibilities to a Consumer:

The researcher will contact you and give you the contact details of the consumer who has agreed to take part in the peer support program. This person will be considered your "partner."

- You will not release any personal information about your partner or his/her family to any unauthorized persons, including your own family and friends. Personal information may be shared with the researcher at any time.
- You will not discriminate against your partner or any member of his/her family based on race, gender, religion, national origin, sexual orientation or disability.
- You agree to respect the values and decisions of your partner and his/her family and not to attempt to impose your values upon them.
- You agree to contact your partner by telephone. In-person meetings with your partner can occur at program-related activities or in public settings.
- You agree to have regularly weekly scheduled contact with your partner, once per week for a period of 8 weeks.
- If you are unable to maintain contact with your partner, you will contact the researcher before ending the relationship.
- You understand the limits of the peer role as outlined in the training program.
- You agree to contact the researcher with concerns about your partner's emotional or mental well-being. If your partner expresses an intent to harm him/herself or others, you will:
 - **Notify the researcher immediately.**
 - If the researcher is not available and your partner is known to a trained professional, you will encourage him/her to contact this professional immediately.
 - If no professional is available, you will encourage your partner to go to the nearest psychiatric emergency room for evaluation.

A Peer's Responsibilities to the Peer support Program:

- You agree to complete any forms relative to evaluation of the peer support program.
- You agree to notify the researcher with any change in your address, phone number or changes in your availability to participate as a peer.

B. PROBLEM SOLVING

People experience problems every day. Most of the time these problems are small, such as losing keys, being late, getting stuck in traffic, or forgetting to bring the mobile phone. Some of these daily problems may be more significant, such as an argument with a friend or family member, not having enough money to pay for things, or failing to complete some work. Such problems may appear small, but over time, if they continue to grow they can cause significant stress. It is best if people can resolve their problems as early as possible.

People may also experience big problems, such as the death of a friend or loved one, moving countries, becoming ill, or losing one's job. Major problems may create additional smaller problems that may make the original problem worse. For example, a person who has a mental illness may find it difficult to carry out daily tasks, such as shopping or cleaning up. Both types of problems, big and small, may lead to additional stress.

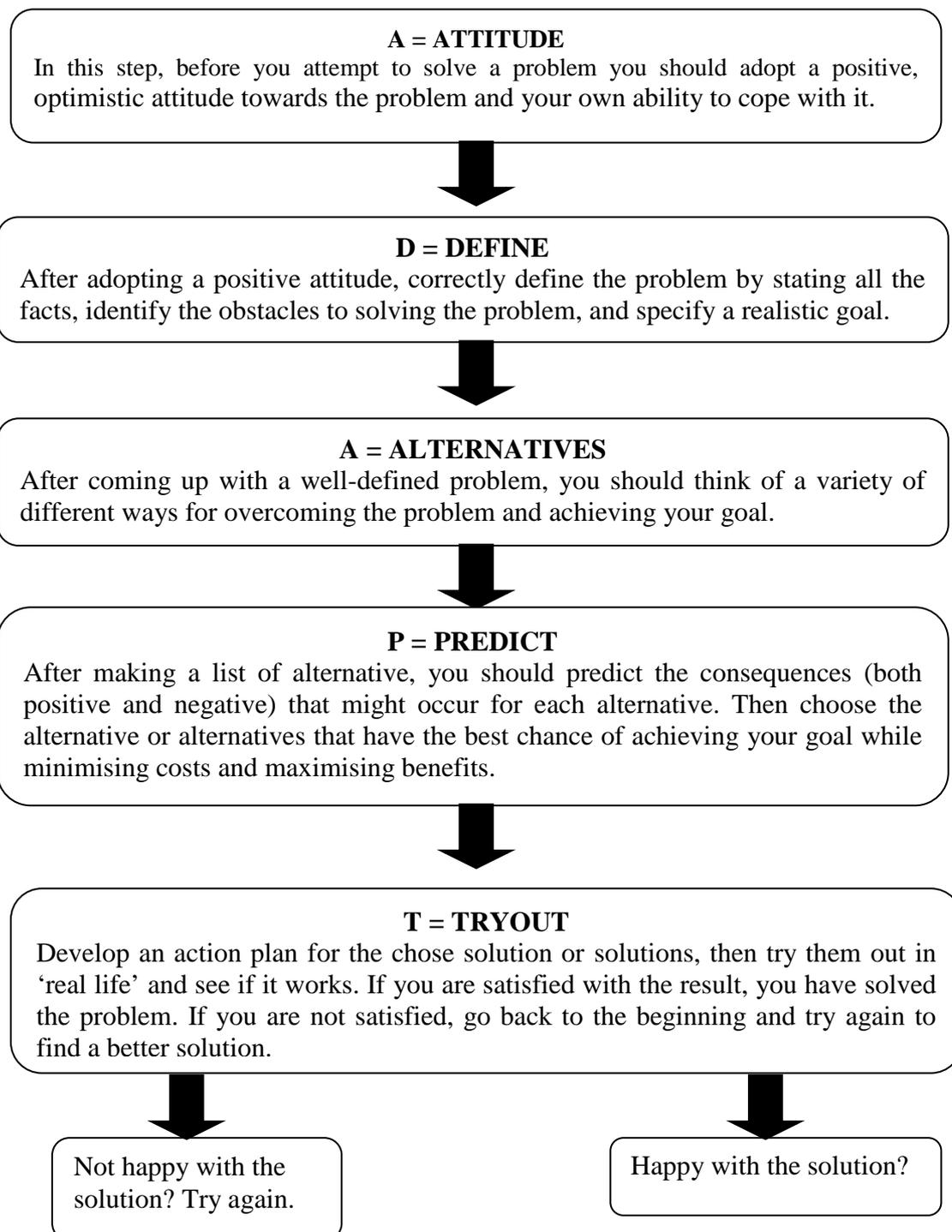
Put simply, problem solving means the person thinks about how to come up with a solution to the problem. There are a variety of problem solving methods in existence, yet they all tend to be similar. When a method is learnt and practised several times it becomes a valuable skill that can be used over and over again to help the person through everyday life.

As a peer, you will utilize problem solving to help a person identify and resolve problems with their medication taking.

The ADAPT 5-step method to effective problem solving

The ADAPT acronym refers to the idea that through problem solving a person can adapt or adjust more successfully to life's stresses and strains. This 5-step method can help a person become better at problem solving and coping with life's stresses.

The five steps to effective problem solving are:



Using the Problem Solving Process to improving medication taking

Attitude

Establish a positive therapeutic relationship with your partner

- Be warm, empathetic, and genuine
- Be enthusiastic and optimistic
- Encourage participation

Define

Discuss with partner their experiences with taking antipsychotic medication. What problems are they having?

Listen and empathize (putting yourself in their shoes and imaging how they are feeling).

Alternatives

Generate a list of alternative ways to improve medication taking. Brainstorm ideas with your partner that could improve their medication taking. What are some of the ideas that have worked for you before?

Predict

Select one of the alternative ways that you both feel may improve medication taking.

Tryout

Talk to your partner about trying out the solution in the next week.

If the solution does not work, then begin the process and go back to other alternatives.

C. SCHIZOPHRENIA

What is it?

Schizophrenia refers to a psychotic illness where the psychotic symptoms or changes in behaviour continue for at least 6 months. Positive, negative, cognitive and affective symptoms may be prominent. The symptoms and length of the illness vary from person to person. Contrary to previous beliefs, many people with schizophrenia lead fulfilling lives, with many learning to effectively manage their illness, gain employment, and start a family.

Hallucinations (false perceptions), delusions (false beliefs), paranoia (feeling persecuted), and disorganised (confused) thoughts and speech are symptoms of schizophrenia or psychosis. These symptoms can seem so real that often the person does not realise they are experiencing psychosis. Psychosis also affects feelings and behaviour.

Psychotic episodes are periods of time when symptoms of psychosis are strong and interfere with regular life. A person with psychosis may not realise that they are ill, or may not understand what is happening to them. This is called lack of insight. Although the length of episodes varies from person to person, and may only last a few hours or days, psychosis is most likely to continue for weeks, months, or even years unless the person is given appropriate treatment.

The experience of psychosis varies greatly from person to person and individuals experiencing psychosis may have very different symptoms. Some people experience symptoms of both a mood disorder and schizophrenia and this is referred to as 'schizoaffective disorder.'

What are the symptoms?

Schizophrenia causes changes in the person's mood and thinking, and behaviour. There are four main types of symptoms that occur: positive, negative, cognitive, and affective.

Positive symptoms

Positive symptoms are called 'positive' because they are viewed as 'in excess' of what people normally experience. Examples of positive symptoms include hallucinations, delusions, and disorganised thinking or behaviour.

Negative symptoms

Negative symptoms are called 'negative' because they reflect a decrease in, or loss of, normal functioning. These symptoms are often less evident than positive symptoms and require careful assessment. Examples of negative symptoms include lowered levels of motivation or drive, limited displays of emotion, not speaking very much, difficulties in thinking or coming up with ideas, and decreased ability to initiate tasks.

Cognitive symptoms

Cognitive symptoms relate to the way the person thinks. Cognitive symptoms include impairments in thinking, such as difficulties with memory and concentration, thinking more slowly, decreased ability to plan or begin tasks, and lack of insight into their illness.

Affective symptoms

Affective symptoms related to the person's mood. Affective symptoms include depressed mood (feeling low, not enjoying life, feeling worthless or hopeless), elevated mood (feeling high or overconfident) or irritability (feeling easily frustrated with others or aggressive).

What are the causes?

There are many theories, but no definite answer. The most common theories implicate genetics, a combination of vulnerability and stress, and the effect of illicit drug use.

Genetics

People have an increased risk of developing schizophrenia if they have close relatives who have the disorder. For example, the risk in the general population of developing schizophrenia is 1%. However, for children of people with schizophrenia, the lifetime risk of developing the disorder is 13% and 9% for siblings (brothers and sisters). It is important to note that a family history of schizophrenia does not mean that others in the family will definitely develop the disorder, but it is more likely if individuals are also exposed to other risk factors. The genetics of this disorder is an extremely complex issue, and at present there is limited understanding of how genetic factors increase the risk.

Neurotransmitters

There is strong evidence that psychoses involve changes to the brain's chemical messengers (neurotransmitters). Neurotransmitters are important for communicating messages throughout the brain and the central nervous system. Of particular importance is the neurotransmitter dopamine, which is thought to be increased in psychosis. Most antipsychotic drugs that control the positive symptoms of psychosis also interfere with the transmission of dopamine within the brain.

Vulnerability and stress

A person's vulnerability (susceptibility) to schizophrenia can be acquired through their genetic predisposition, or as a result of harmful environmental influences on the brain. A history of birth complications or head injuries during childhood as well as childhood trauma, have all been associated with vulnerability to this disorder. Some people may develop psychoses as a result of stress. Stressful situations include significant life events (for example, the death of a loved one, moving to a new city, starting a new job or studies), abuse of alcohol or psychoactive drugs, or stressful living conditions (for example, high levels of family conflict or financial problems). In situation like these, it is thought that if people who are vulnerable to psychosis experience excess and /or prolonged stress, they may develop psychosis.

Treatments

Treatment of schizophrenia should involve the combination of medication, stress management, psychological support, family support and life skills therapies.

Medication

Medication is essential for effective treatment of schizophrenia. It works best when combined with other forms of therapy. Medication helps relieve symptoms such as hallucinations, delusions, anxiety, agitation, mood problems, and social withdrawal. It is necessary to find the right type and dosage of medication, with the least side effects, to treat the symptoms.

The medications works well for many people; they control the illness but do not cure it.

The five main type of medication are:

- Antipsychotics.
- Medication to treat side effects (for example, anticholinergics).
- Mood stabilisers.
- Antidepressants.
- Anti-anxiety medications (anxiolytics).

Please note: The following information is provided as a guide, and is not exhaustive.

Antipsychotic medication

Antipsychotics are the main type of medication used to treat the positive and negative symptoms of schizophrenia, and they help many people return to a normal life. They help with anxiety and agitation, make the person feel less threatened, and reduce disorganised, aggressive, and manic behaviours. Generally, about four out of five people with this disorder benefit from taking antipsychotic medication.

Although these medications may control the symptoms, they do not cure it. The person has to continue taking the medication to stop symptoms returning. Even if the medication helps, the symptoms may still return. This however, is much less likely to happen if the person carries on taking medication.

A small number of people, between 5% and 25%, do not respond to the usual antipsychotics and may need to try several medications as well as other therapies to gain control over their illness.

There are two groups of antipsychotics:

- **Typical antipsychotics (older group)** – which include drugs such as chlorpromazine (Largactil) and haloperidol (Serenace). Typical antipsychotics are particularly effective in the treatment of positive symptoms (for example, hallucinations, delusions, and disorganised speech or behaviour).
- **Atypical antipsychotics (newer group)** – which include olanzapine (Zyprexa), risperidone (Risperdal), clozapine (Clozaril), quetiapine (Seroquel), amisulpride (Solian), aripiprazole (Abilify), ziprasidone (Zeldox) and paliperidone (Invega). Atypical antipsychotics are effective in the treatment of positive symptoms, and may also help negative and cognitive symptoms (for example, social withdrawal, not speaking very much, difficulties in thinking or coming up with ideas, and decreased ability to initiate tasks).

Older (typical) medications are effective, but often have more side effects than newer (atypical) medications, especially if used in high doses. Most people are prescribed newer medications, but some individuals may be prescribed older medications because they respond better to this group of drugs.

Side Effects

Antipsychotics can have a number of side effects that may need to be monitored. Fortunately, most settle within the first few weeks of beginning treatment. Studies have found that, in most instances, newer antipsychotics cause less severe side effects than older antipsychotics. While newer drugs in general have fewer effects on muscle tone and movement, some are more likely to cause weight gain and loss of sexual desire.

It is very important for the consumer to tell their case manager, psychiatrist or GP about any changes or new symptoms the person experiences as these may be side effects of the medication.

Side effects may be grouped under the following three headings:

1. General side effects

- Sedation (feeling sleepy).
- Weight gain – this is linked to increase appetite and decreased activity, but is mainly caused by changes in metabolism – the way the body uses food and converts it to energy or stores it as fat.
- Gastrointestinal problems, such as nausea (feeling sick), diarrhoea or constipation.
- Galactorrhea (excessive or inappropriate production of breast milk).
- Sexual dysfunction in males and females. For example, a drop in sexual desire in men and women, and ejaculation problems in men.
- Metabolic syndrome – this group of symptoms – weight gain and obesity, high blood sugar, high blood pressure, and high cholesterol – puts people at risk of heart disease, stroke and diabetes. The risk is increased by dietary factors, such as drinking sugary, carbonated drinks and eating a lot of fatty, sugary foods.

Everyone, especially those with a family history of diabetes, should have their blood sugar tested while taking antipsychotic medications.

Metabolic syndrome is thought to double or triple the risk of death from cardiovascular diseases.

2. *Movement disorders*

- Muscle spasm (dystonia).
- Tremor, slow movements (called Parkinsonian-like symptoms).
- Feeling restlessness or the inability to sit still (akathisia).

These side effects are more common with the older antipsychotics, but are less common today because most people are prescribed newer antipsychotics.

3. *Tardive dyskinesia*

Tardive dyskinesia is a rare effect of antipsychotic medications, which occurs in 5% of individuals, mainly those who take the older type of antipsychotics. It involves uncontrollable movements of facial muscles (for example, chewing, lip smacking).

Tardive dyskinesia usually affects the face but the limbs can also be involved. It does not usually appear until the person has been taking the medication for two or more years, and it may be irreversible.

Studies have found that newer antipsychotic medications have much lower rates of tardive dyskinesia than older antipsychotic medications.

Blood tests

If the person is taking clozapine, blood tests are initially taken weekly. This is a precaution as clozapine can reduce the number of white blood cells (cells that help fight infection) when it is first taken. Blood tests are needed for as long as the person takes clozapine, but are done less frequently (monthly) after the first six months.

Recovery

Schizophrenia is just like any other illness in that it is treatable. Most people make a good recovery but require maintenance treatment. The pattern of recovery varies from person to person. Some people recover quickly with treatment. Others may benefit from support over a longer period.

Relapse

Relapse means that the person's mental condition has deteriorated to the extent that signs and symptoms associated with the acute phase of the illness have returned. Preventing relapse is vital to the person's recovery. This can be achieved by detecting early warning signs of relapse, seeking help as soon as possible, and sticking to the treatment plan. Generally, the earlier the person gets help when showing early signs and symptoms of relapse, the better the outcome will be.

Sticking to a treatment plan involves taking medication as prescribed, maintaining a healthy lifestyle, engaging in stress management, getting support from friends, family and services, educating themselves and others about the illness, and taking part in therapy where prescribed. Unfortunately, even if the person sticks to the treatment plan, relapse is still possible, but the person will be in a better position to detect signs and symptoms earlier.

There are a number of signs and symptoms that can suggest a relapse, which may be obvious or unclear. The following two sections describe different groups of warning signs and symptoms.

Potential early warning signs and symptoms

There are signs and symptoms that suggest a relapse may occur, or they may simply be indicators of stress. In order to determine which is which, one must determine the seriousness of the signs and symptoms, taking into account how long they have been present and how much the person is affected.

Common signs and symptoms include:

- Changes in sleep patterns (too much or too little).
- Feelings of anxiety.
- Agitation.
- Depressed mood.
- Difficulties in concentrating.
- Social withdrawal
- Irritability

Definite early warning signs and symptoms

The following signs and symptoms are clear warning signs of an impending relapse. Please understand that the warning signs and symptoms may differ from those of past episodes of psychosis and from person to person. Common signs and symptoms include:

- Hallucinations
- Increasing suspiciousness
- Disorganised thoughts.
- Irrational speech.
- Bizarre behaviour.
- Severe mood swings.
- Deteriorating health.
- Excessive alcohol and drug abuse.

The best way to deal with potential and definite warning signs and symptoms is to make plans for what to do when the person experiences them. Therefore when the person starts to show signs that may be stress related or otherwise, you are to contact the researcher immediately, and the researcher will then contact the consumer's case manager, or treating doctor.

Reluctance to Take Medication

People in general do not like taking medications, and those with physical or mental illness are more likely to have problems taking prescribed medications over the long term. For most individuals with schizophrenia, medication, along with psychological treatment, is essential for recovery.

It is important to continue taking medication to prevent symptoms returning, even when the person begins to feel well.

There are different ways in which a person fails to take medication:

- Does not get the prescription on time
- Fails to take the medication.
- Takes the incorrect dose.
- Takes it at the incorrect time.
- Takes it for the incorrect reason.

There are many reasons why a person fails to take medication:

- Co-existing substance abuse, for example, psychosis and alcohol or illicit drug use.
- Troublesome side effects of antipsychotic medications.
- Having to take a number of drugs several times a day.
- Simply forgets.
- Lacks understanding of the medication and/or does not accept they have the illness.
- Specific delusions about taking medication, for example, believing the medications are poisonous, or hearing voices telling the person not to take them.
- Previous history of failure to take medications Cultural beliefs, language differences, or stigma about mental illness and/or taking medication.
- Insufficient support from carers, family and friends.
- High cost of medications, especially if the person does not hold a Concession Card that enables them to be bought at a low cost.
- Poor relationships with health professionals.
- Peer pressure.

- To date, the medication has not been effective.
- Scepticism about the long term preventative benefits of the medication.

Problems with medication taking may occur in the acute or recovery phases of the illness, but particularly during the recovery period when the person begins to feel better and thinks medication is no longer necessary. Problems with medication taking may be minor, such as forgetting, or major, where medication is refused. Major cases should be reported to the researcher, who will then contact the person's case manager or treating doctor.

Some helpful tips about managing medication taking:

- Talking to the person about the reasons why they take medication, what the medication is supposed to do, and what happens if they stop taking the medication too soon.
- Listen to complaints about side effects and encouraging the person to discuss them with their case manager or doctor.
- Encourage the person to develop a daily routine associated with taking medication, such as waking up, having breakfast, brushing teeth, and then taking medications.
- Being aware of when prescriptions need to be renewed and refilled.
- Safely discard unused or old medications.
- Talk about your experiences and give examples that the person may use.

Unhelpful things you should not do:

- Do not alter the prescribed dosage or time it should be taken
- Do not suggest supplementing the medication with herbs, vitamins or other medications.

D. COMMUNICATION SKILLS

Communication is the key to a good relationship with the person you are a partner to. The following gives you straightforward ways to have good communication skills.

Listening Skills: The Basics

Familiarize yourself with the following hints and try to use them in your conversations with your partner:

Listen to the person

Interest – take interest in your partner

Speak less than half the time

Try not to interrupt or change the topic

Evaluate what is said

Notice changes in tone of voice or speed of speaking

Positive Listening Skills

People find **HELPFUL** . . .

Saying nothing at all

Just listening

Being non-judgmental

Hearing what I say

Feeling understood

Listening and taking action

Giving unconditional acceptance

Giving encouragement

Permitting hope and belief

Helping define and focus

Allowing me to interrupt

Talking with me

Showing patience

Giving spiritual support

Having empathy

Being there

Building trust

Reassuring me

Believing I have a brain

Reinforcing my self-esteem

People find **NOT HELPFUL** . . .

Trying to provide quick fixes

Being judgmental

Doing it for me

Patronizing me

Compromising my autonomy – trying to take me over

Being condescending

Thinking “I’m not good enough”

Challenging my perceptions

Talking as if I’m not there

Making assumptions

Insinuating “I’m less than a person”

Talking at me, not talking to me

Stereotyping

Communication Enhancers

Listening

- Be quiet and pay attention. It is difficult to be a good listener when you are talking.
- Don't think ahead to what you are going to say.
- Don't interrupt.
- Listen for feelings beneath words. Try to see situations through your partner's eyes.
- Keep an open mind. Don't judge immediately. Don't allow your personal biases to affect what you are hearing.
- Encourage your partner to continue or clarify what has been said. Ask open-ended questions.
- Make eye contact, because it lets your partner know that you are paying attention and are interested.
- Pay attention to changing body language in your partner.
- Give verbal and nonverbal signs that you are listening.
- Show that you are listening by leaning forward and encouraging the speaker by saying "uh-huh" or "go on".
- Show you are listening by nodding your head. It conveys to the other person that you want to hear more.
- Check out what you understand – repeat or put into your words what you hear.

- Ask if you heard something correctly:
 - If you are right, then you know you understand, and your partner knows you understand.
 - If you are wrong, it gives the speaker an opportunity to clarify.

Levelling

- Be honest in what you say.
- Speak for yourself. Use “I” statements, instead of “you” statements.
- Deal with the other person’s real feelings.
- Don’t give unwanted advice.
- Don’t try to change someone’s feelings. Just listen and try to understand.
- Compliment your partner.

Communication Roadblocks

- Ignoring – not responding at all, or looking around the room
- Name calling or put-downs, because you don’t agree with your partner
- Directing or ordering (not allowing choice)
- Warning or threatening
- Comparing (‘why can’t you be more like...’)
- Kidding or teasing

- Advising ('If I were you...'), rather than offering suggestions
- Persuading and arguing
- Diagnosing (analyzing your partner)
- Oughting or shoulding ('You ought to know better')
- Criticizing
- Speaking for someone else ("oh, she won't mind')
- Saying 'you' when you mean 'I' ('You shouldn't do that', when you really mean 'I want you to stop that')
- Interrupting your partner before he/she is finished speaking
- Making totally unrelated (off-target) remarks
- Changing the topic before your partner has finished speaking
- Talking to someone else when your partner is talking
- Trying to 'top' your partner's story with what you think is a better one
- Denying or minimizing your partner's feelings
- Being overly sympathetic with your partner's feelings

Maintaining a Conversation with Your Partner

Stay in “synch” with your partner’s level of conversation.

- Listen for the level of conversation your partner is sharing with you and respond in a similar fashion.
 - Some conversations can be casual and/or chatty.
 - Other conversations may be more serious and/or emotional.

- Listen for the amount of conversation with which your partner is comfortable, and respond in a similar fashion.
 - Some people are more open than others and will talk easily about themselves. These individuals may require you to limit the amount of time you spend on the phone.
 - Other people may not talk at first, but once they feel comfortable, become more talkative. These individuals often do best with brief calls initially.
 - Some people are shy and prefer not to talk very much. They may do best with brief calls.
 - Some people prefer to “vent” a lot of pent up feelings and to have minimal dialogue with another person. For these individuals, the best approach is just to listen and be the sounding board for the partner.

- Humour may be a great tool in handling some difficult situations... But, be careful of using humour during an emotionally charged conversation.

Whenever possible, add structure to the conversation.

- Set a time frame for each conversation. For example, you may say:

‘I have about 20 minutes free now, and would like to talk with you. If we need more time, we can schedule it at a point later on. How does that sound?’

- Set out an agenda for each conversation. For example, you may say:

‘Let’s talk today about (re-introduce the topics discussed in the last phone call). Which one would you like to discuss?’

‘Can you tell me about what happened about (re-introduce topic) that we were talking about the last time we spoke?’

‘Did anything unusual or different happened this past week that your would like to discuss?’ (This question allows the partner to set the agenda for the conversation)

Key Phrases

Some key phrases may be helpful when you are confused about how to respond or need time to think about an answer:

‘That’s a complicated issue and I’d like some time to think about it before I respond.’

‘Sometimes it takes me a while to formulate my ideas about a topic. Let me get back to you on that after I’ve given it some thought.’

Note: It is good modelling to share with your partner that you often need additional time to think about an issue before responding

Becoming overwhelmed by own personal or emotional reactions

Sometimes issues that your partner is discussing may create intense emotional reactions in you or bring up issues that were painful for you in the past. If you feel yourself becoming overwhelmed by your own emotional reactions, there are several things that you can do:

- Share with your partner that the issue being discussed is bringing up painful memories for you as well. For example, you could say:

‘This (topic or subject) was a very difficult one for me as well, and even now I am experiencing difficulty as you discuss it.’

- Make sure that you reassure your partner that he/she has not done something wrong by discussing issues with you that made you upset.
- Reassure your partner that he/she should not feel guilty. Instead, stress how sharing painful experiences together can be helpful to both of you.
- If you continue to feel overwhelmed, arrange another call and end the conversation. You may want to discuss this further with the researcher.

Redirecting

For many reasons, including stress, your partner may wander off a given topic. The following are suggested to redirect your partner, or yourself, back to a specific topic:

‘We seem to have lost the thread of our conversation (or what we were talking about). I think we were talking about (restate topic or issue being discussed).’

‘Can we put this topic aside for a while and pick up the one that we were talking about before?’

Open-ended questions

Using open-ended questions encourages your partner to talk and avoids “yes/no” answers. Open-ended questions typically start with words like: what, where, why, how, when and who. For example, you may ask:

- ‘How do feel about that?’
- ‘What do you think about that?’
- ‘When are you going to do that activity?’
- ‘Where did you go last week?’
- ‘Why did that worry you so?’
- ‘Who told you that?’

Multiple options

For some people, open-ended questions are difficult due to difficulties with flexible thinking. In this event, offer your partner some alternatives to think about:

‘How do you feel about that issue? Do you feel A, B, or C?’

‘People often feel D, E, and F when faced with this problem. How about you?’

‘Have you thought about doing X, Y, or Z to make you feel better?’

Sharing experiences

Another way of presenting options to a person is by sharing how you or other persons have felt or responded in a similar situation. For example, you could say:

‘I had something similar happen to me and it made me feel sad. My friend who also experienced this felt angry. How do you feel?’

‘My friends had a similar experience. One told me that he did absolutely nothing, while the other complained to her doctor. What do you feel like doing?’

A word of caution ... do not get overly involved with your own experiences; instead, use your experiences and those of others as a means to get your partner to talk.

Ending your phone conversation:

It is important to finish your phone conversation within the time frame; here are some suggestions that may help end the conversation.

‘Since I only have a few more minutes to talk right now, let’s finish this topic and then make a date to speak again.’

‘Since I have only a few more minutes to talk today, can we set aside time next week to talk about (put in topic that is currently being discussed)?’

‘I’d like to have more time to spend discussing this issue with you. How about setting up some additional time to talk next week?’

E. CONTACT WITH YOUR PARTNER

Making the First Call

- When the researcher calls, she will give you the name and phone number of your partner.
- Write down this information on the Contact Log, which you will use to record information about your contacts with your partner.
- The researcher will give you times that your partner will be available to talk with you.
- You may not reach your partner directly on your first attempt. If you do not make contact by the third call, contact the researcher.
- Take a few minutes before placing the first phone call to your partner to read the following tips.
 - Be present in your phone call. This means:
 - Being attentive
 - Showing acceptance
 - Showing sincerity
 - Be aware of your physical surroundings. Things to consider include:
 - Privacy – Are there other people in the room or in the vicinity?
 - Distractions – Are there activities going on around you that will distract you?
 - Timing – Are there times of the day that are worse or better for you?
 - Be aware of your own feelings and “frame of mind” when you call.

- Stay “tuned in” to signs of changes in your own emotions.
- Select the best time for you to reach out to your partner.
- Be aware of your level of fatigue when you call. If you are too tired to talk or are not emotionally prepared to talk, call and reschedule with your partner.
- Organize yourself before starting the phone call. Make a list of issues you want to discuss with your partner. Review the list before contacting your partner, and refer to the list during the contact.

Telephone Instructions

- In an effort to protect the peer’s privacy, the peer support program will not release a peer’s phone number to a consumer. We recognize that sharing your phone number is an individual decision and one that should be made by the peer. We encourage peers to get to know their partner before giving out their phone number.
- If you are having problems getting through to your partner, you should contact the researcher.

Telephone Reimbursement

- The researcher will reimburse you for charges incurred in calling your partner and any other associated charges.

Using Contact Logs

After the first phone call (as with all later phone calls), it is extremely important that you take a few moments to record information about the call on the Contact log.

- Use a separate log for each phone call
- Write the date that you had contact with your partner
- In the space provided write down approximately how many minutes you spoke with your partner
- Use the remaining space to take additional notes about each phone conversation with your partner. For example, you may want to keep track of specific information about what you talked about and what you want to address in the next phone call.

Continuing Contacts

After the First Call

- Before making the next contact with your partner, it will be helpful to review the notes you may have taken about the last phone call. Refresh your memory about what you discussed and what you planned to discuss at the next contact, including anything you promised to do.
- If there are specific things you wish to discuss or ask your partner during the next contact, make a brief reminder list before calling, and have it available during the conversation.
- Review the suggestions discussed regarding “Making the first call” (page 35). For example, “being present”, “being aware of your surroundings” and the other points to ensure a good phone contact.
- Record any information you would like to remember about the call in note pad including the time you agreed to next contact your partner.

Final Contact with Your Partner

- Prior to making the final contact with your partner, review the notes you may have taken. It may be helpful to think about prior issues, areas of concern and the progression of the relationship.
- If there are specific things you wish to discuss or ask your partner during the final contact, make a brief reminder list before calling and have it available during the conversation.
- After your final contact with your partner, the researcher will contact you to discuss any additional issues regarding your partner or thoughts you may have regarding your experience as a peer.

F. Emergency and Crisis Numbers

Fire, Police, Ambulance	000
Mid West Area Mental Health Service MWAMHS	9288 7000
Lifeline 24 hour counselling service for everyone	13144
SANE Mental illness helpline operating Mon-Fri 9-5pm	1800 187263

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5. What is your highest level of education?

- | | |
|-----------------------|----------------------------|
| No formal education | <input type="checkbox"/> 1 |
| Primary school | <input type="checkbox"/> 2 |
| Secondary/High school | <input type="checkbox"/> 3 |
| TAFE | <input type="checkbox"/> 4 |
| University | <input type="checkbox"/> 5 |

6. Do you currently have any form of paid employment?

- | | |
|-----------|----------------------------|
| None | <input type="checkbox"/> 1 |
| Casual | <input type="checkbox"/> 2 |
| Part time | <input type="checkbox"/> 3 |
| Full time | <input type="checkbox"/> 4 |

7. Which mental health service supports you?

- | | |
|----------------------|----------------------------|
| Continuing Care Team | <input type="checkbox"/> 1 |
| Mobile Support Team | <input type="checkbox"/> 2 |
| Community Care Units | <input type="checkbox"/> 3 |

8. How often do you have contact with your mental health service?

- | | |
|--------------------------------|----------------------------|
| Every day | <input type="checkbox"/> 1 |
| 2-3 times a week | <input type="checkbox"/> 2 |
| 4-6 times a week | <input type="checkbox"/> 3 |
| Once a week | <input type="checkbox"/> 4 |
| Fortnightly | <input type="checkbox"/> 5 |
| Monthly | <input type="checkbox"/> 6 |
| Other – (Please specify below) | <input type="checkbox"/> 7 |

9. Are you satisfied with the contact you have with your mental health team?

- | | |
|----------------------------------|----------------------------|
| I am satisfied with the contact | <input type="checkbox"/> 1 |
| Would like more frequent contact | <input type="checkbox"/> 2 |
| Would like less contact | <input type="checkbox"/> 3 |

10. How long have you had your illness?

11. What is the total number of medications you take each day?

12. When do you usually take these medications?

(Tick as many boxes as necessary)

- | | | |
|------------|--------------------------|---|
| Morning | <input type="checkbox"/> | 1 |
| Lunchtime | <input type="checkbox"/> | 2 |
| Teatime | <input type="checkbox"/> | 3 |
| Before bed | <input type="checkbox"/> | 4 |

13. What **oral** antipsychotic medications are you currently prescribed for your illness?

Atypical (Tick as many boxes as necessary)

- | | | |
|------------------------------|--------------------------|---|
| Clozapine (Clozaril) | <input type="checkbox"/> | 1 |
| Olanzapine (Zyprexa) | <input type="checkbox"/> | 2 |
| Quetiapine (Seroquel) | <input type="checkbox"/> | 3 |
| Risperidone (Risperdal) | <input type="checkbox"/> | 4 |
| Other (please specify below) | <input type="checkbox"/> | 5 |

Typical (Tick as many boxes as necessary)

- | | | |
|--|--------------------------|----|
| Chlorpromazine (Largactil, Protran) | <input type="checkbox"/> | 6 |
| Haloperidol (Serenace) | <input type="checkbox"/> | 7 |
| Pimozide (Orap) | <input type="checkbox"/> | 8 |
| Thioridazine (Melleril, Aldazine) | <input type="checkbox"/> | 9 |
| Thiothixene (Navane) | <input type="checkbox"/> | 10 |
| Trifluoperazine (Stelazine, Calmazine) | <input type="checkbox"/> | 11 |
| Other (please specify below) | <input type="checkbox"/> | 12 |

14. Are you **currently** taking any **other** medications that are prescribed by your doctor?

If so, can you tell me the names of these medications?

15. Are you **currently** taking any **other** medications that are prescribed by other doctors?

If so, can you tell me the names of these medications?

16. Are you currently taking any **unprescribed over-the-counter** medications (e.g. that were bought in a supermarket)?

If so, can you tell me the names of these medications?

17. Are you currently using any **recreational substances**, such as nicotine, alcohol, marijuana or speed?

Yes (proceed to the next question) 1

No (proceed to question 19) 2

18. Have you used any of the following **recreational substances** in the past 4 weeks?

(Tick as many boxes as necessary)

- | | |
|---|----------------------------|
| Alcohol | <input type="checkbox"/> 1 |
| Nicotine | <input type="checkbox"/> 2 |
| Marijuana (grass, cannabis, mull, pot, dope, yarndi) | <input type="checkbox"/> 3 |
| Amphetamines (speed, goey, whiz, ice, crystal meth, base) | <input type="checkbox"/> 4 |
| Heroin (Smack, H, Skag, junk, China-White) | <input type="checkbox"/> 5 |
| Cocaine (Crack) | <input type="checkbox"/> 6 |
| Ecstasy (Adam, XTC) | <input type="checkbox"/> 7 |
| Rohypnol | <input type="checkbox"/> 8 |
| Other (specify below) | <input type="checkbox"/> 9 |

19. Have you experienced any **annoying** side effects from taking your antipsychotic medications?

- Yes 1
No 2

20. Approximately how many times over the past 4 weeks did you miss taking your prescribed antipsychotic medications?

Please expand

21 What were the reasons for not taking your prescribed antipsychotic medication?

(Tick as many boxes as necessary)

- I forgot 1
Side effects of the medication 2
I feel that they are making me worse 3
I do not believe I need them anymore 4
I do not believe they are doing me any good 5
Voices tell me to stop taking them 6
Discouraged by family/friends 7
Other (please specify below) 8

APPENDIX 5

BRIEF PSYCHIATRIC RATING SCALE (BPRS)

ID# _____ Date: _____ Baseline / 8week / 14week

(Circle)

Please enter the score for the term that best represents the level of severity for each symptom in the **PAST WEEK**.

0 = Not assessed, 1 = Not present, 2 = Very mild, 3 = Mild, 4 = Moderate, 5 = Moderately severe, 6 = Severe, 7 = Extremely severe

Score

1. SOMATIC CONCERN
Preoccupation with physical health, fear of physical illness, hypochondriasis.
2. ANXIETY
Worry, fear, over-concern for present or future, uneasiness.
3. DEPRESSION
Sadness, unhappiness, anhedonia, preoccupation with depressing topics, hopelessness, loss of self esteem.
4. SUICIDALITY
Expressed desire, intent or actions to harm or kill oneself. Has felt as though life is not worth living, or felt like ending it all. If reports suicidal ideation, does the consumer have a specific plan?
5. GUILT FEELINGS
Self-blame, shame, remorse for past behaviour.
6. HOSTILITY
Animosity, contempt, belligerence, disdain for others.
7. ELEVATED MOOD
A pervasive, sustained and exaggerated feeling of wellbeing, cheerfulness, euphoria, optimism that is out of proportion to the circumstances.
8. GRANDIOSITY
Exaggerated self-opinion, arrogance, conviction of unusual power or abilities.
9. SUSPICIOUSNESS
Mistrust, belief others harbour malicious or discriminatory intent.
10. HALLUCINATIONS
Reports perceptual experiences in the absence of relevant external stimuli
11. UNUSUAL THOUGHT CONTENT
Unusual, odd, strange, bizarre thought content.

12. BIZARRE BEHAVIOUR
Reports of behaviours which are odd, unusual or psychotically criminal. Not limited to interview period. Include inappropriate sexual behaviour and inappropriate affect.
13. SELF NEGLECT
Hygiene, appearance or eating behaviour below usual expectations, below socially acceptable standards, or life threatening.
14. DISORIENTATION
Confusion or lack of proper association for person, place or time.
15. CONCEPTUAL DISORGANIZATION
Thought processes confused, disconnected, disorganized, disrupted.
16. BLUNTED AFFECT
Reduced emotional tone, reduction in formal intensity of feelings, flatness.
17. EMOTIONAL WITHDRAWAL
Lack of spontaneous interaction, isolation deficiency in relating to others.
18. MOTOR RETARDATION
Slowed, weakened movements or speech, reduced body tone.
19. TENSION
Physical and motor manifestations of nervousness, over-activation.
20. UNCOOPERATIVENESS
Resistance, guardedness, rejection of authority.
21. EXCITEMENT
Heightened emotional tone, agitation, increased reactivity.
22. DISTRACTIBILITY
Degree to which observed sequences of speech and actions are interrupted by stimuli unrelated to interview. Distractibility is rate when consumer shows a change in the focus of attention or marked shift in gaze.
23. MOTOR HYPERACTIVITY
Increase in the energy level evidenced by more frequent movement and/or rapid speech.
24. MANNERISMS AND POSTURING
Peculiar, bizarre, unnatural motor behaviour (not including tic).

APPENDIX 6

LIVERPOOL UNIVERSITY NEUROLEPTIC SIDE EFFECT RATING SCALE
(LUNSERS)

ID# _____ Date: _____ Baseline / 8week / 14week (Circle)

The following questionnaire contains information about medication side effects**Please indicate how much you have experienced each of the following symptoms in the last month by ticking the appropriate boxes.**

	NOT AT ALL	VERY LITTLE	A LITTLE	QUITE A LOT	VERY MUCH
1. Rash	<input type="checkbox"/>				
2. Difficulty staying awake during the day.	<input type="checkbox"/>				
3. Runny nose.	<input type="checkbox"/>				
4. Increased dreaming.	<input type="checkbox"/>				
5. Headaches.	<input type="checkbox"/>				
6. Dry mouth.	<input type="checkbox"/>				
7. Swollen or tender chest.	<input type="checkbox"/>				
8. Chilblains	<input type="checkbox"/>				
9. Difficulty in concentrating.	<input type="checkbox"/>				
10. Constipation.	<input type="checkbox"/>				
11. Hair loss.	<input type="checkbox"/>				
12. Urine darker than usual.	<input type="checkbox"/>				
13. Period problems.	<input type="checkbox"/>				
14. Tension.	<input type="checkbox"/>				

- | | | | | | |
|---------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 15. Dizziness. | <input type="checkbox"/> |
| 16. Feeling sick. | <input type="checkbox"/> |
| 17. Increased sex drive. | <input type="checkbox"/> |
| 18. Tiredness. | <input type="checkbox"/> |
| 19. Muscle stiffness | <input type="checkbox"/> |
| 20. Palpitations. | <input type="checkbox"/> |
| 21. Difficulty in remembering things. | <input type="checkbox"/> |
| 22. Losing weight. | <input type="checkbox"/> |
| 23. Lack of emotions. | <input type="checkbox"/> |
| 24. Difficulty in achieving climax. | <input type="checkbox"/> |
| 25. Weak fingernails. | <input type="checkbox"/> |
| 26. Depression. | <input type="checkbox"/> |
| 27. Increased sweating. | <input type="checkbox"/> |
| 28. Mouth ulcers. | <input type="checkbox"/> |
| 29. Slowing of movements | <input type="checkbox"/> |
| 30. Greasy skin. | <input type="checkbox"/> |
| 31. Sleeping too much. | <input type="checkbox"/> |
| 32. Difficulty passing water. | <input type="checkbox"/> |
| 33. Flushing of face. | <input type="checkbox"/> |

- | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 34. Muscle spasms. | <input type="checkbox"/> |
| 35. Sensitivity to sun. | <input type="checkbox"/> |
| 36. Diarrhoea. | <input type="checkbox"/> |
| 37. Over-wet or drooling mouth | <input type="checkbox"/> |
| 38. Blurred vision. | <input type="checkbox"/> |
| 39. Putting on weight. | <input type="checkbox"/> |
| 40. Restlessness | <input type="checkbox"/> |
| 41. Difficulty getting to sleep.. | <input type="checkbox"/> |
| 42. Neck muscles aching. | <input type="checkbox"/> |
| 43. Shakiness. | <input type="checkbox"/> |
| 44. Pins and needles. | <input type="checkbox"/> |
| 45. Painful joints. | <input type="checkbox"/> |
| 46. Reduced sex drive. | <input type="checkbox"/> |
| 47. New or unusual skin marks. | <input type="checkbox"/> |
| 48. Parts of body moving of their own accord eg foot moving up and down. | <input type="checkbox"/> |
| 49. Itchy skin. | <input type="checkbox"/> |
| 50. Periods less frequent. | <input type="checkbox"/> |
| 51. Passing a lot of water. | <input type="checkbox"/> |

APPENDIX 7

Satisfaction with Antipsychotic Medication Scale (SWAM)

ID# _____ Date: _____ Baseline / 8week / 14week
(Circle)

Strongly disagree 1	Disagree 2	Neutral 3	Agree 4	Strongly agree 5
------------------------	---------------	--------------	------------	---------------------

The following questionnaire measures patient's satisfaction with antipsychotic medication. Please choose the most appropriate number (see above) that applies to you.

Section A: Treatment Acceptability

- | | | | | | | |
|-----|--|---|---|---|---|---|
| 1. | I am involved in treatment decisions. | 1 | 2 | 3 | 4 | 5 |
| 2. | If someone said I have a mental illness they would be correct. | 1 | 2 | 3 | 4 | 5 |
| 3. | It is likely that the symptoms of my illness will persist. | 1 | 2 | 3 | 4 | 5 |
| 4. | The consequences of not taking my antipsychotic medication(s) are severe. | 1 | 2 | 3 | 4 | 5 |
| 5. | My health professionals (eg. doctors/nurses) know best. | 1 | 2 | 3 | 4 | 5 |
| 6. | Antipsychotic medication enables me to be independent (eg. carry out everyday activities). | 1 | 2 | 3 | 4 | 5 |
| 7. | It is important to take my antipsychotic medication even when I feel better. | 1 | 2 | 3 | 4 | 5 |
| 8. | My antipsychotic medication makes me feel better. | 1 | 2 | 3 | 4 | 5 |
| 9. | Antipsychotic medication is helpful to me. | 1 | 2 | 3 | 4 | 5 |
| 10. | I feel motivated to take my antipsychotic medication. | 1 | 2 | 3 | 4 | 5 |
| 11. | I am satisfied with the information provided to me about the possible side effects caused by my antipsychotic medication. | 1 | 2 | 3 | 4 | 5 |
| 12. | I am satisfied with the outcome of my last discussion with my health professionals (eg. doctors/nurses) about my antipsychotic medication. | 1 | 2 | 3 | 4 | 5 |
| 13. | Antipsychotic medication prevents future problems. | 1 | 2 | 3 | 4 | 5 |
| 14. | I am satisfied with the way health professionals have dealt with the side effects of my antipsychotic medication. | 1 | 2 | 3 | 4 | 5 |
| 15. | I am satisfied with the communication between myself and health professionals about my antipsychotic medication. | 1 | 2 | 3 | 4 | 5 |

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	2	3	4	5

Section B: Medication insight

16.	Antipsychotic medication interferes with my Everyday activities.	1	2	3	4	5
17.	By taking antipsychotic medication, I do not have control	1	2	3	4	5
18.	Non-drug treatments are more beneficial to me than antipsychotic medication.	1	2	3	4	5
19.	I am embarrassed to be seen taking my antipsychotic medication.	1	2	3	4	5
20.	I am dissatisfied with my antipsychotic medication.	1	2	3	4	5
21.	It's okay to forget to take my antipsychotic medication.	1	2	3	4	5
22.	It's okay to alter the amount of antipsychotic medication I take.	1	2	3	4	5
23.	I find it unpleasant to take my antipsychotic medication.	1	2	3	4	5
24.	I am dissatisfied with the alternative treatment options available to me.	1	2	3	4	5

APPENDIX 8

**Quality of Life Enjoyment and Satisfaction Questionnaire
(Q-LES-Q-18)**

ID# _____ Date: _____ Baseline / 8week / 14week (Circle)

Not at all/Never	Rarely	Sometimes	Often/most of the time	frequently/all of the time
1	2	3	4	5

The following questionnaire measures the quality of life domains of physical health, subjective feelings, leisure time activities and social relationships. Please choose the most appropriate number (see above) that applies to you. If there are any statements you don't feel comfortable responding to, please feel free to miss them out.

During the past week how much of the time have you...

1.	felt at least in very good physical health.	1	2	3	4	5
2.	been free of worry about your physical health.	1	2	3	4	5
3.	felt good physically.	1	2	3	4	5
4.	felt full of pep and vitality	1	2	3	4	5
5.	felt satisfied with your life.	1	2	3	4	5
6.	felt happy or cheerful.	1	2	3	4	5
7.	felt able to communicate with others.	1	2	3	4	5
8.	felt able to travel about to get things done when needed (e.g. walk, use car, bus, or train).	1	2	3	4	5
9.	felt able to take care of yourself?	1	2	3	4	5

The following questions refer to leisure time-activities such as watching TV, reading the paper or magazines, tending house plants or gardening, hobbies, going to museums or the movies, or to sports events, etc?

10.	How often did you enjoy the leisure activities?	1	2	3	4	5
11.	How often did you concentrate on the leisure activities and pay attention to them?	1	2	3	4	5
12.	If a problem arose in your leisure activities, how often did you solve it or deal with it without undue stress?	1	2	3	4	5

During the past week how often have you...

13.	looked forward to getting together with friends or relatives	1	2	3	4	5
-----	--	---	---	---	---	---

Not at all/Never	Rarely	Sometimes	Often/most of the time	frequently/all of the time
1	2	3	4	5

14.	enjoyed talking with co-workers or neighbors?	1	2	3	4	5
15.	felt affection toward one or more people?	1	2	3	4	5
16.	joked or laughed with other people?	1	2	3	4	5
17.	felt you met the needs of friends or relatives?	1	2	3	4	5

Taking everything into consideration, during the past week how satisfied have you been with your...

18.	antipsychotic medication?	1	2	3	4	5
-----	---------------------------	---	---	---	---	---

APPENDIX 9

Consumer Intervention Evaluation Questionnaire

Thank you for consenting to take part in this study. You do not have to answer all the questions but it will be much appreciated if you do. You will not be asked to give your name or address and all answers will be treated with total confidentiality.

ID# _____ Date: _____

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	2	3	4	5

The following questions ask your opinion about the peer support program. Please choose the most appropriate number (see above) that applies to you.

- | | | | | | |
|---|---|---|---|---|---|
| 1. Each telephone call was long enough. | 1 | 2 | 3 | 4 | 5 |
| 2. The space between the calls was about right. | 1 | 2 | 3 | 4 | 5 |
| 3. The length of the program was about right. | 1 | 2 | 3 | 4 | 5 |
| 4. Telephone conversation was a convenient way to deliver the program. | 1 | 2 | 3 | 4 | 5 |
| 5. Overall, program provided helpful information on improving medication taking. | 1 | 2 | 3 | 4 | 5 |
| 6. I was satisfied with the content of the program. | 1 | 2 | 3 | 4 | 5 |
| 7. The program did not help improve my medication taking. | 1 | 2 | 3 | 4 | 5 |
| 8. The program helped me to resolve problems about my medication taking. | 1 | 2 | 3 | 4 | 5 |
| 9. The program made a positive difference to how I felt about taking my medication. | 1 | 2 | 3 | 4 | 5 |
| 10. The program made a positive difference to my life. | 1 | 2 | 3 | 4 | 5 |
| 11. The program was supportive. | 1 | 2 | 3 | 4 | 5 |
| 12. It was easy to talk to the peer about my medication | 1 | 2 | 3 | 4 | 5 |
| 13. I would like to continue with the peer support program in the future. | 1 | 2 | 3 | 4 | 5 |
| 14. The program has helped me talk about my medication issues with my case manager. | 1 | 2 | 3 | 4 | 5 |

Can you think of anything else that would improve the peer support program?

APPENDIX 10

Peer Intervention Evaluation Questionnaire

Thank you for consenting to take part in this study. You do not have to answer all the questions but it will be much appreciated if you do. You will not be asked to give your name or address and all answers will be treated with total confidentiality.

ID# _____ Date: _____

Strongly disagree agree	Disagree	Neutral	Agree	Strongly
1	2	3	4	5

The following questions ask your opinion about the peer support program. Please choose the most appropriate number (see above) that applies to you.

- | | | | | | | |
|-----|---|---|---|---|---|---|
| 1. | Each telephone call was long enough. | 1 | 2 | 3 | 4 | 5 |
| 2. | The space between the calls was about right. | 1 | 2 | 3 | 4 | 5 |
| 3. | The length of the program was about right. | 1 | 2 | 3 | 4 | 5 |
| 4. | Telephone conversation was a convenient way to deliver the program. | 1 | 2 | 3 | 4 | 5 |
| 5. | Overall, the program provided helpful information on improving medication taking. | 1 | 2 | 3 | 4 | 5 |
| 6. | I was satisfied with the content of the program. | 1 | 2 | 3 | 4 | 5 |
| 7. | I found it difficult to talk to the consumer about their medication. | 1 | 2 | 3 | 4 | 5 |
| 8. | The program should have been more structured. | 1 | 2 | 3 | 4 | 5 |
| 9. | I had difficulty contacting the consumer by telephone. | 1 | 2 | 3 | 4 | 5 |
| 10. | It was a worthwhile experience being a peer. | 1 | 2 | 3 | 4 | 5 |
| 11. | The preparation for the peer role was satisfactory. | 1 | 2 | 3 | 4 | 5 |
| 12. | I received adequate support from the researcher. | 1 | 2 | 3 | 4 | 5 |
| 13. | I was given enough information to carry out the role of peer support. | 1 | 2 | 3 | 4 | 5 |
| 14. | I would like to continue with peer support in the future. | 1 | 2 | 3 | 4 | 5 |

Can you think of anything that would improve the peer support program?

Questions for peers

The following questions are about your expectations of the peer support program

1. What initially attracted you to participate in the program?
2. What initial expectations did you have about the program?
 - Having completed your involvement in the program, to what extent, if any, were these initial expectations fulfilled?

The following questions are about your preparation for the peer support program

1. Tell me about your overall impressions of the preparation you were given for involvement in the program?
 - What suggestions, if any, have you about improving the preparation you were given for involvement in the program?

The following questions are about the operation of the peer support program

2. Tell me about your overall impressions of the telephone intervention approach to peer support?
 - What suggestions, if any, have you about improving the telephone intervention approach to peer support?
 - What alternative suggestions, if any, have you to using a telephone based intervention?
3. Tell me about your overall impressions of the problem solving approach used in the program?
 - What suggestions, if any, have you about improving the problem solving approach?
4. Tell me about your overall impressions of the peer support approach used in the program?
 - What suggestions, if any, have you about improving the peer support approach?

The following questions are about the support you received from myself throughout the peer support program

5. Tell me about your overall impressions of the support you received throughout the program?
6. What suggestions, if any, have you about improving the support you received throughout the program?

The following questions are about your own mental wellbeing as a result of being involved in the peer support program

7. In relation to your own mental health wellbeing, what were the good things you experienced, if any, about being involved in the program.
8. In relation to your own mental health wellbeing, what were the difficulties you experienced, if any, about being involved in the program.
9. In relation to your own mental health wellbeing, what suggestions have you, if any, about modifying the program to support your mental wellbeing?

The following questions are about your overall experience of being involved in the peer support program

10. Overall, what good things, if any, did you experience as a result of being involved in the program?
11. Overall, what difficulties, if any, did you experience as a result of being involved in the program?
12. If the program was adopted by community mental health centres on an ongoing basis, would you be willing to be involved as a peer?

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Mental Health Research and Ethics Committee Approval Certificate

The MHREC operates in accordance with the *NHMRC National Statement on Ethical Conduct in Human Research 2007*

MHREC Project No: 2008.38 This is to certify that Approval date: 01/10/2008 Expiry date: 30/09/2011

Project Title: **A peer support intervention program for enhancing medication adherence in consumers with schizophrenia**

Principal Investigator: Professor Terence McCann
 Professor of Nursing Research
 School of Nursing and Midwifery
 Victoria University

Sponsored by: N/A

Protocol No: N/A

Participant Information and Consent Form: Version 1, Dated August 19th 2008 (Peer and Consumer)

Investigator Brochure: N/A

Conducted at: Mid West Area Mental Health Service has been approved.

This proposal meets the requirements of the *NHMRC National Statement on Ethical Conduct in Human Research 2007*.

It is now your responsibility to ensure that all people conducting this research project are made aware of which documents have been approved.

This approval is subject to ongoing, current and valid insurance coverage throughout the duration of the conduct of the study.

You are required to notify the Manager of the Mental Health Research and Ethics Committee of:

- Any change in the protocol and the reason for that change together with an indication of ethical implications (if any) by submitting an amendment to the study;
- Serious adverse effects on subjects and the action taken to manage them, including an amended Patient Information and Consent Form where appropriate;
- Any unforeseen events;
- Your inability to continue as Principal Investigator, or any other change in research personnel involved in the study;
- A delay of more than 12 months in the commencement of the project; and
- The actual date of commencement of the study.

You are required to submit the following reports to the Mental Health Research and Ethics Committee:

- An Annual Report every twelve months for the duration of the project; and
- A detailed Final Report at the conclusion of the project.

The Mental Health Research and Ethics Committee may conduct an audit at any time.

An extension of the project beyond the stated conclusion date should be sought from the Mental Health Research and Ethics Committee.

Signed:

A black rectangular box redacting the signature of the Manager.

Michelle Clemson
 Manager
 Mental Health Research and Ethics Committee

APPENDIX 13

MEMO

TO	Prof Terence McCann School of Nursing and Midwifery St Albans Campus	DATE	29/09/2008
FROM	Dr Harriet Speed Chair Victoria University Human Research Ethics Committee		
SUBJECT	Ethics Application – HRETH 08/136		

Dear Prof McCann

Thank you for submitting this application for ethical approval of the project:

HRETH 08/136 A time series intervention study of a peer support program for enhancing medication adherence in consumers with schizophrenia

The proposed research project has been accepted and deemed to meet the requirements of the National Health and Medical Research Council (NHMRC) 'National Statement on Ethical Conduct in Human Research (2007)' by the Victoria University Human Research Ethics Committee. Approval has been granted from 29 September 2008 to 28 September 2010.

Continued approval of this research project by the Victoria University Human Research Ethics Committee (VUHREC) is conditional upon the provision of a report within 12 months of the above approval date (by **29 September 2009**) or upon the completion of the project (if earlier). A report proforma may be downloaded from the VUHREC web site at: <http://research.vu.edu.au/hrec.php>

Please note that the Human Research Ethics Committee must be informed of the following: any changes to the approved research protocol, project timelines, any serious events or adverse and/or unforeseen events that may affect continued ethical acceptability of the project. In these unlikely events, researchers must immediately cease all data collection until the Committee has approved the changes. Researchers are also reminded of the need to notify the approving HREC of changes to personnel in research projects via a request for a minor amendment.

If you have any queries, please do not hesitate to contact me on 9919 5412.

On behalf of the Committee, I wish you all the best for the conduct of the project.

Dr Harriet Speed
Chair
Victoria University Human Research Ethics Committee