Treatment Adherence Among People with Schizophrenia: An Application of the Theory of Planned Behaviour

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Abstract

Schizophrenia is a severe and persistent psychiatric disorder that, for most sufferers, responds well to a range of pharmacological and psychosocial treatment options. However, management of symptoms and ability to function independently rely on individuals with a diagnosis of schizophrenia engaging in treatment. This study, employing a qualitative methodology, applied a Theory of Planned Behaviour framework to determine whether people with schizophrenia do make reasoned decisions about treatment adherence and, if so, to identify what are the factors that may influence decision-making.

Semi structured interviews were conducted with a purposively selected sample of twelve people living in community settings in parts of the Otago region serviced by the Southern District Health Board (Dunedin City, North and South Otago). Participants had a diagnosis of schizophrenia for which they had received treatment. Theoretical thematic analysis based on the Theory of Planned Behaviour was applied to data.

The study found that while all participants had received anti-psychotic medication, they reported limited experience of receiving psychosocial treatment interventions. The main influence on their decisions to adhere to treatment for schizophrenia was their attitude towards treatment, which in turn were influenced by their beliefs about the benefit of treatments (the likelihood that treatment would contribute to a desired outcome or prevent something undesirable happening), which was based on information from a variety of sources. The subjective normative expectations of others and the perceptions of what people with schizophrenia known to the respondents were doing in regard to treatment was also found to influence treatment decisions.
Overall the study found that people with schizophrenia do make reasoned decisions to adhere to treatment. This finding has implications for professionals working with people with a diagnosis of schizophrenia who do not adhere to treatment tasks. If the reasons for non-adherence can be identified then they can be addressed utilising psychosocial treatment interventions.
Preface

For the past eight years my social work practice has been in the field of psychiatric disabilities, assessing practical support needs and co-ordinating community and residential support packages with the objective of assisting people to manage the tasks of independent living. Approximately half of the people I have worked with have suffered from schizophrenia that proved disabling to some degree. I estimate that most of those people experienced symptom relapse requiring hospitalisation, usually as a result of treatment non-adherence, at least once during the course of their illness. I have witnessed the effects of relapse on some of these people, and others have reported to me experiences that were distressing for themselves and their loved ones. It has been difficult for my clients to talk about their relapses, and the reasons they stopped taking medication has not been clear in all cases. A focus of treatment post-relapse is to ensure medication compliance, and my role in this typically is to arrange a medication supervision service. I recall one particular request from a clinician to arrange this service for a client; when I asked why the client had stopped taking medication, the clinician responded “does it matter?”

I believe it does matter. Forgetting to take medication is different to refusing to take medication. Refusing to take medication because the voices said so is different to not taking medication because of debilitating side effects. I have heard from many clients that it matters to them that clinicians attempt to understand the reasons they have ceased (or wanted to cease) treatment. I believe generally clinicians do try hard to determine the reasons people with schizophrenia stop treatment; however, this may not be easy during the acute illness phase and my impression is clinicians may be largely working on assumptions. I think it is important to identify as closely as possible what causes individuals to cease treatment, in order to know when and how to intervene to prevent relapse.
With this in mind I set out to study the factors that influence decisions to adhere to treatment for schizophrenia, in early stages and during the long term course of illness.
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Chapter 1 – Introduction

Schizophrenia is a severe and persistent psychiatric disorder that, for most sufferers, responds well to a range of pharmacological and psychosocial treatment options. However, management of symptoms and ability to function independently rely on individuals with a diagnosis of schizophrenia engaging with mental health services and adhering to treatment recommended by clinicians.

Schizophrenia is included in the Diagnostic and Statistical Manual (DSM-5) for classification of psychotic disorders (American Psychiatric Association, 2013). Features of schizophrenia include symptoms (such as delusions, hallucinations, disorganized thinking and speech, grossly disorganised or abnormal motor behaviour) and social or occupational dysfunction. (American Psychiatric Association, 2013). McGrath, Saha, Chant, and Welham (2008) report a worldwide lifetime prevalence of schizophrenia estimate of .43%. In New Zealand, the most recent estimated prevalence (2000 – 2003) was .41% (Kake, Arnold, & Ellis, 2008), potentially affecting 15,000 adults nationwide and approximately 700 people in Otago.

Treatment for schizophrenia commonly involves the use of antipsychotic medication, and can also include a range of evidence-based psycho-social interventions such as social skills training, family psycho-education, cognitive therapy and cognitive rehabilitation (Bellack, Gold, & Buchanan, 1999). In New Zealand, treatment in the acute phase of illness targets the most severe psychotic symptoms, and often occurs in a psychiatric inpatient setting. Medication treatment can be aggressive and people commonly experience unpleasant side effects, which can be distressing both for patients and their families. During sub-acute and maintenance illness phases, treatment is typically provided
by community mental health teams, supported by non-government organisations (Southern District Health Board, n.d.).

Engaging individuals with schizophrenia in treatment can be challenging, with many not taking up treatment, or ceasing treatment against the advice, or without the knowledge of practitioners involved in their care. Zygmunt, Olfson, Boyer, and Mechanic (2002) report rates of medication non-compliance among people with schizophrenia to be as high as 50% in the 12 months following discharge from hospital, and that the risk of relapse is almost four times higher for non-adherent patients than adherent patients. Medication non-compliance in schizophrenia has been linked to a number of factors, including patients’ lack of insight into their illness and attitude toward treatment, ambivalence toward change and treatment, a poor therapeutic alliance and cognitive deficits (O'Donnell et al., 2003; Zygmunt et al., 2002). Non-compliance is associated with an increased potential for dangerous behaviours and assaults, particularly in patients experiencing psychosis (Zygmunt et al., 2002). O'Donnell et al. (2003) report two thirds of people admitted to hospital with symptoms of schizophrenia are non-compliant with medication.

It has been assumed that neuro-cognitive deficits caused by a schizophrenic illness affect a person’s ability to perform functional activities related to schizophrenia (Mausbach et al., 2013). Treatment non-adherence could be attributed to this, and therefore beyond an individual’s control. Alternatively, it could be that sufferers of schizophrenia do have agency in the decisions to engage in treatment despite the negative effects of their illness, and if this is the case research into the factors that influence these decisions is warranted, as it can contribute to efforts to increase treatment engagement among this population.

The primary objective of this study is to identify factors that influence an individual’s decisions to adhere to treatment for schizophrenia. In order to meet this objective, a suitable
theoretical framework to apply to the topic is necessary. A number of theoretical frameworks have been used to understand a variety of health behaviours. Common to these frameworks is a decision-making process that involves a rational consideration of all available information pertaining to the health behaviour. Protection Motivation Theory considers the relationship between an individual’s fear and likelihood of a severe health threat, and their desire to take protective action against the threat (Rogers, 1975). The Health Belief Model proposes individuals make decisions regarding health behaviours based on perceptions about their susceptibility to illness and the severity of the illness, and the benefits of taking action weighed against the costs of or barriers to action (Irwin M. Rosenstock, 1966). According to Theory of Planned Behaviour, intention to perform health behaviours is influenced by a combination of attitudes towards the behaviour, the normative expectations of others and perceived behavioural control (Ajzen, 1985). Health Belief Model and Theory of Planned Behaviour have been used to a small degree in studies aimed at understanding schizophrenia treatment behaviour (Budd, Hughes, & Smith, 1996; Conner, Black, & Stratton, 1998; Mausbach et al., 2013), and both show promise as a framework to examine decision processes regarding treatment for schizophrenia, not only with respect to treatment adherence, but also engagement with mental health service providers.

This chapter has provided the rationale for the study by highlighting the importance of people with schizophrenia adhering to treatment (management of symptoms to minimise relapse and associated risks). Also, reference has been made to theories that look promising in providing a theoretical framework for the study. Chapter 2 focuses on schizophrenia diagnosis and treatment, and provides details of prevalence, pharmacological and psychosocial interventions, and service delivery models utilised in Otago. Chapter 3 outlines the Theory of Planned Behaviour, Protection Motivation Theory and Health Belief Model, and proposes a suitable theoretical framework for the study. Chapter 4 describes the
methodology, including details of the sample, data collection and analysis, and ethical considerations. Chapter 5 presents the results of data analysis and Chapter 6 discusses these results in relation to the theoretical framework and prior research. Chapter 7 concludes the study and considers implications for practice, service development and future research.
Chapter 2 – Schizophrenia and Treatment

This chapter begins with an outline of schizophrenia, including a description of diagnostic features, causes and prevalence rates globally and locally. This is followed by a discussion of pharmacological and psychosocial treatments, including a review of the literature on the effectiveness of these interventions. As this study is concerned with people treated for schizophrenia in community settings, outpatient service delivery models are described, along with details of treatment service provision in Otago. The chapter closes with a discussion of treatment adherence, including common measures of medication adherence, prevalence of non-adherence to medication and psychosocial interventions, and factors that influence treatment engagement.

Schizophrenia

Schizophrenia is one of five psychotic disorders categorised as Schizophrenia Spectrum Disorders in the American Psychiatric Association (2013) Diagnostic and Statistical Manual of Mental Health Disorders (DSM5). The key features of psychotic disorders are separated into two categories; positive symptoms (the presence of thoughts and sensory perceptions that people do not usually experience) and negative symptoms (the absence of typical human feelings and behaviours). Positive symptoms include:

- Delusions – “Fixed beliefs that are not amenable to change in light of conflicting evidence” (American Psychiatric Association, 2013, p. 87). Delusions are commonly persecutory, referential, grandiose or somatic in nature.

- Hallucinations – “Perception-like experiences that occur without an external stimulus” (American Psychiatric Association, 2013, p. 87), which have the clarity and impact of normal perceptions and which are not under voluntary control. While
hallucinations can occur in any sensory modality, auditory hallucinations are the most common, usually as voices that are perceived as being separate from the individual’s own thoughts and not related to religious or cultural practices.

- Disordered thinking and speech – “Disordered thinking is typically inferred from the individual’s speech” (American Psychiatric Association, 2013, p. 88), for example switching from one topic to another or giving responses partly or completely unrelated to a discussion being held. In rare cases, speech is severely disorganised to the point of being incomprehensible.

- Grossly disorganised or abnormal motor behaviour (including catatonia) – includes bizarre, rigid posture, resistance to instruction, unpredictable agitation, childlike behaviour, excessive and purposeless activity.

Negative symptoms of psychotic disorders impact on ability to function independently. They include:

- Diminished emotional facial and body expression

- Lack of self-motivated and initiated activities

- Poverty of speech

- Lack of pleasure from positive stimuli and inability to remember pleasure from past experiences

- Lack of interest and limited opportunities for social interactions.

Diagnostic criteria for schizophrenia are:
• The presence of two or more symptoms (at least one must be delusions, hallucinations, or disorganised thinking or speech).

• For a significant period of time since onset, level of functioning is markedly lower than premorbid level.

• Continuous sign of disturbance persist for at least six months, and include at least one month of symptoms (or less if treated successfully).

The remaining four schizophrenia spectrum disorders are brief psychotic disorder, schizophreniform disorder, delusional disorder and schizotypal personality disorder. Diagnostic criteria for these disorders include the presence of psychotic symptoms to varying degrees and severity, in some cases alongside other feature. As this study focuses only on people with a diagnosis of schizophrenia, these other disorders are not described in detail.

**Epidemiology**

McGrath et al. (2008) estimated a worldwide lifetime prevalence of schizophrenia of 4.3 per 1000 and an annual estimate of 3.5 per 1000 Kirkbride et al. (2012) report an annual prevalence estimate of 4.1 per 1000 in the United Kingdom. Wu, Shi, Birnbaum, Hudson, and Kessler (2006) report an annual prevalence estimate of 51 per 1000 in USA. A survey of 1825 Australians suffering from psychotic disorders provided a 12 month prevalence estimate of 4.5 per 1000 (Morgan et al., 2012).

The onset of schizophrenia typically occurs in the early to mid-20s for males and mid to late-20s for females. The condition is 1.4 times more common in males. Schizophrenia is subject to a combination of biological, psychological and social risk factors. The greatest risk factor is genetic, with those who have a direct relative with
schizophrenia being six times more likely to suffer the illness than the general population. Obstetric complications that have subtle effects on brain development in infancy, and adulthood stressors such as social isolation and demands of urban life are also linked to onset of schizophrenia (Picchioni & Murray, 2007). Drug abuse has also been shown to contribute to the onset of schizophrenia. Arseneault et al. (2002) reported on a representative group of 759 (74%) members of a longitudinal cohort study in Dunedin, New Zealand, who had complete data on childhood psychotic symptoms, adolescent use of illicit substances and adult psychiatric outcomes. Results showed that cannabis use before the age of 15 was associated with a four-fold increase in the risk of developing schizophrenia by the age of 26.

**New Zealand**

In New Zealand, two studies have included estimates of prevalence of schizophrenia. Oakley-Browne, Joyce, Wells, Bushnell, and Hornblow (1989) conducted a psychiatric epidemiology study in Christchurch in 1986. 1498 randomly selected adults (aged 18 – 64) living in urban Christchurch were interviewed using the Diagnostic Interview Schedule, a questionnaire designed to formulate a DSM diagnosis from data collected. Results showed a lifetime prevalence estimate of 3 per 1000 and a 12 month estimate of 2 per 1000 for schizophrenia. In a study aimed at estimating the prevalence of schizophrenia among Maori in New Zealand, Kake et al. (2008) examined data from two New Zealand health databases; the National Minimum Dataset (NMDS) which contains records on all people discharged from psychiatric inpatient units, and the Mental Health Information National Collection, a specialised mental health database containing information on inpatient and community mental health service activity. Extracts were taken from both databases for three 12 month periods (2000 – 2003), which included data for people with a diagnosis of schizophrenia and ethnicity information. Annual prevalence estimates were significantly higher for Maori than
non-Maori; 9.7 and 3.2 per 1000 respectively (based on Maori comprising 14% of the population, a prevalence rate of 4.1 per 1000 of the total population is calculated). Although these estimates cannot be considered perfectly accurate, as people with schizophrenia who had not had contact with services were not included, the non-Maori prevalence estimate is consistent with the worldwide annual prevalence reported by McGrath et al. (2008).

The high prevalence of schizophrenia among Maori compared to non-Maori may be due differences in cultural beliefs and interpretation of phenomena. Ministry of Maori Development and Mental Health Foundation of New Zealand (1996) consider psychiatric disorders to be culturally bound to some extent; for example, hearing or seeing dead ancestors could be considered psychotic phenomena by non-Maori practitioners not familiar with Maori tikanga (Kake et al., 2008). The same applies for cross cultural perceptions of disordered thinking; despite most Maori speaking fluent English, thought processes may be culturally different and interpreted as disconnected or lacking in insight (Ministry of Maori Development & Mental Health Foundation of New Zealand, 1996). Sanders, Kydd, Morunga, and Broadbent (2011) report on the comparison between Maori and non-Maori perceptions of the causes of schizophrenia. A quarter of Maori participants believed the main cause of schizophrenia to be either stress, spiritual or chance, whereas Pakeha participants did not consider these to be contributing factors at all; Pakeha participants believed the primary causes to be biological or substance use Sanders et al. (2011). In addition to different cultural perspectives, Kake et al. (2008) believes the high prevalence of schizophrenia among Maori may be attributed to social factors, such as loss of cultural identity and social cohesion, racial discrimination, and exposure to lower socio-economic status.

Not surprisingly, schizophrenia treatment rates are higher among Maori than non-Maori. Ministry of Health (1997) provide psychiatric inpatient figures for Maori throughout
New Zealand in 1993, which show Maori first admission rates to be 2.6 and 2.3 times higher than non-Maori for females and males respectively, and re-admission rates to be 2.7 and 2.5 times higher for females and males respectively. Non-voluntary admission rates were twice as high for Maori during this year. Similar findings are reported by Turner, Smith-Hamel, and Mulder (2006) who analysed the characteristics of 200 people aged 18 – 30 referred to Totara House (an early intervention in psychosis service in Christchurch) over a five year period. 16% were Maori, compared to Maori as 8.8% of the population of this age group in Christchurch at the time of the study. In Otago, psychiatric treatment rates have been shown to be approximately three times higher for Maori than non-Maori. Edmonds, Williams, and Walsh (2000) analysed data for 259 people aged 15 - 45 on first admission to psychiatric hospital in Otago in 1990-91, and report 16% were Maori, compared to total Maori population of 4.8% in Otago. In Otago from 1992 -1997, 14% of people treated under a Mental Health Act Community Treatment Order (n=691) were Maori (Dawson & Romans, 2001). Although these studies reported on a range of psychiatric disorders, figures reported are more or less in line with schizophrenia prevalence rates for Maori and non-Maori.

**Schizophrenia Treatment**

Positive and negative symptoms of schizophrenia can respond to a range of pharmacological and psychosocial interventions. In the early to mid-2000s, The Royal Australian and New Zealand College of Psychiatrists (RANZCOP) coordinated the development of clinical practice guidelines in psychiatry, funded under the National Mental Health Strategy (Australia) and the New Zealand Health Funding Authority. Following a comprehensive review of literature on schizophrenia treatment, RANZCOP produced guidelines for the treatment of schizophrenia and related disorders in Australia and New Zealand, which included the use of both pharmacological and psychosocial treatment
interventions in the acute illness phase and to support and enable ongoing recovery for people with schizophrenia (P. McGorry, 2005).

The following section initially outlines the development of pharmacological treatment for schizophrenia and commonly used medications. This is followed by details of psychosocial interventions with a review of the literature reporting on studies of the effectiveness of these interventions.

**Pharmacological treatment**

Schizophrenia is typically treated with antipsychotic medication. These drugs are not solely for the treatment of schizophrenia, but are used to treat conditions associated with psychosis (delusions, hallucinations, distorted perceptions of reality). The first effective antipsychotic, chlorpromazine, was introduced in 1952, and over the next three decades attention was focussed on the development of antipsychotics that blocked the neurotransmitter dopamine. As such, these drugs, which include haloperidol, fluphenazine and thiothixene, are referred to as “first generation” or “typical” antipsychotics (Reddy & Keshavan, 2006).

“Second generation” antipsychotics, developed since the late 1980s, affect both serotonin and dopamine neurotransmitters. These are referred to as “atypical” antipsychotics, and include aripiprazole, clozapine, olanzapine, quetiapine, risperidone, and paliperidone (Sherin & Marder, 2011). There is evidence for the efficacy of both typical and atypical antipsychotics in the treatment of psychotic symptoms, and their use is recommended for nearly all individuals experiencing an episode of schizophrenia (Buchanan et al., 2010).
The management of schizophrenia matches the phase of a person’s illness. In the acute phase, severe symptoms can lead to agitation and potentially dangerous behaviours, so treatment targets the most severe psychotic symptoms. During this phase, the focus is on finding the most well tolerated antipsychotic at an effective dose. In the sub-acute, or the stabilisation, phase the focus is on finding the dose that has an effect on symptoms with minimum side effects to facilitate long term recovery in the maintenance phase (Sherin & Marder, 2011).

Commonly reported side effects of antipsychotics include sexual dysfunction, dysphoria, weight gain, diabetes, extrapyramidal syndromes (for example tardive dyskinesia, dystonia, parkinsonism) and sedation (Reddy & Keshavan, 2006). In a cross-sectional survey of 876 people with schizophrenia treated with antipsychotic medication in USA, 86% reported at least one side effect (DiBonaventura, Gabriel, Dupclay, Gupta, & Kim, 2012). Three quarters of the respondents in Morgan et al.’s (2012) Australian survey had experienced negative side effects from medication, with 61% reporting functional impairment as a result.

**Psychosocial treatment**

Although most disability caused by schizophrenia is attributable to negative symptoms, the principle focus of pharmacological treatment has been the reduction of positive symptoms (Harris & Boyce, 2013). Nonetheless, a range of non-pharmacological treatment interventions proven effective for reducing the negative symptoms of schizophrenia. (P. McGorry, 2005). The following section outlines psychosocial interventions commonly used in the treatment of schizophrenia; these include psycho-education, family interventions, social skills training, vocational rehabilitation, cognitive therapy and cognitive rehabilitation
Psycho-education interventions aim to increase knowledge of schizophrenia and treatment, and improve subjective insight into illness symptoms and treatment to enable people with schizophrenia to better cope with their illness (Xia, Merinder, & Belgamwar, 2011). These interventions have been found to contribute to increased knowledge about schizophrenia, which can improve insight into illness and the need for treatment. This is demonstrated in Lincoln, Wilhelm and Nestoriuc’s (2007) meta-analysis of 18 randomised controlled trials comparing the long and short term efficacy of psycho-education to standard treatment or non-specific interventions. Although no effect on symptoms was found, psycho-education contributed to knowledge acquisition and reduced rates of relapse in the 12 months following treatment. Similarly, in a meta-analysis of 44 random control trials involving 5142 participants (mostly inpatients) that assessed the effectiveness of psycho-education for schizophrenia compared to standard care, Xia et al. (2011) found people who received psycho-education experienced lower rates of relapse and medication non-compliance. However, the majority of random control trials were conducted in inpatient settings where psycho-education is more prevalent and conditions more conducive to treatment (i.e. available where patients already are); as such, findings may not be applicable to outpatient/community settings.

Family interventions

Family members often become the major source of support of people with schizophrenia, and this can lead to extreme stress and impact on many life domains, including work, social and personal life (Jewell, Downing, & McFarlane, 2009). Family psycho-education interventions typically include an educational component to ensure family members have knowledge about schizophrenia and treatment, and realistic expectations of
their loved one’s functioning, communication and problem solving ability to reduce family conflict and improve adjustment. Education is combined with training designed to support medication compliance, symptom management, handling crisis and conflict, and preventing relapse (Glynn, Cohen, Dixon, & Niv, 2006; Marsh & Lefley, 2003).

Psycho-education for family members has been shown to be beneficial. Sin and Norman (2013) conducted a systematic review of 44 studies in which people providing support or care for a family member with schizophrenia received psycho-education. Results showed psycho-education contributed to improved knowledge, with coping and problem solving strategies proving beneficial to enhancing communication, however, there was minimal benefit on family carers’ psychological distress and perceived burden of care giving. Family members valued participation in groups with others in similar circumstances (Sin & Norman, 2013).

Social skills training

Impairments in psychosocial adjustment are often the result of social skill deficits in occupational, recreational and social situations, which highlight the importance of social skill training interventions that address the constituent behaviours that enable individuals to achieve social competence in daily life. Social skills training typically consists of learning to communicate emotions and requests appropriately in order to achieve goals and improve interpersonal relationships (Kurtz & Mueser, 2008).

Social skills training has been shown to have positive effect on negative symptoms of schizophrenia that affect the performance of activities of daily life, and interpersonal and community functioning. Kurtz and Mueser (2008) conducted a meta-analysis of 22 studies involving 1521 participants to determine the effectiveness of social skills training. Included were randomised controlled trials testing skill instruction, modelling, role play rehearsal and
corrective feedback. Results showed a moderate effect on negative symptoms, community functioning and the performance of daily living skills, and a large effect on content mastery in such skills as interpersonal communication, assertiveness, social problems solving (Kurtz & Mueser, 2008). In a more recent randomised controlled trial, Granholm, Holden, Link, and McQuaid (2014) compared a cognitive behavioural social skills training intervention (CBSST) with a goal focussed supportive contract intervention (GFSC). CBSST was demonstrated to be significantly more effective than GFSC in improving participants’ knowledge of skills, sociality related negative symptoms, functioning and defeatist performance attitudes. Furthermore, social skills training was found to improve positive symptoms (Granholm et al., 2014; Kurtz & Mueser, 2008).

**Vocational Rehabilitation**

According to a low prevalence disorder study, only 28% of people with psychotic disorders in Australia are in paid employment with 80% dependent on government benefits (Chalamat, Mihalopoulos, Carter, & Vos, 2005). In USA, employment rates among this population have been reported to be less than 15% (Twamley, Jeste, & Lehman, 2003). Vocational rehabilitation approaches include work and job search skills training, vocational counselling, job clubs, and transitional and supported employment. These interventions aim to decrease disability and enable entry into voluntary and paid employment (Chalamat et al., 2005; Twamley et al., 2003).

There is evidence vocational rehabilitation contributes to increased employment uptake and work performance among people with schizophrenia. Twamley et al. (2003) conducted a meta-analysis of 11 randomised controlled trials testing the effectiveness of vocational rehabilitation interventions. Results showed a weighted mean effect size of 0.66 for participants who received vocational rehabilitation and worked during the course of
studies. Lysaker, Davis, Bryson and Bells’ (2009) randomised controlled trial aimed to determine the extent to which a vocational intervention in Indianapolis, USA, assisted individuals to participate in vocational rehabilitation and job performance. In the trial, 100 people were offered a six month job placement and randomised to receive a cognitive behavioural group and individual vocational intervention or an alternative support service. Results showed those in the vocational intervention group worked significantly more hours in the six month study period, and had better job performance (Lysaker et al., 2009).

*Cognitive therapy*

Persistent denial of illness among people with schizophrenia is a strong predictor of medication non-adherence. Cognitive therapy aims to reduce the impact of positive symptoms (delusional beliefs and hallucinations) by assisting individuals to find explanations for their experiences that are more acceptable to them, rather than attempting to persuade him or her they have a symptom of a mental illness. In addition, cognitive therapy can also contribute to acceptance of the value of treatment in reducing negative effects of past experiences (Turkington, Kingdon, & Weiden, 2006).

The effectiveness of cognitive therapy for people with schizophrenia is not well established. Zimmermann, Favrod, Trieu, and Pomini (2005) conducted a meta-analysis of 14 studies involving 1484 participants to assess the efficacy of cognitive behavioural therapy on positive symptoms of schizophrenia. Included were studies that compared at least one cognitive behavioural therapy group with a control group and reported on at least one measure of positive symptoms (delusions and/or hallucinations). Cognitive behavioural therapy showed significant effect on reducing positive symptoms compared to treatment as usual or treatment with adjunctive supportive psychotherapy. Cognitive behavioural therapy was more effective with those suffering acute psychosis than those with chronic
schizophrenic illness (Zimmermann et al., 2005). However, these findings differ somewhat with Tarrier and Wykes’ (2004) review of 20 randomised controlled trials involving 739 participants to assess the effect of cognitive behavioural therapy on schizophrenia symptoms, early intervention, speed of recovery in acute illness phase, and relapse prevention. Tarrier and Wykes (2004) report moderate effect sizes on above measures, with strongest evidence for chronic sufferers, and also report effect size to be negatively correlated to methodological quality (biased sample characteristics, non-random treatment allocation, outcome assessment bias), however conclude there is overall good evidence for the efficacy of cognitive behavioural therapy in treatment of schizophrenia.

These contrasting findings may be due to differences in methodological quality. Jauhar et al. (2014) conducted a meta-analysis (which included the two studies reviewed above) with consideration to the potential of bias as a result of poor study quality. Included were 50 studies, which Jauhar et al. (2014) believed to be unaffected by bias, on the effect of cognitive behavioural therapy on symptoms of schizophrenia. Results showed moderate effect on positive symptoms and small effect on negative symptoms (Jauhar et al., 2014). These finding suggest cognitive behavioural therapy to be less effective than previously reported, but still to have some effect, more so on positive symptoms.

Cognitive Rehabilitation

Consistent evidence suggests cognitive deficits to be partly responsible for social and functional disability and the persistence of delusional beliefs in people with schizophrenia (Bellack et al., 1999; Kluwe-Schiavon, Sanvicente-Vieira, Kristensen, & Grassi-Oliveira, 2013). The objectives of cognitive rehabilitative interventions are improving cognitive processes or circumventing impairments related to attention, memory and executive functioning, in order to improve functional outcomes. Interventions typically
consist of eliminating cognitive impairments by correcting underlying deficits and decreasing cognitive demand through environmental changes, such as visual reminders (Twamley et al., 2003).

There is evidence to suggest cognitive rehabilitation may improve cognition and functioning, contributing to treatment adherence and quality of life. Twamley et al. (2003) reviewed 17 randomised controlled trials of cognitive training interventions to improve neuro-psychological functioning in schizophrenia. Included were studies using outcome measures that reflect the generalisability of cognitive therapy. Results showed cognitive therapy to be effective in improving cognitive performance (.32), symptoms (.26) and performance of everyday tasks (.51). Durability of effects was not reported. Wykes, Huddy, Cellard, McGurk, and Czobor (2011) conducted a meta-analysis of 109 reports of 40 clinical trials involving 2104 participants comparing cognitive rehabilitation interventions with standard care. Results showed small effect size on symptoms initially, but not at follow up, and long term moderate effect on global functioning and cognition. Cognitive rehabilitation was shown to be more effective on clinically stable patients and alongside other psychiatric rehabilitation, such as vocational and social skills training (Wykes et al., 2011).

**Out-Patient Service Delivery Models**

Treatment of schizophrenia during the acute illness phase typically occurs in an inpatient setting. Sub-acute and maintenance phase treatment is commonly provided by outpatient clinical services. In addition to treatment interventions, RANZCOP reviewed literature on variety of outpatient service delivery models, and recommended their use for the treatment of schizophrenia in New Zealand and Australia. These models are outlined in the following section.
Case management

Traditional brokerage case management models involve co-ordination of services. The role of the case manager is to assess a person’s needs, develop a care plan, arrange and monitor suitable services and maintain regular contact with the person. Within mental health services this model has evolved into clinical case management, which in addition to the above role, emphasises the professional status and therapeutic skills of the clinician and the healing power of the therapeutic relationship (Max Marshall, Gray, Lockwood, & Green, 1998).

In a review of ten UK studies to determine the effectiveness of case management in schizophrenia, bipolar disorder and affective disorders with psychotic features, Max Marshall et al. (1998) found brokerage case management models to have no advantage over standard care. Clinical case management compared to standard care was found to have modest effect; increased numbers of people remaining in contact with treatment services, and people twice as likely to be admitted to psychiatric inpatient units. One study showed a higher medication compliance rates. No significant difference on mental state, social functioning or quality of life was identified between clinical case management and standard care (Max Marshall et al., 1998).

RANZCOP clinical practice guidelines state continuing care teams and case management are fundamental to systems of care, however, evidence for their effectiveness is inconclusive. A possible explanation is that clinical skills within multi-disciplinary teams are often lost in generic case management (P. McGorry, 2005). RANZCOP recommends case management that utilises the clinical skills of staff within a multi-disciplinary team for a subset of individuals with schizophrenia.
Assertive community treatment

Assertive community treatment is an intensive case management model targeted at people with severe mental illness who have a history of difficulties with engagement with mental health services and frequent hospital admission (M. Marshall & Lockwood, 2000). Assertive community treatment is distinguishable from other models of case management by lower caseloads, a team rather than an individual approach to managing clients, an emphasis on outreach and where possible services provided by the multi-disciplinary team rather than through referrals to other providers (Ziguras & Stuart, 2000).

Assertive community treatment has been shown to reduce the need for inpatient treatment, particularly when delivered in accordance with clinical guidelines. In a meta-analysis of 35 studies of the effectiveness of assertive community treatment compared to clinical case management, Ziguras and Stuart (2000) found a smaller proportion of clients receiving assertive community treatment were admitted to hospital than those receiving clinical case management, and the average number of days hospitalised for those clients was 37% less. No significant differences were found on measures of social functioning, dropout from mental health services, or client and family service satisfaction, although contact with services was less for those receiving assertive community treatment. Latimer (1999) analysed the relationship between programme fidelity and reduction of hospital days in 34 studies of assertive community treatment programmes delivered in community settings, and found high fidelity assertive community treatment programmes reduced hospitalisations by 58% compared to clinical case management, and 78% compared to usual treatment. A recent evaluation of assertive community treatment delivered within two community mental health teams in the UK over a 12 month period was completed by Essock et al. (2006). A sample of 112 patients receiving assertive community treatment had fewer admissions and spent
half the number of nights in hospital compared to the previous 12 months, with fewer contacts from community mental health team staff.

RANZCOP guidelines state assertive community treatment provides significant benefits when implemented according to well established protocols. RANZCOP recommends intensive case management, such as assertive community treatment, based on a clinical skill base and moderate caseloads to allow for flexible outreach, for a subset of individuals with complex schizophrenia presentations (P. McGorry, 2005).

**Early intervention in psychosis services**

Delay in identification and treatment of pre-psychotic symptoms is associated with poor clinical and functional outcomes. Most of the disability associated with longer duration schizophrenia is created in the prodromal phase; neurological changes prior to treatment have been found to result in irreversible damage, effectively placing a ceiling on the level of recovery possible from future schizophrenia symptoms, even with effective treatment following first episode psychosis (P. D. McGorry, Yung, & Phillips, 2001). Reading and Birchwood (2005) suggest the majority of deterioration occurs during the five years following the onset of psychosis, and long term illness trajectories are established during this period. In particular, two year course of illness patterns have been found to be the strongest predictors of 15 year outcome.

Early intervention in psychosis is concerned with providing treatment and support for people in the pre-psychotic or prodromal illness phase, before psychotic symptoms have fully developed. It comprises three components; early detection, reducing delay in treatment and sustained intervention during the critical illness period (up to five years) (Reading & Birchwood, 2005). Early detection has been informed by the work of P. D. McGorry et al. (2001) in Australia, the aim of which is to identify (typically in adolescence or young
adulthood) at ultra-high risk of developing a psychotic illness. Similar to assertive community treatment, early intervention in psychosis is typically delivered by multi-disciplinary clinical teams with small caseloads (P. McGorry, 2005). Entry into these services is based on an assessment of brief psychotic symptoms, genetic risk and recent functional decline.

Although literature on the efficacy of early intervention is limited, there is evidence to support this model. In 2000 and 2001, Garety et al. (2006) conducted a randomised controlled trial comparing the Lambeth Early Onset team programme with standard care in the treatment of early psychosis. The study involved 144 individuals presenting at a community mental health service in Lambeth, an inner city borough of London, randomised to receive treatment from the early onset team or standard care. Early onset treatment, established on the principles of assertive outreach, incorporated medication management, cognitive therapy and family interventions. The programme sought to assist patients retain or recover functional capacity to be able to engage in social, vocational and recreational activities. Standard care involved medication and case management, typically provided by the community mental health service in the area. Two articles report on different findings from this study. Outcomes in medication adherence, vocational and social functioning, satisfaction and quality of life were significantly better for participants in the early onset programme group (Garety et al., 2006). Furthermore, early onset treatment was associated with lower rates of relapse and hospital admissions, and increased engagement with practitioners (Craig et al., 2004). Similarly, Goldsmith, Lewis, Dunn and Bentalls’ (2015) study of 308 people receiving treatment for an acute first or second episode psychosis in England found cognitive behavioural therapy and supportive counselling alongside routine care (pharmacological treatment) improved outcomes at 18 months compared to routine
care. In addition, patient rated therapeutic alliance was related to benefit of the intervention, with therapy proving detrimental in cases of poor therapeutic alliance.

In relation to early intervention in psychosis, RANZCOP recommends specialist early intervention in psychosis services that are easily accessible for people, particularly those aged 14-35, at risk of psychosis without having to reach a high threshold of distress, and a high priority on active retention for the first three to five years of illness. Providing treatment in the community is preferable than inpatient treatment for this population, and psychosocial interventions (particularly cognitive therapies) are a cornerstone of treatment (P. McGorry, 2005).

The outpatient service delivery models described above are used in the treatment of schizophrenia and early psychosis in New Zealand, details of which are provided in the following section.

Treatment in New Zealand

The Ministry of Health (2009) Adult Mental Health Service Specification outlines the services delivered to people with psychiatric disorders by District Health Board funded services throughout New Zealand. These include community clinical mental health services, early intervention for people with first-time psychosis, community day programmes, vocational support services, and day activity and living skills services. The community based service specifications relevant to people with schizophrenia are outlined in this section.
Community Clinical Mental Health Services

These are fully integrated with other mental health services and engage service users and their family/whanau and caregivers. Services includes specialist assessment and diagnosis of psychiatric disorders, provision of medication and evidence-based psychotherapeutic interventions and talking therapies, and regular review of treatment progress, including monitoring of symptoms and social situation. Clinicians consult and liaise with non-mental health services and co-ordinate shared care arrangements. Attention is given to early intervention, relapse prevention, and maintenance of good mental and physical health (Ministry of Health, 2009).

In Otago, outpatient clinical services are provided by community mental health teams (CMHT); North CMHT and South CMHT based in Dunedin, Waitaki CMHT based in Oamaru and Clutha CMHT based in Balclutha. These services are staffed by psychiatrists, psychologists, psychiatric district nurses, occupational therapists and social workers, and operate a generic clinical case management model (Southern District Health Board, n.d.).

Early Intervention for People with First-Time Psychosis

Early intervention in psychosis treatment involves early recognition, assessment, and acute treatment utilising bio-medical, psychological treatments and psychosocial interventions (social skills, psycho-education, family interventions, cognitive therapies). As well as treatment for illness symptoms, there is a focus on support with cultural, social, vocational, housing and income needs, and liaison with other health services. Ongoing follow up during early critical period (between two and five years) is provided, including risk assessment and suicide minimisation, and support with alcohol and other drug problems (Ministry of Health, 2009).
In Otago, these services are provided by the Southern District Health Board Early Intervention in Psychosis Service based in Dunedin, which operates an intensive case management of an assertive community treatment type. (Southern District Health Board, n.d.).

*Community Day Programme*

Community day programme services undertake assessment of clinical conditions and functional abilities, and provide goal oriented and recovery focussed programmes that enable service users to manage illness symptoms and develop problem solving skills and build positive relationships. A range of community based rehabilitative options include occupational therapy, access to recreational and vocational activities, social skills and domestic skills training, assertiveness and self-esteem building, money management training, and developing cultural links (Ministry of Health, 2009).

In Otago, this service is delivered in group settings by the Southern District Health Board Community Day Programmes, via a multi-disciplinary team comprising psychiatrist, psychologist, social worker, occupational therapist and psychiatric nurse. Access to Community Day Programmes groups for people with serious mental health difficulties is via a CMHT. Community Day Programmes also provide closed, fixed period groups (usually 6 weeks) for people with moderate mental health difficulties (Southern District Health Board, n.d.).

*Vocational Support Services*

These are community based services aimed at providing skills training, support and assistance to enable people to gain employment. Services are flexible and determined by individual needs of service users and include activities to enable the development of
educational, employment and social skills (Ministry of Health, 2009). In Otago, vocational support for people with schizophrenia is provided by Work Opportunities Trust, Able Southern and PACT.

*Day Activity and Living Skills Service*

Community based services that provide activities, information exchange, socialisation and mutual support. Mental health recovery and community involvement are promoted and service users are offered key roles in the development of programme content and management. Desired outcomes for service users are participation in community life, acquiring work skills and routines, social connectedness and artistic/creative self-expression (Ministry of Health, 2009). In Otago these services are provided by Pact, Artsenta and Able Southern.

*Schizophrenia and treatment among Maori*

The presence of cultural differences discussed previously highlights the need for practitioners to consider the Maori world-view when working with this population. Recognising this need in the 1980s, the first cultural treatment unit, Whaiora, was opened at Tokonui Hospital in the Central North Island. Medication treatment was provided within a framework dominated by Maori language, customs and values. Over the next decade a number of similar units were created at hospitals in areas with large Maori populations (Durie, 1999). However, despite these advances, and Maori being over-represented in psychiatric disorder prevalence rates and treatment statistics, at the end of the 1990s less than one percent of allied mental health professionals were Maori (Durie, 1999). Durie (2011) acknowledges expansion of the Maori mental health workforce and improvements in mental health assessment and care of Maori, which now incorporates Maori health perspective and psychological frameworks. However, there is still a need for further
development, such as an integration of clinical and cultural perspectives, and an appreciation of the relationship of spirituality and cultural beliefs to mental health (Durie, 2011). This is particularly so in assessing and treating schizophrenia, due to the potential to misinterpret experiences as psychotic phenomena.

Cultural differences are an important consideration when working with Maori in Otago, as there is no cultural treatment unit in the region. While Te Oranga Tonu Tanga, a Southern District Health Board kaupapa Maori service, addresses the needs of Tangata Whaiora with a mental health disorder or diagnosis, clinical treatment is provided by mainstream mental health services. There is limited research on the experiences of Maori working with mental health treatment providers, and pharmacological treatment appears to remain dominant. Gibbs, Dawson, Forsyth, Mullen, and Tanga (2004) report on a small qualitative study involving eight Maori (six of whom had schizophrenia) and their whanau, about their experiences of community treatment orders. Patients benefited from clinical key workers’ kaupapa Maori approach, with emphasis on exploring cultural identity, family history and Te Reo. However, contrary to Maori tikanga, psychiatrists typically represented authority and loss of control, freedom and choice, and were perceived as being highly focussed on medication. Furthermore, whanau commonly reported not always being sufficiently informed or involved in key decisions, and having to take initiative to make contact with clinical key workers. Associated interviews were also held with psychiatrists, clinical key workers and kaupapa Maori supported accommodation providers. Psychiatrists expressed frustration at the constraints of caseloads, and saw the Mental Health Act and medication as the predominately defining features of the relationships with these patients. Clinical key workers and kaupapa Maori supported accommodation staff generally believed the medical model dominated patient care. Apart from frustration over the prevalence of the medical model, patients and whanau generally viewed community treatment orders
positively regarding improving insight and coming to terms with illness, and ensuring safety and treatment (Gibbs et al., 2004). Similarly, Maori respondents (n=41) in a study conducted by Newton-Howes, Lacey, and Banks (2014), the majority of whom had schizophrenia, held a positive view of community treatment orders and believed they were better off with orders in place, although respondents treated within kaupapa Maori services believed treatment interfered with recovery work more so than those treated within mainstream psychiatric services.

**Treatment Adherence**

Adherence to treatment for schizophrenia refers to taking medication as prescribed and participating in psychosocial treatment interventions. Taking medication for schizophrenia as prescribed is crucial, as its primary function is to relieve the positive symptoms that contribute to the majority of risk factors associated with psychosis, for example harming self or others in response to command hallucinations, which commonly present with symptom relapse. The link between these factors and medication non-adherence is well established. Zygmunt et al. (2002) report people with schizophrenia who are medication non-adherent have a 3.7 times higher risk for relapse that those that adhere to medication, and relapse is associated with increased potential for dangerous and assaultive behaviour, especially among people experiencing psychosis.

Not only does medication minimise risks associated psychotic symptoms, it has also been found to reduce the chance of relapse and improve quality of life. Results from Novick et al. (2010) three year follow up study of people commencing treatment for schizophrenia show remission over a three year period was 1.46 times more likely to occur in people who adhered to medication than those who didn’t. Hospitalisation, relapse and attempted suicide were significantly more likely for non-adherent patients. Furthermore, medication adherence
has been shown to have a positive effect on quality of life. In a study of 363 people with schizophrenia treated in outpatient settings in the UK, Hayhurst et al. (2012) found an association between medication adherence and improvement in quality of life scores.

The following section outlines common measures of medication adherence, followed by a discussion of the prevalence of non-adherence to medication and psychosocial interventions, and the factors that have been found to influence treatment adherence.

Measures of medication adherence

There are a variety of medication adherence measures. In a review of 161 studies of antipsychotic adherence, Velligan et al. (2006) found the most common measure to be self-report. 77% of studies relied solely on subjective measures, namely the report of the patient, significant others or clinicians. The remaining 23% used pill counts, blood or urine analysis, or electronic monitoring, by which the medication bottle records each time the cap is removed (Velligan et al., 2006).

Self-report is considered to be unreliable due to the potential for exaggeration, and the reliability of significant other report is dependent on how directly involved these people are in the patient’s care. Direct measures may also be questionable; pill counts may include pills from a previous prescription, and electronic monitoring counts each time the bottle cap is removed but cannot provide evidence the pills have been taken. Blood and urine levels can be affected by behaviours immediately prior to sample being taken (Velligan et al., 2006).

Another variation is the way adherence is defined. Taking medication a proportion of the time (for example 80%) or regularly taking medication as prescribed are common definitions of adherence, and not taking medication a proportion of the time or not taking
medication for at least a week are common definitions on non-adherence. Measures may also be dichotomous, or on a scale (not at all, somewhat, mostly, always) (Lacro, Dunn, Dolder, Leckband, & Jeste, 2002; Velligan et al., 2006).

**Prevalence of medication non-adherence**

Research on the prevalence of medication non-adherence has shown varying results, which appear to some extent to be dependent on the definition of adherence, the method of measurement, and phase of illness. Lacro et al. (2002) reviewed 39 studies of medication adherence among in- and out-patients with schizophrenia, and found a weighted mean non-adherence rate of 40.5%. Due to the perceived unreliability of patient self-report, Lacro et al. (2002) refined the analysis by strict criteria; regularly taking medication as prescribed, with self-reported estimates being verified by significant others or clinicians. Ten studies met this criteria and revealed a weighted mean only slightly higher (41.2%). Lacro et al. (2002) then applied stricter criteria; taking medication at least 75% of the time. Five studies met this criteria and showed a weighted mean non adherence rate of 49.8%. In a more recent review of 86 studies of treatment adherence involving 23,796 people, NosÉ, Barbui, and Tansella (2003) report a weighted mean rate of 26% non-adherence. 13 of the 86 studies were concerned with first presentation of psychosis, and showed approximately 47% of these people were non adherent with medication. 77% of measures were physician report and only 9% were self-reported, which does not support over exaggeration of self-report, as rates are lower than previously reported.

The above reviews do not include research from New Zealand or Australia. Waterreus et al. (2012) conducted a study of medication for psychosis consumption in Australia. Participants for this study were drawn from a large household survey to determine the prevalence of psychotic disorders in Australia. A survey of 857 people with
schizophrenia revealed of the 92% of these people who were prescribed antipsychotics, only 12% reported non-adherence in the four weeks prior to being interviewed. Adherence was defined as taking medication as prescribed, missing only the occasional dose (Waterreus et al., 2012). This low rate could be attributed to the limited time frame being analysed (four weeks) and the inclusion of participants who had self-reported a diagnosis of schizophrenia from the original household survey. Also, the possibility of variation of interpretation of the definition (i.e. missing only the occasional dose) may affect the results; according to alternative definitions, missing doses may be considered non adherent.

**Prevalence of non-adherence to psychosocial interventions**

There is limited research information available on the uptake of, and adherence to, psychosocial treatment for schizophrenia. For example, despite 90% of the respondents in Morgan et al.’s (2012) survey reporting a deterioration in functioning from before being diagnosed; two thirds experiencing a severe decline in social functioning and one third experiencing a severe decline in self-care, only one third of the respondents had engaged in community psychosocial rehabilitation or day programme services. Villeneuve, Potvin, Lesage, and Nicole (2010) conducted a meta-analysis of 74 randomised controlled trials of psychosocial treatment for schizophrenia spectrum disorders, involving 4374 people. Results showed approximately 13% of people who had agreed to participate in psychosocial treatment interventions dropped out prior to starting or during treatment. On average, these interventions were of 25 weeks duration.

The available research information suggests that while the uptake of psychosocial treatment is relatively low, there is also a low dropout rate from intervention programmes. As most of the disability associated with schizophrenia is caused by negative symptoms, and there is empirical support for the efficacy of psychosocial interventions on negative
symptoms, a potential focus for community mental health professionals is actively engaging people with schizophrenia in these interventions.

**Factors that influence treatment adherence**

Adherence to treatment for schizophrenia is influenced by a number of factors including therapeutic alliance, insight into illness, subjective experience of illness and treatment, self-stigma and neuro-cognitive abilities. The following section discusses findings of studies concerned with these factors.

*Therapeutic alliance*

A positive relationship between a person with a schizophrenia spectrum disorder and the provider of treatment has been shown to be influential factor in treatment adherence. Stewart (2012) conducted a qualitative study of the initial engagement experiences of 30 young people who had successfully engaged in first episode psychosis treatment in an early psychosis programme in Australia, and found that patients’ relationships with care providers was strongly associated with service engagement. Likewise, in a study of 32 people diagnosed with a severe and persistent mental illness treated at a community mental health centre in the Midwest USA, Galon and Graor (2012) reported that service engagement was contingent on a therapeutic relationship in which they were perceived as being credible and capable. However, as this study involved a convenience sample, generalisations could not be reliably made about the entire population of people with severe and persistent mental illness. McCabe et al. (2012) examined therapeutic relationship ratings of 507 patients with schizophrenia and 137 clinicians, in six outpatient settings across UK and Europe to determine the association between therapeutic alliance and antipsychotic medication adherence. Patient and clinician therapeutic relationship ratings were weakly inter-related,
but independently both were associated with better medication adherence (McCabe et al., 2012).

Schizophrenia symptoms and patient insight appear to have a bearing on therapeutic relationship. In a study of staff-patient relationships and outcomes in 204 people diagnosed with schizophrenia, Berry, Gregg, Vasconcelos e Sa, Haddock, and Barrowclough (2012) found positive relationships were associated with less severity in symptoms. Furthermore, a contributing factor to a positive relationship was the therapist’s belief that a patient’s problems were not entirely within his or her control (i.e. symptom related). Johansen, Iversen, Melle, and Hestads’ (2012) study of therapeutic alliance in early onset schizophrenia determined the presence of illness symptoms and poor patient insight were both predictors of poor relationship between patient and practitioner. This study involved the use of the Working Alliance Inventory (WAI), a tool developed by Horvath and Greenberg (1989) to measure the quality of the therapeutic relationship between client and practitioner, with questionnaires completed by both parties to reflect both perspectives. WAI was administered to 42 patients with schizophrenia and their practitioners. Findings revealed that low patient WAI scores were commonly associated with the presence of positive symptoms, and low practitioner WAI scores were associated with poor patient insight. However, it is not clear how insight or the presence of symptoms was determined.

A poor therapeutic relationship has been shown to be a primary factor in treatment non adherence. Gibson, Brand, Burt, Boden, and Benson (2013) conducted research which involved 35 people with a diagnosis of schizophrenia or bi-polar disorder completing telephone or online questionnaires regarding whether, how and why they deviated from medication treatment. Results showed instability in relationships between patients and
practitioners, and patients’ dissatisfaction with support, were associated with medication non adherence, however no causal inference was made.

While the studies referred to above demonstrate the association between therapeutic alliance and treatment adherence, it is necessary to also consider the factors that influence an individual’s willingness and ability to enter a therapeutic relationship. Sosnowska et al.’s (2013) study of therapeutic alliance between 64 people with a diagnosis of psychosis and their practitioners, in a community mental health care setting in Poland, reported that past positive experiences of interpersonal bonds in child- and adult-hood relationships correlate with positive therapeutic relationships in treatment for psychosis. Lecomte et al.’s (2008) cross-sectional study with 118 early psychosis individuals assessed the effect of a variety of factors potentially linked to treatment non adherence, and found that unwillingness by patients to form a relationship with treatment practitioners was influenced by symptomology, poor social functioning, certain personality traits (high agreeableness, desire for peer acceptance, mistrust of authority) and childhood trauma.

**Insight**

Insight into illness among people with schizophrenia has been linked to treatment adherence. In a review of literature on insight impairment and aging, Gerretsen, Plitman, Rajji, and Graff-Guerrero (2014) found insight follows a U-shape trajectory. Insight is commonly poor in the prodromal and early illness phase and declines as symptoms emerge, but improves during hospitalisation and outpatient treatment with antipsychotic medication, and can remain stable throughout midlife. However, insight has been shown to decline again with each episode of psychosis and generally as cognitive functioning deteriorates into old age. Mohamed et al. (2009) conducted an 18 month follow up study with 1432 people with schizophrenia in USA to determine the association of insight and attitude toward medication
on symptom and functional outcomes. Higher level of insight at baseline was associated with lower prevalence of positive symptoms at follow up, and improvement in insight was associated with declining symptom severity.

In a study of 3996 admissions to psychiatric hospitals in Greece, Germany, Italy and Spain, poor or no insight was found to be a contributing factor to hospital admissions in all four countries (Gorwood, 2011). Conversely, in a study of the predictors and profiles of treatment non-adherence and service engagement in early psychosis, Lecomte et al. (2008) did not find an association between patient insight and service engagement. However, this study did not include people who had completely refused treatment, and whose non-engagement could be attributed at least partly to poor insight. Gorwood’s (2011) study also found frequent past psychotic episodes and uncooperativeness to be contributing factors to hospital admissions in all four countries, with around half the admissions being associated with these factors. Lecomte et al.’s (2008) study was conducted with people treated in outpatient services, whereas Gorwood’s (2010) research took place in inpatient settings; it would be reasonable to expect that the latter would include people with more severe symptoms and lower levels of insight.

Insight has also been linked to perceptions of fairness and effectiveness regarding the procedures to enhance medication adherence. Jaeger and Rossler (2010) conducted structured interviews with 187 psychiatric patients to assess perceived coercion, fairness and treatment effectiveness, and found patients who have a good level of insight into their illness are more likely to accept informal coercion, persuasion and leverage if they understand the reasons behind it. However, this would be contingent on a good quality therapeutic relationship, in which a patient trusts the intentions of the practitioner.
Subjective experience of illness and treatment

Treatment adherence has been shown to be influenced by prior experience of illness symptoms and treatment, particularly the effectiveness of medication and the presence of side effects. DiBonaventura et al.’s (2012) survey of people with schizophrenia in USA aimed to understand patients’ perspectives on the impact of antipsychotic side effects on treatment adherence. All people interviewed were currently taking antipsychotic medication (72% atypical), and 42.5% reported complete medication adherence. The presence of side effects was defined as those which the person was at least somewhat bothered by. 86% of participants reported at least one side effect meeting this definition. The majority of side effects were associated with increased likelihood of non-adherence; the strongest associations were found with extrapyramidal/agitation related side effects, which is unusual as atypical antipsychotics are generally thought to have lower risk for these side effects. Weight gain, difficulty thinking and concentrating, and sexual dysfunction were also strongly associated with non-adherence (DiBonaventura et al., 2012). Similar results were found in a study involving 213 inpatients at two German hospitals; the presence of side effects was found to lead to negative general and efficacy beliefs about medication, which in turn contributed to non-adherence (Lambert et al., 2004). Gibson et al. (2013) report of particular consideration is the effectiveness of treatment in the management of symptoms, weighted against the side effects of medication. Similarly, in a study of factors that influence medication adherence in first episode psychosis, Hon (2012) discovered that adherence was influenced by the impact of the psychotic illness and the effectiveness and side effects of anti-psychotic medication on quality of life and health status.

While negative effects of illness symptoms may prompt people to adhere to treatment, experience of psychosis may influence the decision to cease treatment. This
phenomena was discovered by Moritz et al. (2013) who administered an online survey to 113 people with self-reported schizophrenia who had received treatment, to understand the reasons for antipsychotic discontinuation. Findings suggest positive attitudes towards positive symptoms contributes to non-adherence, with 28% of participants reporting they either missed the voices, gained a feeling of importance or power, or liked they person they became during a psychotic episode.

*Self-stigma*

Self-stigma occurs when a person with a mental illness internalises negative stereotypes about the illness they suffer from. An individual with schizophrenia will become aware of a public stigma and associate the stereotypes with them-self (Fung, Tsang, & Corrigan, 2008).

There is evidence to suggest self-stigma influences treatment adherence. In a review and meta-analysis of 127 studies regarding the relationship between internalised stigma and a range of variables for people with mental illness (54% of whom has schizophrenia), Livingston and Boyd (2010) found self-stigma to be moderately correlated with medication adherence. 31% of participants in Moritz et al.’s (2013) study identified stigma as a factor in the decision to discontinue antipsychotic medication, a common theme being medication intake amounted to admitting to being ill. Fung et al. (2008) conducted a cross-sectional observational study to determine the relationship between self-stigma and adherence to psychosocial treatment. The study involved 86 people with schizophrenia at a day hospital in Hong Kong. Results showed a high level of self-stigma was associated with poor adherence to psychosocial treatment, with a possible reason being people avoiding contact with psychiatric services in order to keep their schizophrenia secret.
Cognitions can be affected by neuro-cognitive deficits, such as poor memory, attention and problem solving, caused by physical changes in the brain as a result of a schizophrenic illness. Neuro-cognitive deficits, particularly in executive functioning and memory, have been demonstrated to impact on a person’s ability to adhere to treatment for schizophrenia and result in non-intentional medication non-adherence. Donohoe et al. (2001) interviewed 32 patients with schizophrenia consecutively admitted to a psychiatric hospital in Ireland to assess levels of compliance to neuroleptic medications. Memory was found to be the best predictor of partial compliance, with respondents often not taking medication despite intending to. Robinson et al.’s (2002) study of 112 people treated for first episode psychosis in USA aimed to understand medication adherence patterns among this population. Results showed a correlation between poor premorbid cognitive functioning and medication discontinuation during the first year of treatment. Executive functioning was found to be more strongly related to medication discontinuation than memory, with participants demonstrating compromised ability to manage complicated medication regimes, resulting in failure to take medications despite intention to comply (Robinson et al., 2002). Jeste et al. (2003) evaluated the correlation between scores on a cognitive performance scale and medication management among 110 middle aged (mean age 52) outpatients in USA. Strong correlations were found between medication management performance and various cognitive domains; conceptualisation (.57), memory (.55), tasks initiation and perseverance (.47) and attention (.41).

As well as impacting on medication adherence, there is evidence that neuro-cognitive deficits affect performance of tasks related to interventions to improve medication adherence. In a review of 20 studies of performance on neuro-cognitive tests (memory,
attention, problem solving) as a predictor of response to psycho-social treatments for schizophrenia, Kurtz and Richardson (2011) found neuro-cognitive impairments to be associated with reduced progress in behavioural interventions that target improvement in functional activities, one of which being medication management.

**Compulsory treatment**

There is limited research information available on the effect of compulsory treatment on engagement with mental health services and treatment adherence. Kisely, Campbell, Scott, Preston, and Xiao (2007) reviewed eight articles covering five controlled studies that investigated correlations between involuntary outpatient treatment and hospital admissions/duration of stay for 1108 participants in total. There was no significant difference between subject and control groups in measures of hospital admission rates or length of stay in hospital, although across studies these measure were slightly less for involuntary treatment groups. Included in this review was Preston, Kisely, and Xiaos’ (2002) controlled before and after study in Australia, which examined use of all health service use among their sample (n=456), and found contacts with mental health outpatient services increased from 31 to 46 (median) in the year following patients being placed on community treatment orders.

As the above discussion demonstrates, the reasons behind treatment non-adherence are many and varied, however the consequences can be dire regardless. In order to secure treatment adherence among people with schizophrenia, it is necessary to understand the factors that influence it. Therefore, it is important that research into this topic is informed by a sound theoretical framework. The next chapter discusses possible theoretical perspectives.
Chapter 3 – Theoretical framework

This chapter discusses various theoretical frameworks that have been applied to numerous behaviours, in order to understand the decision making process leading to action. The primary focus is on the Theory of Planned Behaviour and its development from the Theory of Reasoned Action, as these frameworks are the most widely applied to health behaviours, however Protection Motivation Theory and Health Belief Model are presented as alternative theoretical approaches. Literature on research using each perspective is reviewed, followed by a brief discussion of how each theory applies to decision making in relation to schizophrenia treatment.

The Theory of Planned Behaviour

The development of the Theory of Planned behaviour is presented in this section, including a review of literature on its application at various stages, starting with the Theory of Reasoned Action.

Theory of Reasoned Action

Fishbein and Ajzen’s Theory of Reasoned Action predicts the performance of volitional behaviours; those which people believe they can perform if they so choose. The theory is based on the assumption that people consider all available information regarding a proposed behaviour, including the implications of their actions, in the formation of an intention to perform the behaviour. Intention is the immediate determinant of the behaviour, and therefore the most reliable predictor (Ajzen, 1985).

The Theory of Reasoned Action postulates two basic determinants of intention; attitudes towards the behaviour (subjective evaluations of the likely outcomes of action) and subjective norms (perceived social pressure to perform, or not perform, the behaviour). An
individual’s intention to perform a behaviour relies on a positive attitude towards it combined with the belief that others think they should. While both attitude and subjective norms are considered necessary to form behavioural intentions, relative weights can vary i.e. normative considerations may be more important than attitudinal considerations in some instances, and vice versa (Ajzen, 1985).

According to the Theory of Reasoned Action, attitudes about a behaviour are determined by behavioural beliefs, which link the behaviour with likely attributes and outcomes. Such attributes and outcomes are evaluated individually and in relation to each other, and ranked by strength of importance and likelihood (Ajzen, 1985). Association of the behaviour with the most probable outcome will determine the attitude towards the behaviour.

The behavioural belief concept is informed by Fishbein’s Expectancy-Value Theory (Fishbein & Ajzen, 1975) according to which an individual’s attitude toward a particular object depends on the value the individual places on the various attributes of the object. As the Theory of Reasoned Action is concerned with attitudes toward behaviours rather than physical objects, the consequences or probable outcomes of the behaviour become the attributes upon which the individual places value (Ajzen, 1985). For example, when considering engaging in treatment for schizophrenia, a person may believe medication will help relieve symptoms (positive outcome) but there may be unpleasant side effects (negative outcome). Evaluation of theses outcomes in relation to each other will result in an attitude towards treatment; if the potential benefit of medication outweighs side effects, the attitude towards taking medication is likely to be positive.

Subjective norms are considered to be determined by normative beliefs. A normative belief is defined as person’s perception of what others think they should do in relation to a given behaviour. Whether or not the person feels motivated to comply with the wishes of
referents depends on the extent to which they value the opinion of those referents (Ajzen, 1985). In the case of the person with schizophrenia, they may be aware that family members think they should take medication, however the person may not value the opinions of those family members, and form no intention to take up treatment.

**Empirical support for Theory of Reasoned Action**

Many studies testing Theory of Reasoned Action constructs have shown accurate predictions of intention to perform behaviours under volitional control, and the influence of attitudes and subjective norms as discrete, measurable components. The theory has been applied to numerous behaviour types, and has generally shown attitudes and subjective norms influence behavioural intention, sometimes in equal measure and in some cases one component is dominant. This section presents findings from a small number of studies representative of the abundance of research on the Theory of Reasoned Action applied to common behaviours.

The Theory of Reasoned Action has been applied extensively to diet and exercise behaviour. Sejwacz, Ajzen, and Fishbein (1980) conducted a study of 88 Massachusetts women who considered themselves to be overweight. Behaviours considered to be necessary
for weight loss were identified (diet and exercise) and intentions to perform these behaviours were assessed. Results showed that the women formed general intentions regarding diet and exercise, and subsequently formed intentions to perform specific behaviours from these two domains. These specific intentions were the direct determinants of actual behaviour. Measures of attitude and subjective norms accurately predicted intentions regarding diet and exercise behaviours related to weight loss.

Attitude and subjective norms have been found to have influence in family planning and child-rearing. Davidson and Jaccard (1975) explored the factors that underlie women’s intention to have a child. Evaluation of consequences such as the cost of raising a child, increased responsibility, the effect on the woman’s marriage and own goals and plans were shown to influence attitudes. The more these consequences were viewed negatively, the less likely the intention to have a child. Women reported social pressure to have a child (or not), and were generally motivated to comply with the views of their husbands and parents. In cases of conflicting opinions from parents and husbands about whether or not to have a child, women were more highly motivated to comply with their husband’s wishes, making husbands the more salient referents (Davidson & Jaccard, 1975). In another study, Manstead, Proffitt, and Smart (1983) applied Theory of Reasoned Action to predict and understand prospective mother’s intentions regarding breast- or bottle-feeding new-born babies. Attitudes, subjective norms and intentions regarding feeding types were assessed during the third trimester of pregnancy, and behaviour was measured 6 weeks postpartum. Results showed intentions and behaviours were strongly related, and attitudes and subjective norms contributed significantly to the prediction of intentions. Attitudes towards breast- or bottle-feeding were influenced by behavioural beliefs concerning cost and convenience, benefits to baby and impact on the mother’s life. Subjective norms contributed to a lesser extent than attitudes, with women reporting they felt motivated to comply most highly with the views
of the baby’s father and medical advisor, followed by the views of their mother and closest female friend (Manstead et al., 1983). Interestingly referents included professionals as well as significant others; presumably the women interviewed were influenced by each for different reasons, for example a medical advisor’s opinion being valued due to expertise and experience, and the husband’s views being influential due to his stake in the wellbeing of the infant and relationship with the mother.

Voting behaviour has also been subject to investigation using the Theory of Reasoned Action. Fishbein, Ajzen, and Hinkle (1980) investigated behaviour among voters in the 1976 USA presidential election by interviewing voting-age residents of Champaign County, Illinois. Intentions to vote, and attitudes and subjective norms associated with each candidate were assessed. Results showed intentions were determined by attitudes and subjective norms. Attitude was commonly influenced by belief that a vote for a candidate was more likely to result in a desired outcome, such as reduced unemployment, tax reform, increased welfare spending. In cases of voters believing that not all desired outcomes will be achieved by the same candidate, voters evaluated and ranked the importance of each outcome and voted on the basis of the cumulative result. Furthermore, perceived social pressure was shown to influence voter intention, with participants motivated to comply with the views of spouses, parents, close friends and co-workers. Fishbein et al. (1980) concluded that, as results of this study confirmed intentions are determined by attitudes and subjective norms, the effect of external factors on intentions is due to their effect on one or both of these components.

While the Theory of Reasoned Action has proven effective in predicting intentions people feel able to act on, it does not account for cases of people not performing behaviours despite clearly intending to. Ajzen (1985) acknowledged the predictive validity
demonstrated in the above studies applies only to behaviours under volitional control, and the need to consider the influential factors in cases of intentions not resulting in actual behaviour. These include internal factors such as lack of information, skills and abilities necessary to perform behaviour, lack of will power, the influence of emotions and compulsions, and external factors such as time and opportunity, and dependence on others. Individual or collective presence of these factors may influence intentions temporarily, however repeated failed attempts to perform a given behaviour is likely to result in a fundamental change in intentions. Also, behaviours that appear to be volitional can be subject to unforeseen circumstances (Ajzen, 1985). With this in mind, Warshaw and Davis (1985) introduce the concept of behavioural expectation, an individual’s estimate of the likelihood that they will perform a behaviour, as an alternative predictor of behaviour to intention. This takes into consideration the individual’s perceived behavioural control; the belief that performance of the behaviour may be influenced by the internal and external factors such as non-cognitive habits, limited ability, environmental constraints and facilitators. If a person’s assessment of these factors is realistic, behavioural expectation will more accurately predict performance of the behaviour than intention. These authors report on a study in which two groups of college students (n=197) were interviewed about 18 common behaviours (for example go for a walk, take a vitamin, go to a party, talk to a stranger). One group was questioned about their intentions to perform the behaviours, and the other about the likelihood (expectation) they would perform the behaviours. Correlations of likelihood and actual behaviour was significantly greater than intentions and actual behaviour (Warshaw and Davis, 1985).
Theory of Planned Behaviour

With consideration to the concepts of behavioural expectation and perceived self-efficacy, Ajzen and Madden (1986) conceived the Theory of Planned Behaviour; an extension of Theory of Reasoned Action with the inclusion of a perceived behavioural control component. Theory of Reasoned Action was considered insufficient in predicting intention and behaviour in cases where behaviour is considered to be not entirely within an individual’s control. According to Theory of Planned Behaviour, perceived behavioural control is influenced by beliefs about all factors that could potentially impede or facilitate the performance of a given behaviour (for example personal skills and resources, reliance on others). Perceived behavioural control would contribute to the prediction of intentions, as well as directly influence actual behaviour (Ajzen and Madden, 1986).

This was tested in two experiments conducted on a group of college students (n = 169) in USA. The Theory of Planned Behaviour was applied to both attendance in class and achievement of A grades. Attitude and subjective norms predicted intentions as expected and as demonstrated in prior studies. The addition of perceived behavioural control greatly improved the prediction of behavioural intention in relation to both attendance in class and achievement of A grades. After controlling for intentions, the relationship between perceived behavioural control and actual behaviour was significant in relation to achieving A grades, but not in relation to class attendance. This difference was accounted for by class attendance being considered volitional and achieving A grades being somewhat reliant on others’ involvement (Ajzen and Madden, 1986). The authors considered the results of these above experiments provide strong support for Theory of Planned Behaviour; that intentions to perform a given behaviour can be predicted with high accuracy from the individual’s attitudes toward the behaviour, normative expectations of others, and perceived behavioural
control; and these intentions, together with perceptions of behavioural control, can reliably predict actual behaviour.

Netemeyer, Burton, and Johnston (1991) compared Theory of Reasoned Action and Theory of Planned Behaviour in separate studies for two behaviours considered to have different degrees of volitional control; voting (high) and weight loss (low). In the first study, 136 tertiary students eligible to vote in USA state elections were interviewed as to their voting intentions in an upcoming elections. The second study involved 184 students who had stated they were considering losing weight, who were interviewed to determine their intention to engage in weight loss behaviour. All participants in both studies were administered Theory of Reasoned Action and Theory of Planned Behaviour questionnaires. Regardless of the degree of volitional control, Theory of Planned Behaviour better predicted intention that Theory of Reasoned Action. For the goal directed behaviour of weight loss, considered to have a low degree of volitional control, the predicted direct influence of perceived behavioural control on intention was supported (Netemeyer et al., 1991).

Two meta-analyses report similar results of the use of Theory of Planned Behaviour in research. Armitage and Conner (2001) conducted a meta-analysis of 185 independent empirical tests of Theory of Planned Behaviour, which studies a range of behaviours including healthy lifestyle, health protection, substance use, smoking cessation, sexual health, sport and environment protection. Overall, Theory of Planned Behaviour accounted for 39% of the variance in behavioural intention. The weakest predictor of intention was found to be subjective norms, and the strongest attitude (average correlation .34 - .49). As well as contributing to intentions, perceived behavioural control was found to directly influence behaviour. Average correlation of intention and perceived behavioural control with
behaviour was .52. Perceived behavioural control did not contribute to the prediction of behaviours with no problems of volitional control (Armitage & Conner, 2001).

The predictive validity of the Theory of Planned Behaviour in relation to health behaviours is well established. In a study of 237 independent tests of the theory applied to behaviours related to healthy lifestyle, McEachan, Conner, Taylor, and Lawton (2011) found that 19% of the variability in action was attributable to Theory of Planned Behaviour measures, intention being the strongest predictor. The strongest predictor of intention was attitude, followed by perceived behavioural control and subjective norms (mean effect size .57, .54 and .40 respectively). Medium effect sizes were found between past behaviour and prospective behaviour (.50) and intention (.47). Theory of Planned Behaviour was most effective at predicting physical activity and dietary behaviours (23.9% and 21.3% variance explained respectively) and least effective at predicting risk detection, safe sex and abstinence behaviours (13.8% - 15.3% variance explained) (McEachan et al., 2011).

**Recent developments in the Theory of Planned Behaviour**

Since its inception in the mid-1980s, and with vast application in a variety of domains, Theory of Planned Behaviour components have been refined. This has included definitions that better reflect theory constructs, and the addition of elements indicated by research. These are presented below, grouped according to the three components of the theory.

**Attitude**

In a refinement of the attitude component, Fishbein (2009) defined attitude as “a latent disposition or tendency to respond with some degree of favourableness or unfavourableness to a psychological object” (page 78). Attitudes towards an object are
influenced by beliefs about the object, which form over time as a result of personal experience, observation, acceptance of information from a variety of sources and inference processes. In this context, a belief is defined as a subjective probability that an object has certain attributes (Fishbein, 2009). The strength of the belief concerning each attribute contributes to the attitude toward the object in proportion to the subjective probability that the object has the attribute. The relative value an individual places on these attributes also influences the attitude towards the object. Salient beliefs are those concerning attributes with the strongest belief strength and highest value. If a person associates positively values attributes with an object they are more likely to hold a positive attitude towards the object (Fishbein, 2009). In the case of treatment for schizophrenia, a person may believe that medication has benefits for relieving symptoms, and also that there are unpleasant side effect of medication. The relative strength of the evaluation of these attributes will determine if the person’s attitude toward medication is favourable or unfavourable. Positive attitudes are associated with a high perceived value of tasks associated with the object and negative attitudes are associated with low task value (Fishbein, 2009).

Studies using the Theory of Planned Behaviour have shown large effect sizes, however a significant amount of variance in intention and behaviour remains unexplained. It is possible that anticipating likely emotional responses from action (or inaction) may influence intention to act. For example, a person may anticipate feeling satisfaction from exercise, and undertake exercise in order to experience this emotion. Sandberg and Conner (2008) proposed anticipated affective responses, such as anticipated regret at not performing a given behaviour, could account for some of this variance, and that anticipated regret would sit within the attitude component of Theory of Planned Behaviour. Furthermore, the authors theorise anticipating regret from a prospective action can minimise the chance of experiencing a negative emotion by informing how to act in order to avoid it. To investigate
this idea, Sandberg and Conner (2008) conducted a meta-analysis of 18 studies that included a measure of anticipated regret, either as a distinct item or in conjunction with other affective responses (for example worry, fear, upset, happiness). In line with the meta-analysis by Armitage and Conner (2001) results showed 30% of the variance in intentions was explained by Theory of Planned Behaviour variables, and anticipated regret increased this by an additional 7%. The average correlation between anticipated regret and intention was .47, and behaviour was .28. The anticipated regret-attitude correlation was .35, but due to the particularly wide confidence interval (CI = .02 - .68) this result was not considered strongly significant, suggesting that anticipated regret could also be viewed as a separate component from attitude. These findings are supported by Ajzen and Sheikh’s (2013) study involving 100 USA college students, in which anticipated affect was added to the Theory of Planned Behaviour applied to alcohol and fast food intentions to determine its contribution to intention when assessed with respect to performing the behaviour or avoiding it. 49 participants answered questionnaires about their intentions to drink and avoid alcohol, and 51 participants about their intentions to eat or avoid fast food. In relation to alcohol, Theory of Planned Behaviour accounted for 60% of the variance in intention to drink alcohol, and anticipate affect with respect to avoiding alcohol increased this variance to 67%. In relation to intention to avoid alcohol, the addition of anticipated affect with respect to drinking alcohol increased the variance from 31 – 58%. In relation to fast food, Theory of Planned Behaviour accounted for 45% of the variance in intention to eat fast food, and anticipated affect with respect to avoiding fast food increased this variance to 51%. In relation to intention to avoid fast food, the addition of anticipated affect with respect to eating fast food increased the variance from 38 – 51% (Ajzen & Sheikh, 2013). These figures show anticipated affect for the opposite of what is being assessed using Theory of Planned
Behaviour variables contribute to intention, particularly if avoiding the given behaviour is being assessed.

**Subjective norm**

The subjective norm component of the Theory of Planned Behaviour was originally conceived as an injunctive norm, defined as social pressure to perform a behaviour according to an individual’s perception of what others think they should do. Ajzen and Fishbein (2005) suggested that observation of what others are doing in similar circumstances influences intentions and behaviour, and proposed the inclusion of this as a descriptive norm measure in the subjective norm component. To determine the effect of injunctive and descriptive norms on intention and behaviour, Manning (2009) conducted a meta-analysis that included 196 studies of Theory of Planned Behaviour applied to a range of behaviours, 19 of which included separate injunctive and descriptive norm items. Injunctive norms were found to have a stronger effect on intentions than descriptive norms (mean correlations .51 and .40 respectively), however, descriptive norms better predicted behaviour than injunctive norms (.34 and .28 respectively) (Manning, 2009). This suggests the perception of what others think influences individuals’ intentions regarding behaviour, but observing what others in similar circumstance are doing is a stronger influencer on actual behaviour.

**Perceived Behavioural Control**

During inception of the Theory of Planned Behaviour, this component was defined as a consideration of the factors that were likely to facilitate or impede the performance of behavioural tasks, resulting in an expectation whether or not action would be taken, but not necessarily a self-perception of ability to manage behavioural tasks. Trafimow, Sheeran, Conner, and Finlay (2002) suggested perceived behavioural control consists of two components; perceived control, defined as the extent to which a person believes a behaviour
is under their volitional control, and perceived difficulty, which refers to how difficult they perceive the behavioural tasks to be. To test this, the authors conducted four studies involving 238 in university students in UK and USA were questioned about perceived control and perceived difficulty in relation to a range of behavioural scenarios, some of which were determined by investigators (for example completing assigned homework tasks, academic achievement, the chances a planned run would be cancelled) and other scenarios were self-determined (“think of a behaviour you are considering performing”). Results demonstrated the possibility of performing manipulations that affect perceptions of difficulty more than perceptions of control, and vice-versa, suggesting that these are two distinct variables. Trafimow et al. (2002) then performed a meta-analysis of 11 studies that reported measures of perceived difficulty and perceived control in addition to usual Theory of Planned Behaviour measures. Perceived difficulty was found to be superior to perceived control in predicting both intentions and behaviour. Perceived difficulty contributed significant additional variance after controlling for attitude, subjective norm and perceived control, but perceived control added little variance after controlling for the other variables.

As well as viewing perceived difficulty as a perceived behavioural control, it could be considered to form the basis of a behavioural belief that influences attitude. For example, a person may hold a negative attitude towards a post-graduate programme if they believe study requirements are too difficult. To investigate this, Gagné and Godin (2007) conducted a meta-analysis of 10 studies that used Theory of Planned Behaviour to examine health behaviours found the easy-difficult item belonged to perceived behavioural control, however in three studies is was also found to be an indicator of attitude. Therefore, while perceived difficulty has been found to fit with both attitude and perceived behavioural control, it appears to be more appropriately associated with the latter.
Developments in the Theory of Planned Behaviour have resulted in the influences on the three components being more clearly defined and categorised, as shown in Figure 2. It appears to account for all influences in intention to act across a variety of behavioural domains.

**Figure 1 - Theory of Planned Behaviour**

- Behavioural beliefs
- Attitude toward behaviour
- Subjective norms
- Intention to perform behaviour
- Performance of behaviour
- Perceived volitional control
- Perceived difficulty
- Anticipated affect
- Injunctive normative beliefs
- Descriptive normative beliefs
- Perceived behavioural control

**Theory of Planned Behaviour and schizophrenia**

While there is a considerable amount of literature regarding the application of Theory of Planned Behaviour to engagement in health behaviour, research that examines how it applies to schizophrenia treatment is scarce. However, two relevant studies were identified.

In a study involving 61 people treated for a psychotic disorder at a community rehabilitation treatment service in UK, Conner et al. (1998) measured antipsychotic medication compliance over a nine week period. 38.1% of the variance in compliance was
explained by intentions and perceived behavioural control. Combined, Theory of Planned Behaviour variables accounted for 65% of the variance in intentions (correlations - attitude .42, perceived behavioural control .38, subjective norms .29). Positive attitudes were found to be based largely on beliefs about the likely outcomes of taking medication, such as staying out of hospital, and maintaining stable mental state and independence. Anticipated affective reactions also added significantly to variance in attitudes explained, as positive attitudes were influenced by beliefs that desired emotional responses will follow from taking medication (Conner et al., 1998). With regards to subjective normative beliefs, intention was influenced by perceived pressure from specific salient others (friends, family members, health professionals) weighted against participants’ motivation to comply with these referents. These results differ somewhat to those reported in Mausbach et al.’s (2013) study, in which 64 individuals with schizophrenia completed a questionnaire assessing the factors influencing intention to engage in functional behaviours, one of which is taking medication. Intention to take medication significantly predicted adherence, and social norms and perceived control over medication behaviour predicted intention, however attitude did not to any great extent. Contrary to the majority of Theory of Planned Behaviour research, perceived behavioural control was not significantly associated with performance of behaviour.

**Evaluation of Theory of Planned Behaviour**

As well as studies concerned with the application of the Theory of Planned Behaviour to schizophrenia treatment and general health behaviours, a number of studies have been conducted to evaluate the relevance and efficacy of Theory of Planned Behaviour. The following is a discussion of findings in favour of, and criticisms of, Theory of Planned Behaviour.
Kopelowicz et al. (2007) utilised an inventory based on Theory of Planned Behaviour to predict medication adherence among 155 Mexican American adults with a diagnosis of schizophrenia across three inpatient and outpatient sites. The findings showed the Theory of Planned Behaviour inventory to have high internal consistency and good predictive ability regarding intentions to take medication, and subsequent actual adherent behaviour. The Theory of Planned Behaviour inventory was administered alongside the Rate of Medication Influence (ROMI), a patient self-report questionnaire, and found to have good concurrent validity with this tool. Kopelowicz et al. (2007) warn that generalizability cannot be assumed as the inventory was applied to an ethnic group that highly values the cultural norms of family and community. This would be a consideration in the NZ context, in relation to Maori and Pacific Island people.

The Theory of Planned Behaviour has been tested to predict the engagement in functional activities (for example, taking medication, socialising, personal care and household tasks) in people with schizophrenia. Positive attitudes, social norms and perceived behavioural control were associated with engagement in these activities, suggesting that people with schizophrenia make reasoned decisions about engaging in functional behaviours (Mausbach et al., 2013).

Several studies discussed in previous sections reported less than 50% variance in behaviour is explained by the Theory of Planned behaviour (see Armitage & Conner, 2001; McEachan et al., 2011). While these figure have been presented as evidence to support the use of the theory, Sniehotta, Presseau, and Araújo-Soares (2014) refer to such findings as proof that the majority of variability in observed behaviour is not accounted for by Theory of Planned Behaviour measures, and therefore the theory has limited predictive validity. Sniehotta et al. (2014) believe that when developed, the Theory of Planned Behaviour
provided new explanatory measures and contributed to the development of knowledge of human behaviour change, however the theory has lost its validity as it does not lend itself to experimental tests or help practitioners develop useful interventions. Many studies that have used the Theory of Planned Behaviour in the development and evaluation of interventions have concluded that the evidence available is insufficient to draw conclusions about the usefulness of it (Hardeman et al., 2002). Sniehotta et al. (2014) report that experimental tests of the Theory of Planned Behaviour are rare, and those that have been conducted have not supported its assumptions. Furthermore, Theory of Planned Behaviour may be less predictive and compatible with populations in which behaviour change is most needed than among the young fit and affluent, the populations on which the majority of Theory of Planned Behaviour research has been conducted (Sniehotta et al., 2014).

A further criticism of the Theory of Planned Behaviour is that it does not theorise on how cognitions change, and can therefore not be consider a theory of behavioural change (Sniehotta et al., 2014). However, Theory of Planned Behaviour aims to assess the influence of cognitions on intention, and is not a model of cognitive or behavioural change. Specific motivational, cognitive and behavioural techniques already exist that can be utilised to bring about change. Finally, Sniehotta et al. (2014) highlight concerns about the predictive validity of Theory of Planned Behaviour due to self-reported measures of intention and behaviour change; indeed, McEachan et al. (2011) found the Theory of Planned Behaviour to be considerably less predictive when measures were taken objectively rather than self-reported. A number of studies referred to in this literature review also considered self-reported measures (namely adherence to medication) to be a limitation (Mausbach et al., 2013; Gibson et al., 2013; Conner et al., 1998). However, this may not be a significant limitation, given that a primary function of the application of Theory of Planned Behaviour
is to examine influences on the intention to perform behaviours, not the actual performance of the behaviours in question.

Despite the limitations suggested by Sniehotta et al. (2014), the Theory of Planned Behaviour appears to consider all factors that influence behavioural intentions with the possible exception of therapeutic alliance, which has been shown to influence schizophrenia treatment adherence (discussed in Chapter 2). However, the injunctive normative belief component of the theory may incorporate a concept close to the influence of therapeutic alliance. Motivation to comply with the wishes of referents depends on the degree to which a person values the opinions of those referents; for referents who are practitioners, the perceived value of the relationship with that referent may influence motivation to comply with the referent’s wishes.

While the Theory of Planned Behaviour appears more than sufficient as a framework for understanding decision making regarding treatment for schizophrenia, it is appropriate to also examine alternative theoretical perspectives. The following section discusses Protection Motivation Theory and the Health Belief Model, including a review of literature on studies of each perspective.

**Protection motivation theory**

Protection motivation theory, first proposed by Rogers (1975) considers the relation of fear to attitude change. Individuals are exposed to persuasive communication that indicates an imminent noxious event, which threatens bodily harm. Remedial courses of action to avert the danger are recommended, which require the individual to adopt alternative attitudes and act on them. Fear is conceptualised as a motivational state to protect oneself from danger; if fear is aroused by persuasive communication, individuals are motivated to
reduce it. Rogers (1975) applied the expectancy value model to fear communication and devised three crucial fear appeal variables:

1. Noxiousness – the magnitude of the noxiousness of a prospective event (value).

2. Probability – the likelihood of the event occurring provided no action is taken to prevent it (expectancy).

3. Response efficacy – the effectiveness of a coping response in averting the noxious event (another expectancy).

The tendency to act depends on the expectancy that certain consequences will follow from action and the value attributed to these consequences (Rogers, 1975).

In a later development of protection motivation theory, Rogers, Cacioppo, and Petty (1983) posit attitude change is not the result of an emotional state of fear, but rather the degree of protective motivation elicited by cognitive appraisal processes. Persuasive communication initiates both threat and coping appraisal. Sources of information include environmental (verbal persuasion, observation of others’ experiences) and intrapersonal (personality traits, prior experience of similar threat and coping activity). Influenced by Bandura’s (1977) self-efficacy work, Rogers et al. (1983) add self-efficacy to the protection motivation model, proposing that it is not sufficient for a person to believe a coping response to be effective, they must also believe they are able to make that coping response. Coping responses vary across situations; a person may be required to start or stop something, or undertake single, repeated, multiple or multiple repeated actions. Appraisal processes are biased by judgements from prior learning experiences, and therefore decision makers are not assumed to be rational. The amount of protective motivation is best measured by
behavioural intentions. The intentions – behaviour relationship is informed by Theory of Reasoned Action.

Rogers et al. (1983) consider motivation to protect oneself from a perceived threat to be a positive linear function of four beliefs:

1. The threat is severe.
2. One is personally vulnerable.
3. One has the ability to perform coping response.
4. Coping response will be effective.

Also a negative linear function of:

1. Reinforcements associated with maladaptive responses.
2. Response costs.

From a motivational perspective, positive evaluation of an outcome (for example, symptom relief) can be conceptualised as a reward, or a need a person is seeking to meet. Conversely, negative evaluation of an outcome (for example, experiencing side effects) can be conceptualised as a consequence a person wishes to avoid.

Protection Motivation Theory has been shown to have predictive validity. Milne, Sheeran, and Orbell (2000) report on a meta-analysis of 27 studies of disease detection and prevention behaviours. Threat appraisal was the strongest predictor of behavioural intentions (although not significant) followed by coping appraisal. Intentions were strongly associated with actual detection and prevention behaviour. Similar results were found in Floyd, Prentice-Dunn and Rogers’ (2000) meta-analysis of 65 studies that represented 20 health
issues, however threat vulnerability was also associated with intentions to undertake health protection behaviours. Furthermore, consistent with the theory, decreased response costs and maladaptive response rewards contributed to adaptive behavioural intentions.

Protection Motivation Theory appears sufficient to predict behaviour intentions from the point of view of forming beliefs about the costs and benefits of protective action, and self-efficacy to perform behavioural tasks. However, it does not take into account the influence of others on intentions and behaviours. Furthermore, the vulnerability component suggests an appraisal of a health or disease threat there is a reasonable chance of any person succumbing to, such as cancer or heart disease, the chances of which can be reduced by taking preventive action. The theory may not be applicable to schizophrenia, as vulnerability cannot be reduced by taking specific action. Application of vulnerability related to schizophrenia would therefore be limited to symptom relapse.

**Health Belief Model**

The Health Belief Model was proposed by Irwin M. Rosenstock (1966) to understand individuals’ behaviours in relation to preventing and detecting health threats. According to Irwin M. Rosenstock (1966) Health Belief Model consists of four dimensions:

- *Perceived susceptibility* – the subjective probability of contracting a given condition or illness, which can take into account statistical probability. Ranges on a continuum from complete denial of the possibility to a belief of a real danger.

- *Perceived severity* – subjective appraisal of the difficulties likely to arise from having the illness or condition, including medical, clinical and functional consequences, and impact on family, occupational and social life.
- **Perceived benefits of taking action** – subjective beliefs about the effectiveness and availability of various actions to reduce the health threat.

- **Perceived barriers to taking action** – may include the action is unpleasant, expensive, inconvenient or painful.

The likelihood of an individual taking action to reduce a health threat can be predicted by their readiness to change. The level of readiness, based on perceived susceptibility and severity, provides the force to act and the perception of benefits (weighted against barriers) of available actions informs the path to action. However, action is unlikely without a cue of sufficient intensity, for example illness symptoms, to act as a trigger. Cue intensity is relative to readiness to act; a high level of readiness will require a cue of high intensity (Irwin M. Rosenstock, 1966).

![Figure 3 - Health Belief Model](image)

To test the predictive validity of Health Belief Model, Janz and Becker (1984) reviewed 46 studies using Health Belief Model between 1966 and 1984. 24 studies examined behaviours to prevent or detect health threats, 19 explored sick role behaviours of people
already diagnosed with health conditions, and three focussed on clinic utilisation for illness symptoms. Preventive health behaviours included influenza inoculations; medical and dental check-ups; screening for hypertension, cancers, and genetic disorders; adherence to diet and exercise regimens; risk behaviours such as smoking, drug use and drink-driving. Sick role behaviour included adherence to treatment and lifestyle regimens for hypertension, diabetes and renal disease; parents’ compliance with children’s asthma, obesity and general medical regimens. Clinic utilisation included adult and paediatric visits for illness symptoms (Janz & Becker, 1984). Findings from this review showed substantial support for Health Belief Model in understanding health behaviours, with perceived susceptibility, severity, benefit and barriers showing significance ratios of .81, .65, .78 and .89 respectively. Apart from perceived severity, significance ratios were consistent between preventive and sick role behaviours; severity was much higher for sick role than preventive behaviours (.88 and .50). This was considered to be due in part to those in the health threat prevention studies being required to conceptualise illness severity without having had personal experience of the illness in question, as opposed to those already diagnosed with and experiencing symptoms. For both preventive and sick role behaviours, perceived barriers to action was the strongest predictor of health behaviour (.93 and .92). This dimension had a much lower significance ratio for clinic utilisation (.50) (Janz & Becker, 1984).

Harrison, Mullen, and Green (1992) questioned Janz and Becker’s (1984) claim of Health Belief Models predictive validity. They challenge the use of significance ratios to assess predictive power, due to this method being subject to the influence of sample and effect size. Also questionable is the inclusion of studies with no comment on reliability of measures. This accounted for all but six of the studies included in Janz and Becker’s (1984) review. Harrison et al. (1992) conducted a meta-analysis with inclusion criteria based on reliability and validity of measure, which involved 18 studies. Using effect sizes, Harrison
et al. (1992) found significant positive relationships between Health Belief Model dimensions and health behaviours. Results indicate that at best less than 10% of variance could be accounted for by any one dimension. Carpenter (2010) conducted a meta-analysis which included 18 studies of Health Belief Model applied to preventive and sick role (treatment) behaviours, similar to those reported on by Janz and Becker (1984) and Harrison et al. (1992). Perceived benefits and barriers were found to be the strongest prediction of health behaviours. Contradictory to findings of Janz and Becker (1984), benefits were a stronger predictor of preventive than treatment behaviour. Perceived severity was shown to be a relatively weak predictor, and susceptibility was almost always unrelated to preventive or treatment behaviour (Carpenter, 2010).

For the first two decades, Health Belief Model had not been applied to psychiatric disorders in research. Kelly, Mamon, and Scott (1987) conducted the first known mental health study with 107 outpatients treated with antipsychotic medication in Maryland and Pennsylvania, USA. Health Belief Model was used as a framework to understand medication compliance. Perceived susceptibility referred to likelihood of being hospitalised and perceived barriers were related only to medication side effects. Findings revealed this population had clear and identifiable beliefs about treatment and subjective effects, and that health behaviours are rationally motivated. 20% of variance in self-reported compliance was accounted for by Health Belief Model measures, with benefits and barriers being the strongest predictors of compliance behaviours (Kelly et al., 1987). However, limiting barriers solely to side effects overlooked the potential role of other perceived barriers, such as limited self-efficacy, inconvenience and financial costs associated with accessing services.
Budd et al. (1996) administered a health belief questionnaire to 20 compliant and 20 non-compliant patients from two neuroleptic depot clinics in Wales, to assess the ability of the Health Belief Model to predict depot medication compliance. The focus of investigation was beliefs about relapse; perceived susceptibility to and severity of relapse, and perceived benefits and costs of medication to prevent relapse. Levels of insight, illness knowledge and health locus of control were incorporated into the Health Belief Model framework, as these factors had previously been shown to contribute to medication compliance. Health Belief Model susceptibility, severity and benefits dimensions significantly discriminated between compliers and non-compliers, with strong correlations between dimensions. Those in the compliance group consistently believed they were susceptible to relapse, that relapse would be severe and that medication would be beneficial in relapse prevention. The costs dimension did not have discriminative power. Levels of insight, illness knowledge and health locus of control were found to have no predictive power in addition to Health Belief Model variables (Budd et al., 1996). With regards to Health Belief Model variables, Adams and Scott (2000) found similar results in a study of 39 outpatients with severe mental disorders (27 affective, 12 schizophrenia), 19 of whom were classified as highly adherent and 15 as partially adherent (the remaining five could not be reliably classified as either). 43% of variance in adherence behaviour across subjects was explained by perceived severity of illness and perceived benefits of treatment. Fear of hospitalisation as a result of relapse (perceived susceptibility) and a perception that relapse would be severe were shown to be significantly stronger influences on medication adherence among the highly adherent group than the partially adherent group. In contrast to the findings of Budd et al. (1996), health locus of control was found to have discriminative power, with those in the highly adherent group having a stronger belief that health was externally controlled by chance or by powerful
others than the partially adherent group. Dysfunctional attitudes were also found to discriminate between the groups (Adams & Scott, 2000).

The Health Belief Model does not account for the presence of barriers that override a person’s ability to adhere to treatment, such as neurocognitive deficits, which may not be recognised by the individual within the Health Belief Model perceived barriers construct. Perkins et al. (2006) suggest the inclusion of such barriers, as well as the external support factors that mitigate them (for example being reminded to take medication) in a Health Belief Model for schizophrenia. Perkins et al. (2006) tested their modified Health Belief Model on 254 people recovering from a first episode of schizophrenia, schizophreniform or schizoaffective disorders in USA. The constructs included the need for treatment (not explicitly stated but appears to refer to perceived susceptibility and severity), benefits of medication, negative aspects of medication and external support factors. Findings showed the strongest predictor of medication non-adherence was the belief that the need for treatment (perceived susceptibility and/or severity) was low and medication was of little benefit. Correlations between non-adherence and change in symptoms and side effects from baseline, and hospitalisation were also found. These were objectively measured, not subjective perceptions, therefore did not fit in the Health Belief Model framework (Perkins et al., 2006). The addition of the external support construct to a Health Belief Model is questionable, as it is not a subjective perception construct, and as shown did not add value to this study which reportedly used Health Belief Model as a theoretical framework.

Baloush-Kleinman et al. (2011) report on a study that examined the longitudinal utility of the Health Belief Model in medication non-adherence in early episode schizophrenia. 112 people with a diagnosis of schizophrenia or schizoaffective disorder were
assessed on symptom severity, drug attitudes, side effects and adherence at four occasions over a six months period. Findings were presented in three groups of variables:

- **Symptom severity** – severity of illness; positive, negative and disorganised symptoms; level of functioning.

- **Perceived illness** – awareness of illness, consequences, need for medication; perceived threat, environmental factors, therapeutic alliance, family involvement; family attitudes to medication.

- **Perceived benefit of medication** – attitudes toward medication; subjective experience of side effects; severity of side effects.

Results partly support the Health Belief Model; illness severity was found to be directly related to adherence, and awareness of medication needs (influenced by perceived severity and evaluation of consequences) contributed to attitudes toward medication, which was identified as the primary predictor of adherence. Additional influences on attitudes (non-Health Belief Model variables) were awareness of illness and illness consequences (insight), perceived value of therapeutic alliance, family involvement in treatment and family attitudes toward medication (Baloush-Kleinman et al., 2011).

Wiesjahn, Jung, Lamster, Rief, and Lincoln (2014) present a process model, derived from the Health Belief Model, which emphasises the importance of subjective evaluative processes that precede antipsychotic medication behaviour, and which contained similar variables to those reported by Baloush-Kleinman et al. (2011). Variables include insight (illness and symptom awareness, need for treatment), psychopathology (positive and negative symptoms), side effects, therapeutic alliance, social support, causal beliefs, metacognitions regarding paranoia, medication attitudes of social environment. Wiesjahn et al.
(2014) tested the model via an online survey with 84 people with a self-reported psychotic disorder, and report findings to largely support the model.

Due to the presence of delusions or hallucinations, Health Belief Model assumptions that underlie emotional response to physical illness may not be appropriate for application to psychotic illnesses. To test this, Kinderman, Setzu, Lobban, and Salmon (2006) conducted qualitative interviews with 10 inpatients experiencing psychosis and 10 outpatients in remission to understand psychotic illness beliefs. Thematic analysis revealed those in the inpatient group did not belief their symptoms to be illness experiences separate to their identities or consider them to be distinct disease entities, and therefore did not hold illness beliefs. Patients in remission distinguished past psychotic experiences from their current (well and real) selves. They acknowledged periods of being out of touch with reality, characterised by dysfunctional thoughts and actions, but did not view these as properties of an illness entity.

**Suitability of the Theory of Planned Behaviour**

In relation to schizophrenia treatment adherence, the Theory of Planned Behaviour, Protection Motivation Theory and the Health Belief Model each sufficiently explain how behavioural beliefs influence intentions to adhere to treatment. Within all three frameworks, beliefs about the effectiveness of treatment (for example to relieve symptoms or prevent them re-occurring, or to improve functioning) are weighed against perceived negatives (such as medication side effects) to influence treatment decisions. However, neither the Health Belief Model nor Protection Motivation Theory account for the influence of the opinions and wishes of salient others on an individual’s decision to adhere to treatment. As discussed previously in this chapter, studies applying the Theory of Planned Behaviour to a range of behaviours, including schizophrenia treatment, found subjective normative expectations to
influence behavioural intentions. For this reason, it is crucial to include this component in a theoretical framework. Furthermore, both the Theory of Planned Behaviour and Protection Motivation Theory account for an individual’s perception of their ability to perform behavioural tasks, whereas the Health Belief Model does not. Studies discussed in this chapter have found perceived behavioural control, to varying degrees, to also influence behavioural intentions. Therefore, this is also an important component in a theoretical framework.

With consideration to the above, I have chosen the Theory of Planned Behaviour as a framework for this study, as it has the potential to address the various influences on treatment adherence among people with schizophrenia, without the need for alteration or additional theoretical components.
Chapter 4 – Methodology

For this study, I chose a qualitative approach with a cross-sectional design, and the Theory of Planned Behaviour as a framework. This chapter provides details of this approach, followed by sampling and data collection and analysis methods, and closes with a discussion of ethical considerations.

Quantitative research emphasises a deductive approach to the relationship between theory and practice, and involves the generation of theories and development of instruments to measure data in order to test hypotheses related to theory. Quantitative research adopts a positivist perspective, that phenomena can be viewed as an external objective reality. Common data collection methods include experiments and surveys; data is collected using indicator measures, such as a Likert scale, to produce data in numerical form which can be analysed using statistics, in order to yield unbiased results that can be generalised to larger populations (Given, 2008).

A limitation of quantitative social science research is that the pre-occupation with instruments to measure social reality overlooks the various social or cultural influences on how people interpret the world around them, and therefore phenomena studied in the realm of social sciences cannot be measured in the same manner as those in natural science (Bryman, 2012).

On the other hand, qualitative research is predominantly an inductive approach to the relationship between theory and research that enables the examination of people's experiences. Common data collection methods include focus group discussions, in depth interviews, observation, life histories and biographies. Listening to stories with an open mind and empathy allows researchers to understand interpretations and meanings
participants give to objects, events or behaviour, and how experiences are shaped by the cultural and social contexts of their lives (Hennick, Hutter, & Baily, 2011).

Qualitative research has been criticised for limited generalisability. Due to the subjective nature and small sample sizes common to qualitative research, it can be difficult to apply results to populations outside of those in which research has been conducted. Another criticism of qualitative studies is they can be too difficult to replicate if they do not follow a standard structure or procedures, but rely on the ingenuity of researchers (Bryman, 2012).

A qualitative strategy was chosen for this study due to the differences in presentations of people with schizophrenia. While all individuals with schizophrenia will share common illness features, such as delusions, hallucinations and limitations in functioning, the manifestation of these varies from case to case. Therefore it will be difficult to determine a standard set of illness features among this population. Additionally, I expected that participants would have unique demographic profiles which would influence how they interpreted their illness and experiences. Rather than attempting to generate and test a hypothesis about why people with schizophrenia adhere to treatment, it seemed more appropriate to ask a small number of people to tell their stories; using a less structured approach will allow participants to talk about what influences their decisions while leaving space for unanticipated responses.

Design

A cross-sectional design was used to explore this topic with a small, purposively selected sample of people with self-reported schizophrenia living in Dunedin City and North and South Otago. The cross-sectional design is described by Bryman (2012) as a study of more than one case at a single point in time to collect data on one or more variable to identify
patterns of association. From the start I acknowledged the limitations of this design; limited generalisability due to a small sample size relative to the entire population of people with schizophrenia, and the effects of demand characteristic of qualitative interviews on participants, who may feel obliged to give what they believe to be the right information rather than their own beliefs or experiences. The potential unreliability of self-report was also considered a limitation, due to the possibility of recruiting people who falsely claimed to have had experience of schizophrenia. Despite these limitations I considered this design appropriate for preliminary exploration of the range of variables related to individuals’ decision making regarding schizophrenia treatment.

The research proposal was submitted to the Human Research Ethics Committee and approved in June 2015 (Appendix 1). Consultation was undertaken with the Ngai Tahu Research Consultation Committee in April 2015, who provided a letter of suggestion, recommendation and advice (Appendix 2).

**Epistemological position**

The aim of this study is the generation of realist knowledge. According to Willig (2013) researchers aiming to generate realist knowledge use methods of data collection and analysis to gain a detailed and accurate picture of social or psychological processes and mechanisms in relation to a particular aspect of human psychology or the social world.

In particular, this study will generate naïve, or direct, realist knowledge, with the assumption that there is a relatively uncomplicated and direct relationship between the data and reality, in contrast to critical knowledge, in which data are not taken at face value, and must be interpreted to access the structures underlying what is manifest (Willig, 2013). The aim is to shed light on the influences on decision-making regarding treatment adherence, rather than to offer reflections about treatment adherence as an experiential phenomenon.
Imported theory

Willig (2013) comments on the role of imported theory in qualitative research, namely generating insights into experiences that have been identified as of interest to researchers prior to commencing data collection, by providing a lens through which data can be viewed. Researchers' prior theoretical understanding of the phenomenon being studied informs what topics will be covered and how investigators will elicit information relevant to the topic Ryan and Bernard (2003). Here, the question of how people decide to engage in treatment for schizophrenia is considered using the Theory of Planned Behaviour (Ajzen & Madden, 1986), which proposes individual's intentions to perform a particular behaviour are influenced by their attitudes towards the behaviour, the normative expectations of others and their perceived ability to perform the behaviour. Theory of Planned Behaviour has been applied to numerous health behaviours, including seeking treatment for mental health disorders, but there appears to be limited application of Theory of Planned Behaviour to schizophrenia treatment.

For this study, the interview has been structured to capture data concordant with the components of Theory of Planned Behaviour. Analysis of data revealed themes consistent with Theory of Planned Behaviour concepts, and these were grouped according to Theory of Planned Behaviour components.

On the surface, the Theory of Planned Behaviour does not neatly account for individual's perceptions of the extent to which the quality of the relationship with their primary clinician influences adherence to treatment for schizophrenia, although this could be conceptualised as the individual's motivation to comply with the wishes. There is limited literature available on studies of the relationship between therapeutic alliance and schizophrenia treatment adherence; two studies were reported on in Chapter 2 (McCabe et
al., 2012; Stewart, 2012). It was necessary to consider this factor in the development of the interview protocol.

**Sampling**

Purposive sampling was used to select participants for this study. Purposive sampling is concerned with the selection of units relevant to the proposed research, and the research questions give an indication of what units/participants need to be sampled (Bryman, 2012). This differs from probability sampling, in which all units within the population of interest have an equal chance of selection (Bryman, 2012). Participants were selected from the population of people with schizophrenia located within the Dunedin boundary, and North and South Otago. This geographical area was selected partly because the Southern District Health Board (DHB) provides secondary mental health services to this population from within its Otago range of services (North CMHT, South CMHT, Early Intervention in Psychosis Service, Te Oranga Tonu Tanga [kaupapa Maori] based in Dunedin City; Waitaki CMHT based in Oamaru; Southern Rivers CMHT based in Balclutha) and also because the maximum distances required to reach participants are manageable from my location, and provide cross section of both urban and rural populations. According to the 2013 NZ Census (Statistics New Zealand, n.d.) the population of Otago, serviced by the Southern DHB (Otago region) and included in this study is 157,965. My objective was to recruit sufficient number of people to represent each region and the Maori population.

**Sample size**

Warren, in Bryman (2012) considers the minimum number of interviews needed for a qualitative interview study to be between 20 and 30. This served as a guideline and a target sample of 25 (at least 20 and no more than 30) participants was decided upon. Members of the Human Ethics Committee considered a sample size of 15 -20 would be sufficient to
achieve theoretical saturation, and the target sample size was reduced accordingly. However, this number was not achieved, possibly due to the nature of schizophrenia, characterised by paranoia and suspicion.

**Inclusion criteria**

To minimise the likelihood of interviewing people experiencing acute or sub-acute psychotic symptoms, the first inclusion criterion was to be residing in the community. This included people who were living in mental health supported accommodation. Other inclusion criteria included a self-reported DSM (Diagnostic and Statistical Manual) schizophrenia diagnosis and experience of treatment from a clinical mental health service, age of at least 18 years, competent to consent to participate in the study, and English speaking.

**Exclusion criteria**

These included the presence of symptoms that were likely to preclude informed consent or participation, intellectual disability, receiving treatment in a psychiatric inpatient setting, and individuals I have previously worked with as a mental health practitioner.

**Recruitment**

A number of NGO mental health service providers were identified and approached to support the study. These include Pact, Corstorphine Baptist Community Trust, Otago Mental Health Support Trust, Carroll St Trust, Able Clubhouse, Miramare Needs Assessment and Service Co-ordination, and Artsenta. These agencies provide support and/or advocacy services to people with schizophrenia in Otago. Southern DHB Te Oranga Tonu Tanga (TOTT) kaupapa Maori service was approached with the aim of seeking people of Maori ethnicity. Between August 2015 and March 2016 I presented the study to staff and
service users, individually or at community meetings depending on the circumstances of the
service provider, and people were invited to make contact to discuss participation.

Participants

Promotion of the study resulted in 19 people making contact, either directly or with
assistance from a support person, to seek more information. One did not have subjective
experience of schizophrenia; two opted not to continue once the study was explained in more
detail; three did not respond following initial contact; one became unwell and required
hospitalisation. A participant information sheet was provided to the remaining 12 people
outlining what the study entailed, and the each was contacted by telephone within the
following week. All 12 chose to proceed.

Participants were given the choice of interview venue; either a room provided by the
interviewer, at their home or an alternative venue of their choice. Two chose to be
interviewed at home and the remainder at a room provided by the interviewer. Participants
were advised they could have support people present if they chose, however all declined.

Prior to being interviewed, participants went through the consent process, and signed
the consent form when it was determined they understood the purpose, nature and
expectations of the study.

Data collection

A semi-structured interview protocol was developed with the objective of collecting
data on subjective experience of schizophrenia and treatment, the perceived value of
therapeutic relationships and the factors that influence adherence (Appendix 3). The semi
structured interview method has strength in collecting data in a manner that reflects each
individual participant’s perspective, and allows participants to indulge in rich descriptive
narratives about their subjective experiences, while at the same time being grounded in a framework of the topics that are particular to the research question.

The interview protocol was organised around the key constructs of the Theory of Planned Behaviour, and started with a vignette of a typical case of schizophrenia relapse; a young man who had stopped making medication following a period of successful treatment of symptoms. The aim of this was to elicit spontaneous views on why people may decide to cease treatment. This was followed by an invitation to talk about subjective experience of illness and treatment to gain information regarding attitudes towards treatment and perceived behavioural control over tasks associated with treatment elements. A further focus of the interview protocol was the beliefs and opinions of others, and how those influenced participants’ intention to adhere to treatment. With consideration of the limitation of the Theory of Planned Behaviour regarding the influence of therapeutic alliance in treatment adherence, I included questions in the interview protocol to discover the influence of the quality of relationships between participants and clinicians on decisions to adhere to treatment. I piloted the interview format with two mental health colleagues (one male, one female) which indicated it would elicit sufficient relevant information. (Interview protocol in appendix).

I conducted interviews with participants, and recorded them on an electronic device for transcribing at a later time. Interviews ranged from 22 to 53 minutes duration (median 43 minutes). At the end of their interview participants were asked if they would like to review transcripts, and all declined. All participants agreed to being contacted if there was clarity needed, or if results indicated further information was needed.
Data Analysis

Braun and Clarke (2012) describe thematic analysis as “a method for systematically identifying, organising and offering insight into patterns of meaning (themes) across a data set.” (Page 57). Braun and Clarke (2012) state what is common across a data set is not necessarily important, and a task of thematic analysis is determining the patterns of meaning that are relevant to the topic or research question under investigation.

I employed a theoretical thematic analysis strategy to analyse data. This method is driven by the researcher’s theoretical interest in the topic, and the process of coding data results in a detailed analysis of particular aspects of the data rather than a rich description of overall data. In contrast to an inductive strategy, such as grounded theory, in which the identified themes are closely connected to the data (Braun & Clarke, 2006). Ryan and Bernard (2003) caution prior theorising may restrict the investigator to finding only themes that fit with the theory, at the expense of missing surprising connections in data. Nonetheless, this approach was chosen as the aim of the study was to identify as succinctly as possible the particular factors that influence treatment decisions rather than report on participants’ experiences of schizophrenia and treatment from a more general perspective.

Braun & Clarke (2006) distinguish between identification of themes at a semantic level, in which themes are taken from within the surface meaning of the data and organised into patterns of semantic content, and latent analysis which involves searching for the ideas underlying the semantic content (Braun & Clarke, 2006). I considered identification of themes at a semantic level using theoretical thematic analysis appropriate for this study as it is expected the surface meaning of the data content will be sufficient to provide insight into the influences on decision making regarding treatment in this population, with consideration to Theory of Planned Behaviour.
Data were analysed according to Braun and Clarke's (2012) phases of thematic analysis:

**Familiarising self with data**

I transcribed interviews verbatim and checked transcriptions to ensure accuracy. Unintelligible parts were recorded as question marks, and pauses in speech were recorded as such. Transcriptions were read once from beginning to end, and sections that appeared relevant were highlighted. Transcriptions were then analysed in more detail and statements directly related to the topic were extracted. The first participant's transcription resulted in ten themes; extracts from the remaining transcriptions fitted into some or all of these themes and yielded an additional eight themes.

**Generating initial codes**

I created a code table and collated extracts into 18 initial codes. On review, the number of initial codes reduced to 16, as two instances of two similar codes were combined and reworded to form new codes. A code guide was created, which included the reworded codes and criteria that needed to be met for extracts to be coded as such. Each code was analyse to identify sub codes, and the code table was re-written to include these.

Codes were written as yes/no statements, so a separate code table was created to plot each participants' position in relation to each statement i.e. yes/no/unsure/ambivalent. If there was no information provided the space was left blank.
Searching for and defining themes

Codes were collated into potential themes. As this was a theoretical thematic analysis, Theory of Planned Behaviour provided an initial framework for organising codes into themes – attitude towards treatment; subjective norms; perceived behavioural control. Therapeutic alliance was added as a theme, as the influence of the relationship between clinician and patient is not dealt with that well by Theory of Planned Behaviour. A themes table was created to show the codes (including sub codes) collated into each theme. Themes were checked to ensure they worked in relation to the coded extracts and entire data set. In keeping with the research question, themes were defined as factors influencing treatment adherence.

Case studies

Analysis of data revealed participants shared common treatment experiences depending on whether their first contact with psychiatric services was pre- or post-deinstitutionalisation of the early 1990s. I considered this to be of significance, and separated participants into two groups based on this criterion. I was able to refer to the code tables already created to identify themes that were common to participants according to period of first contact for schizophrenia. From this, cases studies representative of each cohort were created. These two case studies are presented in Chapter 5, to illustrate the differences in treatment approaches between these two eras.

Peer review

I presented an overview of the study, including the theoretical framework, data collection and analysis methods, and preliminary findings to a focus group of representatives of Miramare, Corstorphine Baptist Community Trust, Able Southern and Carroll St Trust. These agencies work with people with schizophrenia in the community and were involved
in the recruitment of participants. The purpose of the peer review was to seek feedback on validity of the methods used, and whether or not results were what attendees expected, based on their experience.

**Reflexivity**

Jootun, McGhee, and Marland (2009) refer to reflexivity as the researcher continuously reflecting on the impact of his or her values and preconceptions about the research topic, along with the behaviour and presence of him/herself and participants, on the interpretation of responses. Speziale and Carpenter (2007) recommend researchers consciously reveal what is believed about a topic at the outset, to make clear the suppositions, thoughts and personal biases about the topic in order to approach the study openly and honestly. Furthermore, exploring personal beliefs enables the researcher to become aware of judgments that may potential arise during data collection and analysis that are based more on these beliefs than actual data.

Jootun et al. (2009) suggest a process of reflection that involves internal dialogue, by which researchers scrutinise what they know about their topic and how they know it. I found this a useful exercise as I started data collection, and it was necessary to ensure interview questions did not merely lead to responses that supported my beliefs and suppositions, which at that point had been informed by the review of literature and my recollection of anecdotal accounts of people I have worked with. For example, I had often heard from people with schizophrenia that they did not feel listened to by clinicians, and I needed to be aware not to seek responses that supported that concept. I was also aware that asking closed questions would potentially elicit what participants believed to be the ‘right answer’.
Ethical considerations

During planning the study, a number of potential ethical issues were identified. These are described below, along with how they were minimised.

Harm to participants

People with schizophrenia may be at risk of mental harm due to the stress of participating in interviews, for example the desire to be helpful, giving what they perceive to be the right answers. This could be particularly true of people who have a history of receiving treatment that is defined and prescribed by mental health practitioners, and who perceive themselves to have very little control regarding treatment options. To minimise the risk of harm from the interview, it was made clear to participants at the start that their involvement was entirely voluntary, they were free to withdraw at any time, and they were welcome to have a support person attend at their interview.

Lack of informed consent

Although research participants may be considered competent to give informed consent, it is important to ensure that they can demonstrate an understanding of what the proposed study entails and what the expectations of them as participants are. Disordered thought and perception are common to people with schizophrenia, including those receiving treatment, and this has the potential to distort an individual’s understanding of what is being asked of them. To minimise this, during the informed consent process, participants were asked to explain in their own words what they understood would be expected of them.
Invasion of privacy

The presence of positive symptoms of schizophrenia, such as delusional thinking and paranoia, has implications for respecting the privacy of research participants. While, participants will have agreed to take part in the study, it is important to be aware that some of the questions may seem intrusive to some people.

Due to paranoia, there can be reluctance from people with schizophrenia to sign consent forms, or put their names to documents, even though they have understood what is being proposed and have agreed to participate. This is due to a fear that their personal information will be used inappropriately, and usually attributed to the positive symptoms of their illness; regardless, it can be a real fear and very difficult to mitigate. To minimise the perceived risk of invasion of privacy, participants were reassured they would not be identified in written material, apart from their signed consent form which would be kept securely. Fortunately, no participants suffered from paranoia to the degree it impacted their willingness to sign consent or take part in an interview. Furthermore, this risk was minimised generally by the exclusion of people known to be suffering from acute illness symptoms.

This chapter outlined the theoretical framework for the study, the sample, and data collection and analysis methods. The next chapter presents the results from data analysis.
Chapter 5 – Results

Initially this chapter presents some demographic characteristics of participants. This is then followed by the list of themes that were identified in data analysis. Each theme is then described in detail. Finally, two case studies are presented to demonstrate the typical experiences participants diagnosed with schizophrenia and treated prior to deinstitutionalisation of the early 1990s, and considers the differences for people treated post these years.

Participants

Semi structure interviews were conducted with 12 participants; nine males and three females. The age range was 35 to 62 years, median average 55.5 years. 10 participants were of New Zealand European ethnicity, one Maori and one Scottish. Nine participants lived within the Dunedin City Boundary, one each lived in Balclutha, Oamaru and Kurow (rural Waitaki) – See Table 1. All participants reported being diagnosed with schizophrenia and receiving treatment.
Table 1 – Participant characteristics

<table>
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<th>Ethnicity</th>
<th>Location</th>
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<td>Tony</td>
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<td>David</td>
<td>M</td>
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<td>Sarah</td>
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<td>56</td>
<td>Maori</td>
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</tr>
</tbody>
</table>

Themes

Data analysis resulted in the identification of 16 themes. These include:

- Participants experience of treatment
- Possible reasons for ceasing medication
- Benefits of treatment
Treatment to prevent something undesirable

Medication side effects

Information about illness and treatment

Stigma

Significant others

Relationships with clinicians

The experiences of others with schizophrenia

Involvement in treatment decisions at onset of illness

Involvement of treatment during course of illness

Barriers to treatment

People with schizophrenia are more likely to listen to others with similar experiences

Involving significant others in treatment

Advice for people recently diagnosed with schizophrenia.

Themes are discussed in the following section

Participants’ experience of treatment

Participants were invited to talk about their experiences of schizophrenia and treatment. All participants had experience of anti-psychotic medication to treat psychotic symptoms. Participants were generally unfamiliar with psycho-social interventions (social
skills training, vocational rehabilitation, cognitive therapy, cognitive rehabilitation, psycho-
education, family education) and did not remember having been offered these; Tony recalled
psychotherapy and Ronald completed a number of sessions with a psychologist. However,
while participants were unfamiliar with the interventions by name, most recognised social
skills training and vocational rehabilitation by description and were able to make
associations between these interventions and non-government agencies they had been
involved with, such as Able Southern (also known as Tapestry Clubhouse) and Work
Opportunities Trust, or groups they had attended in hospital. Psycho-social interventions had
not been offered as standard treatment components by community mental health clinicians.

Possible reasons for ceasing medication

In response to the question in relation to the vignette “If we are trying to figure out
why Joe ceased his medication, what should we think about and ask him?”, as well as side
effects, participants proposed two additional reasons:

Medication not working

This reason was suggested by three participants, who wondered if the medication
was the wrong type or dose, for example:

- ...whether the medication was the right one for him (Tony).

- ...might work for a bit and they might build up a reaction to it...might not be
  quite strong enough (Ronald).

No longer needed
This was the most common reason, reported by eight participants from two viewpoints. Firstly, feeling well and therefore no longer needing medication, a view expressed by Angela:

- *He might have thought it was safe enough, he was well enough to go off it.*

A second viewpoint is the presence of psychotic symptoms influencing the decision to cease medication, such as paranoia about medication and suspicion about treatment and/or providers, reflected by Sarah’s comment:

- *Well the first thing I would ask him is whether or not he heard voices telling him to do that.*

**Benefits of treatment**

In response to question about the role of perceived benefits of treatment on symptoms and daily functioning, ten participants indicated they adhere to treatment if they perceive there are or will be benefits, including the benefit of medication on illness symptoms, the contribution of treatment towards a desired outcome or life goal, and in some cases concurrent with a recognition that circumstances were serious enough to seek help. Participants associated benefits not only with medication, but also with interventions aimed at the improving functional life skills. Two participants did not provide information about this.

Three participants indicated negative experiences that were serious enough at illness onset to make them engage with mental health services and adhere to treatment, although they did not necessarily attribute these experiences to psychotic phenomena. Ricky and Rogers’ responses were illustrative:
• There was a number of ah quite significant things that happened, happened within a period of about three weeks...they were things that were really traumatic (Ricky).

• I decided the situation was probably serious, serious enough to um warrant going on medication (Roger).

Relief of illness symptoms was reported to be a benefit of medication by four participants, for instance:

*It grounded me...I had the ability to reason and it sort of brought me back into reality a bit more - Clark*).

Roger stated medication did not help symptoms however he continues to take medication despite this. Sarah, the only Maori participant, had a different view on the benefit of medication on illness symptoms:

• To be honest, I don’t think there’s anything medication can do for you...you decide you’re gonna get well you get well, and I’ve been doing that for quite some time now.

Seven participants indicated the belief that treatment contributes to some desired outcome, related to the ability to attend to tasks and activities of daily living or quality of life, for example:

• I can drive, I can walk, I can go shopping...I’m ah I’m my own free boss (Angela)

• I knew I’d get to where I wanted, I knew I’d get to where I am now (David).
Three participants made reference to their involvement with an agency that provides employment assistance, schizophrenia education and fellowship, and how their decision to engage was influenced by their perception of benefits based on experiences, both positive. This point is demonstrated by the comments of Clive and Christine:

- **Well I have been involved with tapestry clubhouse and they, they got me ah into work really** (Clive).

- **My nurse had me at clubhouse, but that’s, I wouldn’t recommend that place for anybody…we were just sitting around a table with other people, just sitting there doing nothing** (Christine).

**Treatment to prevent something undesirable happening**

Eight participants indicated following treatment (i.e. taking medication as prescribed) to prevent something undesirable occurring, which included the threat of forced treatment, the fear of hospitalisation, the belief that illness symptoms would return and would have a negative impact on life. Four participants did not provide information about this.

For those who perceived a threat of forced treatment, this was either in the form of an ultimatum or merely an uncertainty regarding whether or not they would be subject to some form of compulsory treatment. For example, Christine recalled being given a choice between complying with treatment or having treatment forced upon her via methods she feared:

- **I was told the easy way or the hard way…and the hard way is you get injections if you want them or not…the hard way’s going to be electric shocking cos they still do it.**
Roger did not recall a direct threat, however knew that not complying with treatment would result in something happening he did not want

- *I had to either ah receive treatment or I was not too sure what was going to happen*.

Fear of hospitalisation referred largely to participants wanting to avoid psychiatric inpatient units based on past admission experience. This included memories of specific unpleasant occurrences in hospital and a perception that inpatient units were not conducive to mental health recovery, reflected in Sarah and Tony’s comments:

- *I also remember quite a lot of times I was locked up in a time out room* (Sarah)
- *I was in hospital and sometimes I think that’s the worst place to be because you’re around a lot of other people that are unwell* (Tony).

There was also an indication that hospital represented a step backwards in recovery, as participants expressed a desire to not relive past experiences or become trapped in a cycle of hospital admissions:

- *I’m, you know ah focusing pretty well really. I don’t want to go back to hospital* (Clive)
- *I want to stay well clear of that…I don’t want to be going in and out of hospital all the time* (Roger).

Related to past experience, but not necessarily associated with hospitalisation, was a fear of illness symptoms recurring as an influence on treatment adherence. This was expressed in two cases as taking medication as security:
• ...only with that half tablet at night I prefer to leave that as security unless the re-occurring illness comes back (Ronald)

• I don’t want to go off it, cos, just in case cos I’ve got a whole lot of symptoms that I don’t know about that um my psychiatrist has seen (Roger).

The most commonly indicated undesirable effect was the fear of the impact of schizophrenia on daily life; this was apparent in the accounts of four participants. This fear was based either on recollection of how life was during the presence of psychotic symptoms compared to life at the time of data collection or a belief in the possibility of negative impact on life or wellbeing, as illustrated by Angela and David:

• I know that I don't want to ever, ever get sick and has to go away back to the old days where I was years ago, cos I'm so much healthy from what I was then (Angela)

• I don’t want to be an old man and sort of sitting in a wee room sort of waiting for a nurse to come (David).

**Medication side effects**

Participants were asked to talk about medication side effects and the role they play in deciding to follow treatment. Ten indicated the presence of what they believed to be side effects of antipsychotic medication that had influenced their attitude towards treatment. Two did not provide information about this. Commonly reported side effects included tiredness, incontinence, weight gain and suicidal thoughts. Tardive dyskinesia was observed in three participants, although only one (Sarah) reported this as a side effect. In response to the question in relation to the vignette “If we are trying to figure out why Joe ceased his medication, what should we think about and ask him?” four participants considered side
effects a possible reasons for ceasing medication. Tony and Ricky held this belief despite not ceasing or altering medication themselves due to side effects.

While side effects contributed to a negative attitude toward medication, participants generally accepted side effects as part of medication. This is demonstrated by Rodney:

- *Both (medications) have got their side effects but there’s nothing I can do about that (Ricky).*

In all but one case (Sarah) side effects had not been significant enough to cease medication. Sarah stated she had stopped taking medication specifically because of side effects, which resulted in her being hospitalised. Three participants had considered ceasing medication because of side effects but had not, as they considered this to be unwise, although Clive had experimented with his dose in order to overcome side effects:

- *When the side effects started to get very bad, you know, that’s when I started to mess around with the medicines.*

Participants were comfortable discussing side effects with medication prescribers, but reported side effects were not considered significant by clinicians. This is illustrated by Tony:

- *They [psychiatrists] would always down play side effects (Tony).*

Two participants were aware of weighing up side effects against the benefits of medication in deciding whether to continue taking the medication.

*Information about illness and treatment*

Six participants indicated they did not receive sufficient information about
schizophrenia and treatment at illness onset, and four reported they did. Two did not provide information on this. Generally those who believed they were not well informed were older participants who experienced illness onset 30 to 40 years ago, prior to psychiatric deinstitutionalisation that occurred in Otago in the early 1990s, commonly associated with the closure of Cherry Farm Hospital. Clive and Christine recall being unaware they had been diagnosed with schizophrenia:

- \textit{…straight away they put me on a strong ah sedative without, without informing me what it was, what was going on} (Clive)

- \textit{I didn’t actually know I had schizophrenia, I knew I had medication} (Christine).

Two participants who believed they did not receive sufficient treatment remembered some information but not enough to feel well informed. However, it was also acknowledged that psychotic symptoms at illness onset possibly prevented information being received or understood.

Those who believed they received sufficient information recall having schizophrenia and treatment explained to them relative to their circumstances, for example:

- \textit{The psychologist was very understandable, he was um diagnosing me and also explaining different situations at the same time} (Ronald)

- \textit{…to explain this is what schizophrenia is, this is what hearing voices is and this is what the medication you’re taking is} (Ricky).

This experience was common among participants first treated since the early 1990s.
Participants were asked to describe their experiences of stigma in relation to schizophrenia, and whether they thought stigma would prevent a person from seeking help for psychotic symptoms. Nine referred to stigma, however no particular sub themes regarding stigma were identified. Some had either encountered stigma or believed that stigma existed, due to misconceptions about schizophrenia among the general population. A commonly expressed belief was that knowledge about schizophrenia among the general public is influenced by how the illness is portrayed in entertainment or media reporting of incidents involving people with schizophrenia. Three quotes are particularly illustrative of beliefs about stigma:

- "...someone you meet for the first time, they’re very friendly...when they find out you’re schizophrenic then the barrier goes up straight away (Clive)

- "...but the term [schizophrenia] is such a horrible name, it sounds like it’s come out of a bucket bin of blood and guts (David)

- "...you hear about, yeah that psychotic people are committing crimes and things, some of that stuff doesn’t stack up very well (Tony).

Three participants believed stigma existed but recognised efforts have been made in recent years to educate communities about schizophrenia and the general public are becoming more accepting of those with the illness although ongoing education is needed, particularly aimed a school aged children, to bring the illness out into the open:

- "...there’s been more and more written and published about it, people are beginning to accept it more (Ronald)
• *I think people can see that people with schizophrenia can go on to lead relatively normal lives* (Ricky)

• *...should be written into the school [curriculum]* (David).

The influence of stigma on significant others’ attitude towards schizophrenia was discussed by three participants. The common experience among these three people was that family members tried to distance themselves during acute illness phases, due to fear of risky behaviour and/or reluctance to acknowledge their loved one was suffering from schizophrenia. This is reflected in the following quotes:

• *Because of the state I was in being in the hospital, mum stayed away from that…I think she feared for my sister’s life once* (Sarah)

• *...my family are afraid [of schizophrenia]...that’s why they isolate themselves from me* (Christine).

Although they recall feeling angry and let down at the time, upon reflection participants could understand the reactions of family members, for instance:

• *...they were a little bit discriminatory earlier on but I can understand that…it’s not the easiest thing to experience schizophrenic episodes* (Clark).

No participants reported not seeking help due to stigma or not wanting to acknowledge they had a mental illness. Only two expressed beliefs regarding stigma preventing people from seeking help for psychotic symptoms due to reluctance to acknowledge the presence of mental illness:

• *I do think people might not want to get help because they don’t want to be seen as mentally ill* (Sarah)
I don’t know, I don’t think they know they’re mentally ill until they perhaps have an intervention (Clark).

Significant others

Participants were invited to talk about people of significance to them, and the influence of the opinions of those people in decisions regarding treatment. Seven indicated they valued the opinions of others regarding treatment; the most valued opinions belonged to family members (parents and siblings), friends/associates and support people (informal or support service providers). The two participants (Sarah and Roger) who did not value opinions of family members had reported negative relational experience with family members and had chosen to rely instead on friends for support.

There were a variety of reasons given for participant’s valuing the opinions of certain others. The most common reason, indicated by six participants, was a close relationship, characterised by qualities such as trust, honesty and genuine concern for wellbeing, for example:

- My dad... is my biggest hero... he saw the, the value of um getting myself straight and narrow (David).

Three participant’s identified the perception a significant other had knowledge or experience with mental illness in a professional capacity as a reason to value that person’s opinion. This is reflected by Clive’s comment:

- I suppose my mother was, being a nurse she um she could see when I was being um, getting unwell (Clive).

The seven participants who indicated they valued the opinions of others also
indicated the opinions and wishes of those people influenced treatment decisions, due to a desire to do what those people think, a perception the person’s wishes and actions would be good for them, or in response to group pressure. These points are illustrated by the following quotes:

- They said not to stop unless you talk to your doctor and they didn't tell me to stop so I just carried on (Clark)

- If anything happened to me they’d pick me up and then they would take me to...the ah um hospital (Rodney)

- With the pressure of my family and you know other, other people um sort of would always go along with what was thought to be in my best interests (Tony).

Ricky spoke positively about relationships with family members and friends, however he did not value their opinions regarding taking up treatment recommended by mental health professionals, although at this stage he had not accepted he had a psychotic illness:

- Some would say you should see a psychiatrist um that that really tended to get my, my hackles up...it’s not a psychiatrist is what I need, what I need is ah the right space for me to work things out.

Relationships with clinicians

Participants were asked to comment on whether they thought they had good relationships with clinicians, and the qualities about clinicians that contributed to relationships. Ten indicated they had good relationships with clinicians, the remaining two
were somewhat ambivalent, but not negative, for example:

- This doctor is um friendly and ah kind, we don’t talk um, they just ask are you hearing noises are you hearing voices and you know basically that’s about it (Clive).

Participants valued relationships within which they felt listened to and taken seriously, particularly if they were not happy with some aspect of treatment:

- I had a psych district nurse who, who helped me ah convince my psychiatrist to, to start taking quetiapine (Ricky)
- ...he listens to what I’m saying (Rodney).

Also of value was clinicians taking a genuine interest in participants’ circumstances, and wanting to get to know them:

- ...even tempered, willing to talk, takes an interest...she's really good (Clark)
- ...he [nurse] says I’m not leaving today until we have a cup of tea (Angela).

Participants also describe personality traits that made them feel comfortable within relationships, for example:

- Very caring, kind caring personality (Ronald)
- ...um the niceness of the people in it...the decency, the respect...the non-prejudicial judgment (David).

Sarah and Christine both valued doctors being up front and direct:

- ...right from the start shook your hand and looked you straight in the
I like people to be straight to the point and I’ve found my doctor’s very good at that (Sarah).

Four participants identified knowledge about schizophrenia and clinical experience as factors that contributed to high value of the relationship with their clinician, as they trusted the clinician would provide the proper treatment. This is illustrated by Ricky’s quote:

They dealt with clients similar to me all the time...because of that I would trust them...they knew more about schizophrenia and treating it (Ricky).

In Ronald’s case, in addition to professional knowledge and experience, learning that his psychiatrist also had personal experience of a family member with psychosis enhanced the value of his relationship with that person.

Three participants reported liking long relationships with psychiatrists expressed frustration about having to change doctors frequently or not having time to get to know their doctor. Sarah and David said:

Over the years I’ve had different psychiatric doctors...I like to have long relationships and I think a lot of other patients would too (Sarah)

I think, you know, some of what she represents is a bit kind of, you know, hey man this is our job, let’s do it (David).

The influence of the value of relationships with clinicians on decisions regarding treatment was difficult to determine from this sample; only Ricky volunteered information about this:
- Having constant ah persistent contact with PDNs and OTs and social workers as well as regular ah psychiatrist visits too, that would have had a big impact on me seeing the need to take my medication.

Tony’s response to being asked if there was a connection between relationships with clinicians and his decision making was uncertain:

- um historically there hasn’t been, but I don’t know, I guess there could be.

**The experiences of others with schizophrenia**

In response to being asked if they knew others with schizophrenia, participants indicated they either did, or they knew people they believed to have schizophrenia, particularly those who attended services specifically for people with schizophrenia. Participants were generally uncomfortable discussing this topic, as they believed other people's illness was not their business and they were not typically aware of what others were doing regarding treatment. These points are reflected in the following quotes:

- I don’t nose into people’s ah business about that type of thing (Roger)

- I know people with schizophrenia...don't know what they do regarding treatment, why people have stopped medication (Tony).

Three participants indicated the influence of people they had known with schizophrenia had influenced their own treatment decisions. For two, their perception of the negative experiences others have had with treatment methods was an influential factor:

- ...and I thought oh cos of my brother and electric shock treatment and I knew I didn’t want to have that (Christine)
I would be reluctant [to take clozapine] based on the experiences of other people (Ricky).

David spoke of having a relative on a psychiatric ward at the time he was admitted, and how her experience made him feel more comfortable about being in hospital:

- his [dad’s] sister was in cherry farm in the early 80s...it was like arriving on the ward and having her, her around...you know caretaker sort of thing.

**Involvement in treatment decision making at onset of illness**

Participants were asked if they recalled being involved in treatment planning during early contact with mental health services. Seven indicated they were not involved in treatment decisions during first episode psychosis and early stages of treatment. Of these seven, five distinctly remember not being given choices and being told what was going to happen. Sarah’s quote is representative of this:

- Other people made decisions, and not me, I didn’t know why...I had no choice (Sarah).

Christine stated she knew she needed treatment, but would have liked to have been given alternative treatment options, such as a herbal remedy.

Four participants remembered consequences, or the threat of consequences, in the form of forced treatment from not complying with initial treatment decisions made by psychiatrists, as illustrated by these quotes:

- I refused to go to day hospital and um ah I was sent out to Cherry Farm, I didn’t have much of an option at that point after that (Roger)
...they said if you don’t come down here [depot clinic] before four o’clock we’re going to call the police on you - Ronald).

However, not having choice in treatment decisions was not necessarily viewed negatively if there was something to be gained from complying, as Tony pointed out:

...so I wanted to get out [of hospital] really um sort of just give them the benefit of the doubt I guess...I um was aware that I was quite unwell – Tony).

Three participants could not remember being involved in decision making, but if they were not, did not view this as a problem. For example, Ricky said:

...as far as being told it would be my choice to take it, I can't really remember if that mattered to me - Ricky).

Involvement in treatment decision during course of illness

Participants were asked to talk about their involvement in treatment planning since becoming stabilised following their first psychotic episode. Ten indicated they had been involved in treatment decisions during the course of their illness. Roger stated he had not been involved in decisions to change medications, and David said only that he recalled many times he had no choice in treatment, but at such times he was able to reframe negative thoughts about this and move forward. Proposed changes to treatment were raised by psychiatrists, if there were concerns about how participants were responding to medication, or who would suggest alternative new medications or treatment options. Three quotes are representative of changes to treatment:

(...always asked if I felt overmedicated... and some, yes, yeah sometimes yes... so he’d cut back (Christine)
• I've asked about are there any new treatments that might help...and they've said well yes there is...they let me decide really (Clark)

• ...maybe a referral onto other things, psychotherapists or...other mental health type services that I could access (Tony).

Ricky recounted being offered a change to a new anti-psychotic, framed as a choice but in a way that favoured the wish of the psychiatrist and highlighted the downside of not changing:

• ...pretty much I was told that the [existing] depot would become less and less effective as time went on.

Three participants stated they were subject to Mental Health Act compulsory treatment orders, but despite this believed they had some say in treatment decisions, for example:

• Being on the compulsory treatment order [laughs] means I am, I’m coerced a bit; yeah I have power to make my own decisions (Clive).

Ronald recalls being offered a new medication that was thought to be better than what he had been, and was able to decline. However, when he later found out the new medication meant he could take pills instead of a depot injection, he agreed.

**Barriers to treatment**

The most common potential barriers to treatment were medication prescription costs, memory deficits and confusion regarding taking medication, cost and inconvenience of travel (to doctors, depot clinic, and support agency) and difficulty swallowing pills. These were each reported by at least two participants. Further potential barriers were
inconvenience of having to get regular blood tests (Clive) and making sure pills are kept securely (Ronald).

Ten participants reported barriers had not been significant enough to prevent them taking medication, due to being perceived as relatively minor to start with or have been overcome with or without the support of others. Three quotes are illustrative:

- *It only takes a couple of seconds and you've had it...that is it you've, it's there, you've swallowed it, what are you worried about* (Rodney)

- *...it’s all locked up where I live anyway...just in case anybody broke in or if there were any children there* (Ronald)

- *...nurse would visit me on the same, on the right day and give it to me at home* (Angela).

There was a link between the perceived benefit of treatment and the severity of barriers. For example:

- *I’ve recognised that, that it’s [medication] a must, it’s a necessity, with, regardless of how much money I have* (Ricky).

Roger identified the cost of accessing Tapestry Clubhouse in relation to the benefit of the service:

- *...um it costs money to go out there in the car...since the price of the meals has gone up I’ve decided not to go out there cos it’s too much of a financial burden.*
Unanticipated themes

People with schizophrenia are more likely to listen to other with similar experiences

When asked if they thought people with schizophrenia were more likely to listen to others who had experienced the illness than those who hadn’t, participants' responses were varied. Three thought this was the case, for instance:

- *I’ve been able to tell people that the huge difference between the old medicines and the new medicines you know, and they’ve listened to me and got on to the new stuff* (Clive).

Three others were not sure, but thought it dependent on whether or not the speaker was able to provide helpful information, as reflected in comments by Tony and Roger:

- *it depends on whether they see them as [pause] someone who’s you know got enough functionality to help out* (Tony)

- *…probably not if they’ve, they’re all wound up in the situation they don’t know* (Roger).

Ricky believed the insights and experiences of people with schizophrenia were valuable for professionals working with this population:

- *I think it helps for, for ah students, train, trainee doctors to hear people’s personal experiences of, of schizophrenia and how it affected them, how their voices affected them and how medication affected them.*

Involving significant others in treatment

All participants spoke of family members being present during early psychosis and
contact with mental health services; in eight cases it was significant others who noticed symptoms but were not able to identify them as psychotic and who sought help on their behalf. Ricky’s quote illustrated this:

- *My family and friends could recognise things wrong with me but they couldn’t actually identify it and put a finger on it* – Ricky.

Four participants spoke of family members facilitating contact with mental health services but not being informed about the illness their loved one was suffering from or the treatment that would be provided. As family members were not informed, they were not able to pass on information to participants or support them to accept help, for example:

- *My mum and dad didn't know anything about mental illness so they couldn’t help* (Roger).

In contrast, four participants recalled family members being well informed about their loved one's illness and treatment. Although not strongly indicated it was suggested that these participants' family members had proactively sought information in order to understand what their loved one was going through and support them through treatment. For example, Tony's parents had sought as much information as possible:

- *probably too much...to the point they probably think they know better about what's going on that me.*

As well as receiving information, the family members of four participants were involved in discussions regarding treatment, either in a caring and concerned way or in Sarah's case (aged 16 at the time) a manner that wasn't so helpful:

- *...family were there at um PMH sort of with the psychiatrist (Jeremy)*


- I found out when I was given shock treatment that my mum, she could have signed a letter saying I didn’t have to have it, but she didn’t (Sarah).

Advice for people recently diagnosed with schizophrenia

Participants were asked what advice they would give to people recently diagnosed with schizophrenia. Ten offered advice, the most common being to follow treatment in order to gain control of the illness from the start and seek positive relationships. Four quotes were illustrative:

- *nail it first time round... just follow what ordinary good people do and take your medicine* (Clive)
- *Stay on the medication they were given* (Ronald)
- *To be open with the link staff and open with the mental health staff* (Angela)
- *...find someone you can relate to* (David).

Other advice included thinking positively and remaining calm, and finding meaningful things to do:

- *Not to give in, to be positive* (Sarah)
- *Just sort of take it easy, don’t stress, passing through the system yeah* (Jeremy)
- *Doing different activities during the course of the day if you learn new skills* (Ronald)
- *...really just find some work to get involved with* (Clive).
Peer Review

Eight professionals attended the peer review focus group. Attendees confirmed the themes identified were consistent with their experiences working with this population, and made the following comments, which I have addressed below:

*Antipsychotic medication may be associated directly with the illness, i.e. a person may believe if they stop taking the medication the illness will no longer exist. This may be an influence on the decision to discontinue the treatment.* This is not explicitly reflected in the results of this study, however possibly there is content of this nature in auditory hallucinations telling a person they no longer need medication. However, this is difficult to determine from participants as data collected on this topic was in relation to why another person may have ceased medication, not participants own experiences.

*Younger people generally are more aware of deterioration in their mental health state and more inclined to ask to return to hospital for treatment, motivated by a desire for wellness. Older people are reluctant to return to hospital due to negative past experiences and what the hospital represents.* This is partly reflected in the results of this study, as for participants diagnosed and treated prior to deinstitutionalisation hospital represents forced treatment using unpleasant methods and little understanding of what was happening to them. Although data does not show participants whose first treatment for psychosis was in the post deinstitutionalisation era have necessarily positive experiences of hospitalisation, there are generally positive experiences of treatment, which may be positively associated with hospital.

*People with schizophrenia nowadays receive better information about the illness and treatment, but is it clear whether or not they appreciate this? Although a small number of participants spoke positively about having schizophrenia and treatment explained to them,
whether or not they appreciated this can only be inferred.

*People may feel more involved in treatment decisions but do they feel they have control over treatment (if treatment choices are determined and limited by clinician)?* While participants may believe treatment choices are dictated by clinicians, the accounts described in the section concerning involvement in treatment decisions demonstrate participants feel they have control when it comes to communicating dissatisfaction about treatment and requesting changes.

**Case studies**

The accounts of participants first diagnosed and treated prior to deinstitutionalisation in the early 1990s differ from those who had first experience of treatment in more recent years; the differences can be demonstrated in the following case studies.

*Michael – first episode psychosis, 1984*

Michael is a 30 year old male. When he was 22, he began acting in an uncharacteristically aggressive manner towards family members, who contacted their family doctor. He was taken to emergency psychiatric services and admitted to a psychiatric ward out of his home city, where he was put on sedative, without being informed what it was. Michael’s family were told he would need to stay in hospital until he was no longer deemed a risk to himself or others, however they did not receive information about his illness and did not ask questions, and trusted the ward staff to do their job. Similarly, Michael was not given information about illness, only told he would need to take medication. He acted out aggressively as he did not understand why he needed to be in hospital, and his behaviour often resulted in seclusion for many hours at a time. Michael experienced unpleasant side effects from medication but was told by doctors he would need to tolerate them as it was
important he took medication. Following discharge from hospital, Michael’s treatment was characterised by conflict with clinicians and threats of compulsory treatment. He ceased medication which lead to relapse, and was subsequently considered to be non-compliant and placed on mental health act compulsory treatment order. As years go by, Michael learns more about his illness and comes to recognise the need for treatment. He fears relapse, and is reluctant to ask for help as this is associated with negative experience of hospital admission. Michael’s decision to engage in treatment is influenced primarily by the desire to avoid something undesirable happening (i.e. returning to hospital).

Luke – first episode psychosis, 2009

Luke is a 30 year old male. When he was 22, he began acting in an uncharacteristically aggressive manner towards family members, who contacted their family doctor. He was taken to emergency psychiatric services put in contact with the local early intervention in psychosis service and subsequently admitted to a psychiatric ward close to his home, due to risk and for further assessment. Clinicians explained to Luke and his family that he had been suffering from psychosis and provided information about illness and proposed treatment, and family are referred to service that provides information and support for family members. Luke was initially resistant to treatment and sometimes aggressive towards staff and fellow patients, which was managed using behavioural strategies. Luke experienced unpleasant medication side effects which clinicians attempted to relieve with medication changes. A psychiatrist explained proposed changes and Luke man goes along with what the psychiatrist wants to do. He was discharged from hospital following a short admission, and re-connected with the early intervention service who work intensively with him so he could recognise relapse warning signs and manage symptoms. Luke continues to receive treatment from an adult community mental health team, and has occasional brief
hospital admissions after noticing psychotic symptoms and discussing these with clinicians. Luke’s decision to engage in treatment is influenced by perception of the benefits of treatment and wanting to follow the wishes of family members.

This chapter reported the results of data collection, and the two case studies above demonstrated the typical experiences of people pre- and post-deinstitutionalisation of the 1990s. The next chapter will discuss results in relation to theoretical frameworks and prior research.
Chapter 6 – Discussion

This chapter begins with an overview of the study’s findings from a Theory of Planned Behaviour perspective. Themes are then discussed in more detail, in relation to the theoretical perspectives outlined in Chapter 2, and also compared to literature reviewed in Chapters 2 and 3. The strength of a theme is determined by the number of times it was reported, or its prominence in participants’ accounts; a theme that is considered to be strongly associated with decision to adhere to treatment is one that was commonly the first statement made on a topic, or reported by more than four participants.

Overview of results

Participant characteristics

There were no consistent differences in the accounts of participants based on gender, ethnicity, location (rural or urban) or age. The case studies outlined in Chapter 5 are representative of first treatment experiences of participants according to era (pre- or post-deinstitutionalisation), and demonstrate consistent differences between these two cohorts. However this was not necessarily related to age, as first presentation did not always occur within the typical age range of early to late 20s (for example Ronald's first presentation was at the age of 43 in 2000).

With respect to the Theory of Planned Behaviour framework, the respondents in this study indicated that the strongest influence on their decision to adhere to treatment was their attitude toward treatment, determined by beliefs that link treatment with attributes and desired outcomes. There appeared to be a common perception that despite unpleasant side effects, medication would have benefits by relieving psychotic symptoms and contributing to improved quality of life. A further influence was a desire to prevent something undesirable
from occurring, such as hospitalisation and forced treatment. From a Theory of Planned Behaviour perspective, avoiding something undesirable could be perceived as a benefit of treatment, which would influence attitude towards treatment. Information appeared to influence attitude towards treatment, participants demonstrated the ability to consider all sources of information and weigh cost against benefits.

Injunctive normative beliefs (the perception of what others believe participants should do regarding treatment) appeared to have stronger influence on subjective norms than descriptive normative beliefs (the perception of the treatment experiences of other people with schizophrenia), and the influence of the opinion of significant others was related to the extent to which participants valued the opinions of those people. Descriptive normative beliefs were shown to influence decisions regarding treatment adherence for a small number of participants.

Perceived behavioural control was expressed in relation to involvement in developing treatment plans and ability to complete the tasks associated with treatment, which included consideration of the ease of tasks and barriers to completing those tasks. Also of consideration was the ability to overcome barriers. Potential barriers were identified but were either considered not significant or participants were able to overcome them, and successfully complete the tasks associated with treatment. Perceived behavioural control did not appear to influence decisions to adhere to treatment.

The following section discusses results in detail, starting with treatment experience followed by themes grouped according to Theory of Planned Behaviour.


Participants’ experience of treatment

I expected that all participants would have experiences of pharmacological treatment, (described by Reddy and Keshavan (2006) and Sherin and Marder (2011)), but limited experience of psychosocial interventions, which was confirmed. Management of symptoms matched illness phase, with the most severe symptoms in the acute illness phase being treated aggressively in inpatient settings. Medication changes have occurred throughout the subsequent course of illness, aimed at minimising side effects while successfully managing positive symptoms. Changes have been in response to developments in medication, proposed by clinicians as better alternatives, or participants requesting changes due to dissatisfaction at current treatment or being aware of new medication.

The primary focus of treatment for schizophrenia is typically medication despite the majority of disability being attributable to negative symptoms (Harris & Boyce, 2013). This seems to be the case among participants in the current study, as most had limited knowledge or experience of the range of evidence based psychosocial interventions recommended by RANZCOP (P. McGorry, 2005), which include patient and family psychoeducation, social skills training, vocational rehabilitation, cognitive rehabilitation and cognitive therapy. Generally participants could not identify interventions by name, although Tony was aware he had participated in psychotherapy and Rodney recalled sessions with a psychologist that were helpful as he was better informed about his illness. All participants described involvement to some degree with Tapestry Clubhouse (part of Schizophrenia Fellowship) which provides social and vocational opportunities, and education and support for family members of people with schizophrenia. Accounts of participants suggest higher prevalence of psychoeducation post deinstitutionalisation of the early 1990s, commonly associated with
Cherry Farm closing in 1991, as these people reported themselves and family member receiving better information.

It appears psychosocial treatments have not been provided by clinicians in secondary community mental health services in Otago, despite these services being staffed by a multidisciplinary team of psychiatrists, psychologists, nurses, social workers and occupational therapists. As suggested by P. McGorry (2005) clinical skills, which can be utilised to deliver specific psychosocial interventions, within mental health teams may have been lost to the generic case management roles of staff working in these teams.

**Attitude toward treatment**

*Benefits of treatment / treatment to prevent something undesirable / medication side effects*

I expected positive past experience of treatment and the presence of unpleasant side effects to have a strong influence on decision to adhere to treatment. According to the Theory of Planned Behaviour, the perception that schizophrenia treatment will have certain attributes, both desirable and undesirable, influences a person’s attitude towards treatment dependant on the relative value the person places on each of these attributes (Ajzen & Madden, 1986). Similarly, Health Belief Model (Irwin M Rosenstock, 1990) and Protection Motivation Theory (Rogers, Cacioppo, & Petty, 1983) applied to people with schizophrenia would propose an individual's adherence to treatment would be a response to a perceived susceptibility to illness symptoms alongside how severe these symptoms are likely to be, and treatment decisions influenced by a consideration of the perceived benefits weighted against the perceived costs and barriers. Similar results to this study are reported in studies using a Health Belief Model framework; Perkins et al. (2006) found the strongest predictor
of medication non-adherence was the belief the need for treatment was low and that medication was of little benefit.

The accounts of participants in the current study do not fit well with Theory of Planned Behaviour, Health Belief Model or Protection Motivation Theory concerning first episode psychosis and initial treatment, as due to the nature of psychotic phenomena many did not recognise they were unwell or in need of treatment; it was significant others who noticed changes in behaviour and initiated treatment. It is possible that people in hospital recovering from acute first episode symptoms would be in a better position to comment on the factors that influenced them thus far. However, it was decided not to include these people due to the likelihood of symptoms that would preclude their ability to consent or safe participation in the study.

Decisions regarding treatment following the acute illness phase appears to fit with these theoretical frameworks. A significant influence on taking medication, reported by ten participants, was the perception that there would be benefits, such as relief of symptoms or the contribution to a desired outcome or life goal. Seven of these ten reported the presence of side effects, and indicated a process of weighing up side effects against benefits, in line with other studies’ findings that subjective experience of schizophrenia and treatment is a factor influencing antipsychotic adherence (Gibson et al., 2013; Hon, 2012). Both these studies showed people considered the effectiveness of medication on illness symptoms and its contribution to quality of life, weighed against medication side effects. Moritz et al.’s (2013) finding that positive attitudes towards psychotic symptoms contributes to medication non adherence was not reflected in this study, as no participants reported favourable attitudes towards symptoms.
Consistent with the Theory of Planned Behaviour, perception of benefits was informed in a variety of ways, including recollection of past experience of symptoms and treatment, both positive and negative, and knowledge of medication gained from various sources (clinicians, pamphlets, and media). In all case, benefits outweighed side effects in what appeared to be a conscious decision making process. Only Sarah had ceased medication due to side effects, and at the time did not appear to have considered benefits at all. Findings regarding the influence of medication side effects on attitude towards treatment and decision to adhere to treatment differed to findings reported by DiBonaventura et al. (2012) and Lambert et al. (2004). Similar to this study, the majority of subjects in DiBonaventura et al. (2012) study report the presence of side effects, however DiBonaventura et al. (2012) reported a strong association between side effects and non-adherence, with over half admitting to some degree of non-adherence. Lambert et al. (2004) also found side effects contributed to negative beliefs about the efficacy of antipsychotic medication, which in turn contributed to non-adherence. It is interesting to note that four participants thought side effects may have played a part in the vignette case Joe ceasing medication, despite only one of those respondents actually ceasing medication for this reason. A possible explanation for this difference is how non-adherence is defined. Participants in the current study discussed the influence of side effects on ceasing medication, whereas the above mentioned studies defined non-adherence as deviating from treatment as prescribed, or not taking medication some of the time; according to these definitions Clive's account “I started to mess around with the medicines” would be viewed as non-adherence.

A common theme (indicated by nine participants) was taking medication to prevent something undesirable happening, which included illness symptoms returning, re-admission to hospital and being forced into treatment. This would be viewed by Health Belief Model and Protection Motivation Theory as taking steps to protect oneself from a perceived threat.
likely to have severe consequences. Using a Health Belief Model framework, Adams and Scott (2000) found fear of hospitalisation as a result of relapse, and belief relapse would be severe, to be strong influences on medication adherence. When considered using Theory of Planned Behaviour, preventing an undesirable consequence of treatment non-adherence could be viewed either as a perceived benefit or an influential factor in its own right. Fear of an undesirable event fits Sandberg and Conners’ (2008) concept of anticipated affect, which they suggested as an addition to Theory of Planned Behaviour's attitude construct. Regardless, Theory of Planned Behaviour would view this as an influence on a person’s attitude towards treatment. Eight participants indicated both perceived benefits and preventing something undesirable happening as strong reasons to follow treatment.

From a Theory of Planned Behaviour perspective, results of the current study show participants’ decisions to adhere to treatment to be influenced in part by their attitude towards treatment, in turn influenced by behavioural beliefs; that despite unpleasant side effects (negative attribute) there will be benefits from taking medication, such as the relief of symptoms and preventing something undesirable happening (positive attributes). In all but Sarah’s case, positive treatment attributes were valued higher than negative ones, thus influencing the decision to adhere to treatment.

Findings regarding the influence of attitudes on treatment decisions were consistent with those of Conner, Black, and Stratton (1998), who applied Theory of Planned Behaviour to antipsychotic medication compliance and discovered attitude to have influence on intention to take medication. Similarly, attitudes were influenced by beliefs about the likelihood of medication contributing to improved mental health state, independence with daily tasks and staying out of hospital. However, different to findings reported by Mausbach
et al. (2013), although that study investigated a range of functional behaviours among people with schizophrenia, taking medication being only one of these.

Although data was limited regarding psychosocial treatment, consideration of benefit appears to be on a usefulness continuum. Three participants discussed the usefulness of a community agency based on what they got out of their involvement with that agency, for example employment. Studies reviewed in Chapter 2 report rates of adherence to psychosocial treatment but do not offer reasons people did not take up or complete these interventions, therefore no comparison can be made.

**Information about illness and treatment**

I expected limited information provided at illness onset, and insufficient knowledge of schizophrenia and treatment to contribute to negative attitude towards treatment. Lack of information at illness onset was reported by six participants. As Theory of Planned Behaviour considers information from various sources influences attitude towards a behaviour, it could be presumed that information about schizophrenia and treatment provided to people at illness onset would have some influence on their attitude towards treatment. A Protection Motivation Theory and Health Belief Model would view information obtained from a variety of sources as contributing to an individual’s motivation to act on the threat of suffering psychotic symptoms based on appraisal of the likely success of the proposed treatment. These theoretical approaches assume some degree of rational thought process is possible. It should be noted that due to the nature of a psychotic episode, people are often not in the right frame of mind to process information in a rational manner. It could be that information was provided at illness onset, but participants were not able to receive or understand it.
Of the six participants who indicated they did not receive sufficient information at illness onset, three reported actively resisting treatment, by absconding from a treatment facility or refusing to take medication. One other (Tony) agreed that better information would have helped him make informed decisions. However, information as an influence on attitude toward treatment can only be inferred, as apart from Tony's case, no other participants indicated strongly that information, or the lack of it, was an influential factor in treatment adherence.

It was clear from the language used by participants, particularly discussing psychosis and various medications, that information had increased during the course of illness. This appeared to be attributable to a need to educate oneself following an increased awareness of the effect of illness, and also due to contact with clinicians and others with schizophrenia.

The influence of information about schizophrenia and treatment on attitude towards treatment and/or treatment adherence was not clear. This is consistent with studies reviewed; Budd et al. (1996) found illness knowledge held no predictive power regarding medication adherence and Baloush-Kleinman et al. (2011) found awareness of illness did contribute to attitudes towards treatment, however to what extent was not clear. Both studies were within a Health Belief Model framework. Conner et al. (1998) and Mausbach et al. (2013), using a Theory of Planned Behaviour framework, did not provide details of the specific influence of knowledge of illness and treatment on intentions to take medication or actual compliance.

**Stigma**

I expected people may be reluctant to admit they had mental illness, however this was not generally the case. On the surface, Health Belief Model and Protection Motivation Theory do not adequately account for the role of stigma in decision to adhere to schizophrenia treatment. However, according to Protection Motivation Theory, stigma could
be considered a response cost in that there may be a personal cost to an individual from acknowledging they have a mental illness by default when they accept treatment. Health Belief Model would possibly view this acknowledgement as a barrier to treatment, if it played a part in a person decided not to seek or accept treatment. From a Theory of Planned Behaviour perspective, stigma would be considered an information source that influences attitude, as an individual informs themselves what it means to have schizophrenia.

Participants generally had encountered stigma or believed it existed, based on misconceptions about schizophrenia most likely gained from how the illness is portrayed in the media and entertainment. There were no reports that participants had not sought help for psychotic symptoms because of stigma, and no strong belief that others would not seek help for fear of being seen as mentally ill. However, as pointed out by Clark, it could be that people are not aware they are mentally ill until they have an intervention, therefore not consciously thinking about stigma.

It was not clear from the current study whether or not stigma plays a role in influencing treatment decisions, as no strong stigma themes were identified. I expected stigma may prevent people from seeking help for psychotic symptoms, consistent with findings from Livingston and Boyds’ (2010) meta-analysis that found a moderate correlation between stigma and medication non-adherence, and two additional studies that found self-stigma to be strongly associated with discontinuation of antipsychotic medication (Fung et al., 2008) (Moritz et al., 2013), however this was not the case. A possible reason is the participants in the current study appeared cognitively relatively high functioning and therefore more able to combat self-stigmatising thoughts.
Subjective normative beliefs

Influence of significant others / the experiences of others with schizophrenia

I expected the desire to please and trust the opinions of significant others, and perception of the experiences of others with schizophrenia to influence decisions, which was confirmed to some extent. A reason for not using Health Belief Model or Protection Motivation Theory as a framework for the current study is that neither account for the influence of other people in an individual’s decision to perform health behaviours. The Theory of Planned Behaviour considers the role of injunctive normative beliefs (perception of what others believe a person should do) and descriptive normative beliefs (perception of what others in similar circumstances are doing) as influences on behaviour.

Results were consistent with the Theory of Planned Behaviour's view that injunctive normative beliefs have some influence in intentions to perform behaviours, related to how much the individual values the opinions of referents. Most participants reported valuing the opinions regarding treatment for schizophrenia of people they perceived cared about them and understood their situation, and a perception that they had some knowledge of the illness. Typically significant others included family members and friends, and appeared to have some influence in participants' treatment decisions due to a desire please these people and/or a willingness to trust their best interests were being considered. For participants who did not value the opinions of family members (such as Sarah and Roger) these family members had no influence on treatment decisions. This reflects the findings of Conner et al. (1998); that pressure from salient others was associated with intention to take anti-psychotic medication, dependent on respondents motivation to comply with the wishes of those people.

Similarly, as per the Theory of Planned Behaviour, descriptive normative beliefs were influential for a small number of participants, based on the perception of what others
in similar circumstances were doing. This was either deciding to accept treatment based on positive experiences of others (for example David) or deciding against a particular treatment based on a perceived negative experience of others (for example Christine). However, generally participants were not aware what others were doing regarding treatment as they considered it to be none of their business. I was expected that participants generally would be more likely to seek information about treatment and consider advice from people who had experience of schizophrenia than from people who hadn’t, however this was not the case, as participants were more likely to base decisions on perceptions of benefits and disadvantages of others’ experiences rather than what they said.

So it appears injunctive normative beliefs had a stronger influence than descriptive normative beliefs on decisions to adhere to treatment. This is consistent with Manning’s (2009) meta-analysis that found injunctive normative beliefs had a stronger effect on intentions to perform behaviours than descriptive normative beliefs. It is worth noting that apart from in research using a Theory of Planned Behaviour framework, the beliefs and wishes of others and the perception of what others are doing regarding treatment were not reported in studies investigating influences on treatment adherence.

**Relationships with clinicians**

I expected positive relationship to contribute to decision to adhere to treatment, however while this could be inferred, it was not explicitly clear. Participants valued therapeutic relationships in which they felt respected, listened to, understood, involved in treatment decisions and appreciated clinicians who they perceived to have good knowledge of schizophrenia and treatment and who showed a genuine concern for their well-being.

While participants generally reported good relationships with clinicians, it was not clear to what extent this influenced decision to adhere to treatment, possibly because
participants were not asked directly about this link and did not provide information. At best, the association between therapeutic alliance and treatment adherence can be inferred, as participants report following treatment as recommended by clinicians they have had good relationships with, in contrast to times of low adherence or resistance to treatment, when mistrust and suspicion of treatment providers were features, particularly in early stages of treatment. This would be consistent with Stewart's (2012) study, which found relationships with practitioners to be strongly associated with service engagement during first contact for psychosis, and Gibson et al.'s (2013) study that identified instability in relationships to be a reason for deviating from treatment. In the current study, it could be that the focus of treatment, targeting the most severe symptoms, occurred at the expense of building therapeutic alliance.

Although not explicitly expressed by participants, poor engagement with service providers and clinicians could possibly be attributed to psychotic symptoms and lack of understanding of illness onset and the need for treatment. Severe symptoms were reported by Berry et al. (2012) as associated with negative relationships with clinicians, and patient insight was found by Johansen, Iversen, Melle, and Hestad (2013) to contribute to therapeutic alliance.

Protection Motivation Theory and Health Belief Model do not account for the influence of the value of therapeutic relationships on behaviour. According to Theory of Planned Behaviour, the value of a relationship with a clinician contributes to an injunctive normative belief, as an individual would be more inclined to act in accordance with what the clinician wanted and recommended. Viewed from this perspective, participants’ accounts reflect findings of Conner et al. (1998) that intention to take anti-psychotic medication as
prescribed was stronger among people who were motivated to comply with the wishes of the health professionals recommending the medication.

**Perceived behavioural control**

*Involvement in treatment decision making at illness onset / involvement in treatment decision during course / barriers to treatment*

I expected participants to have had limited involvement in treatment planning at illness onset, as they would go along with clinicians’ wishes. I also expected cognitive deficits, such as poor memory or difficulty managing complexity of medication regime to be perceived barriers that influenced decision to adhere to treatment.

Protection Motivation Theory, Health Belief Model and Theory of Planned Behaviour view a person’s self-perceived ability to perform behavioural tasks as an influence on whether the person decides to undertake the behaviour. This involves consideration of the ease of behavioural tasks alongside factors that are likely to facilitate or impede completing the tasks.

Using Theory of Planned Behaviour’s perceived behavioural control construct, schizophrenia treatment tasks include development of treatment plans and associated tasks, such as taking medication and attending appointments with clinicians. Behavioural control over treatment plan development refers to participants both being ‘able’ and being ‘allowed’ to be involved in treatment planning.

Generally participants believed they were not involved in development of treatment plans at illness onset, as they were not invited. In most cases this meant not being offered options and being told what treatment was to be provided. A possible explanation for this is the presence of severe symptoms and lack of insight precluding practical involvement or
rational decision making, and as reported, in some case participants were not bothered by not being involved. However, a small number of participants believed they were able to make decisions and should have been offered options. There is possibly a link between this factor and poor relationship with clinicians.

Involving family members in treatment at illness onset appears to be more prevalent since deinstitutionalisation of the early 1990s. Prior to this period, participants believe family members were not involved beyond ‘handing over’ their loved one to the care of psychiatric institutions. Participants whose first contact for psychosis occurred since deinstitutionalisation recalled and appreciated family members being better informed and more involved, as the role of family members as primary support people was recognised.

Almost all participants indicated they have been involved to some degree in ongoing treatment planning, and it appears these people perceived they have the ability to make decisions regarding treatment. In some cases participants have suggested alternatives to medication or requested a change to medication they have found out about, or clinicians have proposed a new treatment they believe to be better. While participants have appreciated being involved in treatment decisions, choices are seen as being between options clinicians have identified, and therefore limited. If clinicians have not supported an option (e.g. herbal remedy) it is not available to be chosen.

Taking medication was identified by participants as the primary task associated with treatment. There were no accounts of participants doubting their ability to follow medication regimes, and those who had experienced barriers had been able to overcome them, either using their own resources or with assistance from others. Negative symptoms, such as a-volition or cognitive deficits were identified early on and solutions incorporated into treatment plans, for example medication managed by support staff.
Cost associated with treatment was also considered by some to be a barrier. This included financial cost, such as travel to appointments or costs of GP visits and prescriptions, and the amount of time spent getting to or completing treatment tasks. As well as a consideration of the ability to overcome these types of barriers, participants weighed up costs against the benefits of treatment to decide if they were actual barriers. So while cost is weighed against benefits in influencing attitude towards treatment (described above), financial cost can also act as a barrier to treatment, if a person decides the cost does not outweigh the benefit but is unaffordable.

Participants who reported being involved in treatment decisions, and/or not experiencing barriers to treatment significant enough to cause them to stop, are currently treatment adherent. However, it is difficult to determine to what extent these factors influenced the decision to adhere to treatment as only two (Sarah and Clive) had identified side effects as a reason to deviate from treatment plans. Prior research on the link between perceived behavioural control and schizophrenia treatment adherence is scarce but suggests intention to take anti-psychotic medication is partly influenced by perceived behaviour control (Conner et al., 1998; Mausbach et al., 2013). However, as Sarah and Clive both no longer view side effects as barriers to successfully taking medication, and this is different to when they did deviate from treatment, the perceived behavioural control construct could be inferred to have had some influence in treatment decisions.

Similarities and differences to literature

The finding that attitude toward treatment was the strongest influence on participants' decisions to adhere to treatment is not surprising, given attitude was shown in early studies to strongly influence intentions to perform a variety of behaviours, including having a baby (Davidson & Jaccard, 1975), breastfeeding (Manstead et al., 1983) and voting (Fishbein et
al., 1980). More recent studies of health behaviours using the Theory of Planned Behaviour have also shown attitude toward behaviour to be a strong influence on intention (McEachan et al., 2011; Armitage & Conner, 2001).

What is surprising, however, is that perceived behavioural control appears to have little or no influence on treatment decisions among participants in the current study. This is in contrast to the meta-analyses performed by Armitage and Conner (2001) and McEachan et al. (2011) (which included a number of the same studies) which found perceived behavioural control to be the second strongest predictor of intentions to perform a variety of health behaviours, although there were no reports of mental health behaviours. However, as treatment for schizophrenia is a health behaviour, it is important to consider why perceived behavioural control was not found to influence treatment decisions.

Initially the Theory of Reasoned Action was used to explain and predict performance of behaviours people believed they had volitional control over i.e. that weren't dependent in part on another person or circumstance. Trafimow et al. (2002) proposed the perceived behavioural control construct of the Theory of Planned Behaviour was comprised of two distinct concepts; perceived volitional control and perceived difficulty of behavioural tasks. The primary behavioural task in the current study was taking medication as prescribed (i.e. the right dose at the right time). With regards to perceived difficulty, this task is generally reasonably straightforward, and factors known to impede taking medication, such as negative symptoms of schizophrenia, can be anticipated and addressed early on in treatment. Therefore an individual in early stages and throughout the course of illness can be confident that taking medication as prescribed will not be difficult. Accounts from participants indicate times taking medication was not entirely within their volitional control; threatened or actual
use of the Mental Health Act for compulsory treatment meant treatment decisions were made for them.

The effect of neuro-cognition on treatment decisions was not clear from participants in the current study. This could be explained by the relatively high cognitive abilities of most participants. Prior research has indicated a link between neuro-cognitive deficits and medication adherence, but not the influence of neuro-cognition on decisions to adhere to treatment. Donohoe et al. (2001) found memory to be the best predictor in partial medication compliance and Robinson et al. (2002) report pre-morbid cognitive functioning to be associated with ability to manage complicated medication regimes. Both studies identified these reasons among people not taking medication despite intending to. In the current study, Angela and Ronald presented with what appeared to be some cognitive deficits (difficulty with comprehension and attention) during interviews, and reported medication needing to be managed by clinicians and support staff despite them being happy to take it. It could be that these participants were able to decide to adhere to treatment but were not able to manage the demands of medication regimes.

Summary

This study has highlighted some key factors about why people drop out of treatment. As such, the findings have provided some very important insight into some possible influences on a person’s decision to adhere to treatment for schizophrenia. The study has also shown why people cease treatment (or would like to), against the advice or without the knowledge of clinicians involved in their care. For some people this will involve a decision making process, and for others it is the result of not being able to manage treatment tasks despite intending to. The numerous reasons behind treatment non-adherence can be addressed with a variety of interventions. Furthermore, it is important that clinicians do not
view all people not involved in treatment as being non-compliant. They need to look further and try to identify what are the factors that have influenced the person’s decision not to comply with recommendations from their treatment team.

The lack of uptake of, and adherence to, psychosocial treatment interventions is concerning, as such interventions would likely address the reasons people do not adhere to pharmacological treatment. The main influence on treatment decisions in the current study was found to be attitude towards treatment, which was influenced by beliefs regarding the benefits of treatment in contributing to a desired outcome or preventing something undesirable occurring, weighed against perceived costs or negatives (for example medication side effects). As these beliefs and perceptions were found to be based on subjective experience and information gained from a variety of sources, there is potential for psychosocial interventions to be used to influence attitude. Psycho-education, found by Lincoln et al. (2007) and Xia et al. (2011) to be associated with lower rates of relapse and medication non-compliance, can provide people balanced information about their illness and what to expect from treatment (including potential negatives) in order to make informed decisions. Beliefs that result in resistance to treatment can be addressed with cognitive behavioural interventions, which aim to reduce the impact of positive symptoms (delusional beliefs and hallucinations) by assisting individuals to find explanations for their experiences that are more acceptable to them (Turkington et al., 2006), thus changing attitude towards accepting treatment. These interventions have been found to have effect on both acute psychosis (Zimmermann et al., 2005) and chronic schizophrenia (Tarrier & Wykes, 2004).

Motivational interviewing is commonly used to address ambivalence regarding behaviour change, and has been used with success in mental health and addictions, although has had limited application with people suffering from schizophrenia. Studies of
motivational interviewing with this population have not found an effect on medication adherence (Vanderwaal, 2015), however motivational interviewing has been associated with increased perception of treatment benefits (Ertem & Duman, 2016) and increased attendance at cognitive therapy sessions (Fizdon, Kurtz, Choi, Bell, & Martino, 2016), suggesting value in enhancing adherence to psychosocial interventions.

As injunctive normative beliefs were found in the current study to have influence over treatment decisions, there is potential for the influence of significant others to be enhanced by providing them with good information about illness symptoms and treatment. The common experience of those whose first contact with psychiatric services was prior to deinstitutionalisation was family members received very little information. Family psycho-education, which involves education alongside training designed to support medication compliance, symptom management, handling crisis and conflict, and prevent relapse, has been found to contribute to improved knowledge and the use of coping and problem solving strategies among family members (Sin & Norman, 2013). As participants in the current study reported valuing the opinions of significant others who understood their circumstances and had knowledge of schizophrenia, and these people had influence over treatment decisions to some degree, it is important to ensure significant others are properly educated.

It is possible that psychosocial interventions are prevalent in early intervention services, as the focus of these services is to identify those at risk of developing psychotic disorders, and provide comprehensive treatment and education within a multi-disciplinary team. Similarly, psychosocial interventions are readily available to inpatients as typical of treatment in acute illness phase. However, this cannot be reported on in the current study as people in current contact with these services were not included in the study. Apart from experience with community agencies that provide education and vocational assistance,
participants did not recall psychosocial interventions delivered by mental health clinicians aimed at enabling informed decisions about treatment or enhancing treatment adherence.
Chapter 7 – Conclusion

This chapter concludes the study, in doing so the main implications for practice and service delivery are discussed, as are the limitations to the study. Finally, recommendations for future research are made.

Implications

A practice implication for the findings of this study is for clinicians to consider the way medication non-adherence is viewed. For instance, the reasons a person forgets to take medication are vastly different to why they refuse to take medication. As has already been demonstrated, the reasons behind treatment non-adherence can be addressed utilising a variety of interventions, and it is important the model chosen matches the issue identified. A further practice implication is for clinicians to be trained and supervised in the use of psychosocial interventions, and models are targeted at non-adherence influences according to the needs of each individual. For example, it will be appropriate to employ motivational interviewing for a person who is ambivalent, however they may not need assistance with communication or social skills. Alternatively, for a person who does not see the need for treatment, individual and family psycho-education may be the most appropriate intervention.

From a service development perspective, there is potential for Southern District Health Board community mental health teams to address treatment non-adherence by better utilising the clinical skills and knowledge of staff from each discipline. To this end, a project to develop a service model for community-based rehabilitation (recovery) services for adults with high/complex & long term mental health needs is underway. This model is consistent with the characteristics of assertive community treatment outlined by Zigarus & Stuart (2000); lower caseloads, team approach to client management and the use of clinical skills.
Evidence to support this model of care is provided in Chapter 2 (see Essock, 2006; Latimer, 1999; Zigarus & Stuart, 2000). Included in the target population for Southern District Health Board project is people with schizophrenia with a significant history of medication non-adherence, relapse, hospitalisation and difficulties engaging with clinical services. With consideration to the results of this study, a recommendation for the proposed Southern District Health Board service is to target the factors contributing to treatment non-adherence utilising the clinical expertise of multi-disciplinary team members and evidence based psychosocial interventions recommended by RANZCOP, as well as therapeutic models such as motivational interviewing to enhance engagement in these interventions.

**Limitations**

Several limitations in this study were related to the small sample size. The target sample was 15 – 20, however despite the assistance of professionals involved with people with schizophrenia in Otago communities, this was not achieved. A possible explanation for low uptake is the reluctance of people with a history of psychotic symptoms, often characterised by suspicion and paranoia, to talk openly about their experiences, particularly if they have been seen as delusional in the past or have negative recollections of talking to health professionals. A further limitation is the low number of Maori (1) and female (3) participants. Although one in twelve (8.3%) is roughly representative of the population of Maori in relation to the total population in Otago (7.4%), it is difficult to generalise the accounts of this one person to the population of Maori with schizophrenia. Furthermore, as schizophrenia is 1.4 times more likely in males than females (Picchioni & Murray, 2007), five female participants would have been desirable.

A further limitation is the potential unreliability of self-report in relation to schizophrenia diagnosis and experience of treatment. Participants’ diagnoses and treatment
details were not verified, although it was clear from the descriptions of experiences and language used, particularly in relation to psychotic episodes, that participants had suffered from schizophrenia as classified in DSM-5 and had received treatment as would be expected. As the study focussed on decision making processes regarding treatment adherence and not actual adherence, there was no need to verify participants’ accounts.

A third limitation is the lack of data on decisions regarding treatment for first episode psychosis due to the time elapsed since first contact with mental health services. The median age of participants was 55.5 years (youngest 35, oldest 62); as is typical with age at illness onset, participants generally suffered first episode psychosis in their 20s, and were in most cases recalling experiences from at least 20 years prior. Due to this, participants may have misremembered what had occurred, or may not have been able to remember at all, and provided information based on what they thought may have happened. People in inpatient units were intentionally excluded due to likely presence of acute illness symptoms, however it may have been appropriate to recruit people in sub-acute phase during first hospital admission as these people could possibly been able to recall more clearly first treatment experiences and influences on decision making. It is possible recruiting people from early intervention services may also have provided valuable insight into influences on early stage treatment decisions.

Future research

There are two areas of future research highlighted from this study. Firstly, as participants were generally middle- to older-aged and had difficulty recalling experiences of first presentation and treatment for psychotic symptoms, no conclusions could be reliably drawn about influences on early treatment decisions. Therefore, research into the factors that influence treatment decisions regarding first episode psychosis is warranted. As age of onset
of psychotic disorders is typically early- to mid-20s, research in collaboration with early intervention in psychosis services in Otago may be the optimum way to understand the experiences of this cohort.

This study intentionally did not include people in inpatient settings, primarily to exclude those suffering from acute symptoms. However, there may be the potential for inpatients in the sub-acute phase of recovery to provide some valuable insight into the reasons they discontinued treatment, and these experiences may be relatively recent. It is likely that people in this recovery phase will not suffer symptoms to the extent they are unable to participate in research, therefore future investigation with this cohort locally is recommended.
References


Stewart, K. D. (2012). Factors contributing to engagement during the initial stages of treatment for psychosis. Qualitative health research, 1049732312468337.


Appendices

Appendix 1 – Ethics Committee Letter

Professor A Barusch
Department of Sociology, Gender and Social Work

22 June 2015

Dear Professor Barusch,

I am writing to let you know that, at its recent meeting, the Ethics Committee considered your proposal entitled "How do people with schizophrenia decide whether or not to engage in treatment?".

As a result of that consideration, the current status of your proposal is: Approved

For your future reference, the Ethics Committee’s reference code for this project is: H15/059.

The comments and views expressed by the Ethics Committee concerning your proposal are as follows:

The Committee would like to thank Rob Willers, the student investigator, for attending the Human Ethics Committee (Health) meeting to discuss the project.

In the meeting Rob gave an overview of the study as well as his experience of working in mental health and addiction.

The Committee commended the research and raised the issues that the participants who are to be interviewed will be those who are in a non-psychotic phase of their illness and usually able to make rational decisions. The Committee commented, however, that when people with schizophrenia need to engage with treatment they are often psychotic and, therefore, not usually able to make reasonable decisions. The Committee asks that this is kept in mind when writing up the results of the study.

The Committee also asked for clarification of the sample size chosen indicating that 15-20 participants could be adequate. Rob agreed that saturation may be reached before the stated number of 25 and would keep this in mind.

While approving the application, the Committee would be grateful if you would respond to the following:
The Committee suggest that an Information Sheet is developed for those assisting with the recruitment and asks to be provided with a copy of the letters of support from the organisations from where participants will be recruited.

Please provide the Committee with copies of the updated documents, if changes have been necessary.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

http://www.otago.ac.nz/healthandsafety/index.html

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:

gary.witte@otago.ac.nz

jo.farronediaz@otago.ac.nz

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.
Yours sincerely,

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Professor H R Campbell  Head  Department of Sociology, Gender and Social Work
Tuesday, 21 April 2015.

Professor Amanda Barusch,
Department of Sociology - Gender and Social Work,
D U N E D I N .

Tēnā koe Professor Amanda Barusch,

*How do people with schizophrenia decide whether or not to engage in treatment?*

The Ngāi Tahu Research Consultation Committee (the committee) met on Tuesday, 21 April 2015 to discuss your research proposition.

By way of introduction, this response from the Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the stated principles of the memorandum it states “Ngāi Tahu acknowledges that the consultation process outlined in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago”. As such, this response is not “approval” or “mandate” for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGeachan:

> "Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the latest census.

The Committee suggest the researchers consider the substantial work of Professor Sir Mason Durie in this area of mental health.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and the committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 21 April 2015 to 21 October 2016.

Nāhaku noa, nā

Mark Brunton
Kaiwhakahaere Rangahau Māori
Research Manager Māori
Research Division
Te Whare Wānanga o Otago
Ph: +64 3 479 8738
Email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz
Appendix 3 – Interview protocol

The following is an outline of the topics covered in the semi structured interview with participants, including possible questions that will be used to elicit information. The interviews will be conducted by Rob Willers, student investigator, who has a post graduate social work diploma and 13 years practice experience.

The interview consists of:

1. A vignette as a warm up and to start some discussion about schizophrenia and treatment.
2. Subjective experience of illness and treatment to gain information regarding attitudes towards treatment and perceived behavioural control over elements of treatment.
3. Beliefs and opinions of others and how they influence participants’ intention to engage in treatment.
4. Closing discussion.

Vignette

“Joe is a 30 year old man diagnosed with schizophrenia at age 24 during a 2 month hospital admission. He had confronted his neighbour due to beliefs that the neighbour was a SIS spy. Joe was involved with the Early Intervention in Psychosis Service for two years; he was treated with antipsychotic medication and learned ways to recognise early warning signs and manage symptoms. He was transferred to an adult community mental health team for three monthly reviews with a psychiatrist.

Recently Joe’s parents noticed bizarre behaviour/comments consistent with initial psychosis, and contacted his psychiatrist. It was discovered that Joe had ceased medication; due to safety concerns Joe was admitted to hospital”

Question - If we are trying to figure out why Joe ceased medication, what should we think about and ask?

Subjective experience of schizophrenia and treatment

Tell me about your experience of schizophrenia (eg age when symptoms first appears, what symptoms you experienced, the impact it had on your life, treatment components used, hospital admissions)

How much information were you and family etc given at the start?

What treatment choices or alternatives were you given to start with?

How involved are you in decision making regarding treatment now?
**Medication**

Tell me about your experience of medication

To what extent do you think medication has been effective in the treatment of schizophrenia/contributed to wellness?

Is there anything you don’t like about medication?

Is there anything you find difficult about taking medication (eg memory, swallowing tablets, can’t get to pharmacy, prescription costs)

How confident are you in overcoming these barriers?

How do you think your life would be if you weren’t taking medication?

Do you intend to continue with medication?

(Summarise the above) – which of these factors do you think influence your intention to medication?

**Have you had any experience of other treatment or support? (eg therapy, clubhouse – use table for prompts)** Same questions

<table>
<thead>
<tr>
<th>Treatment component</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>Relieve symptoms</td>
</tr>
<tr>
<td>Social skills training</td>
<td>Manage relationships and social interactions</td>
</tr>
<tr>
<td>Psycho education</td>
<td>Education re illness symptoms, treatment. To inform decision making and learn to manage symptoms</td>
</tr>
<tr>
<td>Family education</td>
<td>Provide education to significant others; Develop strategies for communication and problem solving</td>
</tr>
<tr>
<td>Cognitive therapy</td>
<td>Develop ways to cope and control residual symptoms</td>
</tr>
<tr>
<td>Cognitive rehabilitation</td>
<td>Improve memory, attention and problem solving ability; Improve functioning</td>
</tr>
<tr>
<td>Vocational rehabilitation</td>
<td>Assist to find employment/course</td>
</tr>
</tbody>
</table>

**If you were offered alternative treatment or support, how would you decide to try it?**
Beliefs and opinions of others (subjective norms)

Do you know other people with schizophrenia?
Are you aware of what they are doing regarding treatment?
Do you think your situation is similar to these people?
Tell me about the people who are important to you
What do they think you should do regarding treatment?
Are there other people in your life? (not including clinicians)
What do they think you should do regarding treatment?
Whose opinions/beliefs do you value most? Whose do you value least? Why do you think that is?
How would you describe your relationship with your primary clinician? What are the qualities about them you like?
To what extent do you value the opinions/beliefs of this person?
What do you think the general public perceptions about schizophrenia are? Any idea what general public think people with schizophrenia should do regarding treatment?
To what extent to the opinions/beliefs of the people we have talked about influence your intention to engage in treatment?

Family
Friends
Treatment providers
Other

Closing discussion

The information you have given me will be very helpful in understanding people’s experiences of schizophrenia and treatment. Is there anything else you think would be useful for me to know?

Do you think people are more likely to listen to others who have had similar experiences?
What advice would you give to a person who has just been diagnosed with schizophrenia?
In your opinion, what are the things that contribute to quality of life?

Thank you for your participation.