Caregiver experiences of parents who support adult children with schizophrenia

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# TABLE OF CONTENTS

LIST OF TABLES ............................................................................................................ ii  
ATTESTATION OF AUTHORSHIP ................................................................................ iii  
ACKNOWLEDGEMENTS .................................................................................................. iv  
ABSTRACT ......................................................................................................................... 1  
CHAPTER ONE: INTRODUCTION .................................................................................... 2  
CHAPTER TWO: LITERATURE REVIEW .......................................................................... 4  
  Background on schizophrenia ....................................................................................... 4  
  Research on carer burden .............................................................................................. 5  
    Impact on caregivers.................................................................................................... 6  
    Factors which affect carer burden .............................................................................. 7  
    Gender ....................................................................................................................... 9  
    Ethnicity ................................................................................................................... 10  
  Research on positive experiences of caregiving ........................................................... 10  
  Caregiver coping and supportive factors ..................................................................... 12  
   The New Zealand context .......................................................................................... 15  
  Summary and justification for the current study ........................................................... 16  
CHAPTER THREE: METHODOLOGY ............................................................................. 18  
  Methodological approach ............................................................................................ 18  
  Epistemological position ............................................................................................. 19  
  Reflexivity ................................................................................................................... 20  
  Recruitment of participants ......................................................................................... 21  
  Data collection ............................................................................................................. 22  
  Method of analysis ...................................................................................................... 24  
  Ethical considerations .................................................................................................. 26  
  Quality and credibility ................................................................................................. 28  
CHAPTER FOUR: RESULTS ............................................................................................ 30  
  Psychological factors .................................................................................................. 31  
    Theme 1: Emotional burden .................................................................................... 31  
    Theme 2: Cognitive coping techniques ................................................................... 35  
      Subtheme 2A: Knowledge acquisition .................................................................... 35  
      Subtheme 2B: Positive thinking ............................................................................ 37
LIST OF TABLES

Table 1: Participant demographics .................................................................................. 30
Table 2: Themes generated by the analysis ..................................................................... 31
ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university of institute of higher learning.

Signed: ____________________

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ABSTRACT

Over the past 60 years there has been a progressive shift in mental health service delivery away from mental hospitals and towards community-based care. In many cases this shift has resulted in family becoming the main care providers of relatives with long-term, chronic and disabling mental disorders, who would have previously been institutionalised. A large number of studies have shown that caring for a family member with major mental illness is associated with reduced quality of life and has significant impacts on the mental health and functioning of caregivers. However, positive impacts of caring are also documented and family can play an important role in recovery. Such research demonstrates the importance of understanding the complexity of the experience of family caring for an individual with schizophrenia. There is currently little research on family carers in New Zealand, particularly those who are caring for an individual with mental illness. This study uses a qualitative framework to develop a more in-depth and detailed understanding of caregiver experiences in the New Zealand context. Six parents who are providing long-term care and support for adult children with schizophrenia were recruited with the help of Supporting Families in Mental Illness. Data was gathered via face-to-face semi-structured interviews and an interpretive phenomenological analysis used to identify six themes in the data: 1) emotional burden, 2) cognitive coping techniques (containing two subthemes, 2A) knowledge acquisition and 2B) positive thinking), 3) the importance of communication and collaboration with mental health professionals, 4) the importance of group and peer support, 5) family support and family conflict and 6) lack of resources and support for caregivers. These were grouped into three superordinate categories: psychological factors, external support factors and systemic factors. The findings of this study have important implications for developing effective supports and services that can help families to better manage long-term and severe mental illness.
CHAPTER ONE: INTRODUCTION

Schizophrenia is a chronic, severe and disabling mental disorder that causes serious consequences for those with the illness, as well as those who care for them. Over the past 60 years there has been a progressive shift in mental health service delivery away from formal institutions and towards community-based care (Baronet, 1999; Vella & Pai, 2013). The closure of mental hospitals and discharge of patients has resulted in a shift of care for individuals with schizophrenia to informal care providers, such as families and non-profit community based organisations (Awad & Voruganti, 2008).

Estimates drawn from data in European countries suggest that somewhere between 50 and 90% of chronically ill psychiatric patients now live with family (Awad & Voruganti, 2008). In New Zealand, it is estimated that 10% of the population are caregivers for family members with physically disability or illness (Jorgensen, Parsons, Jacobs, & Arksey, 2010). As yet, there is no data on the number of family carers of individuals with mental illness in New Zealand. Even when not living with family, individuals with schizophrenia can still require significant emotional and financial support (Awad & Voruganti, 2008). Caring for a relative with a severe, long-term and disabling mental disorder places large demands on family members and has considerable economic and emotional implications for caregivers (Baronet, 1999; Davies & Drummond, 1994).

This study explores the experiences of parents who are providing long-term care and support for adult children with schizophrenia in New Zealand. The aim of this research is to investigate both the positive and negative experiences of caregiving, carer coping strategies, supportive factors, attitudes and perceptions. It is hoped that this investigation will provide a holistic conceptualisation of the experiences of this population of caregivers, as well as provide valuable information and awareness to mental health clinicians on the current issues for family caring for an individual with schizophrenia. Caregivers in general, and in particular those caring for a family member with major mental illness, are an under-researched group in New Zealand. The sharing of these experiences will help to increase knowledge on schizophrenia and the role played by family carers, as well as aid in the development of effective intervention and support strategies for individuals with mental illness and their families in New Zealand.
A qualitative methodology was selected as the most suitable way to develop an in-depth understanding of caregivers’ experiences in the New Zealand context. This research uses an interpretive phenomenological analysis (IPA), a methodology that represents both an epistemological position as well as a practical guideline for conducting qualitative analysis (Smith, 2004; Smith & Osborn, 2007). Studies using IPA aim to explore in detail participant’s lived experiences as well as how they make sense of those experiences (Smith, 2004). This framework draws on phenomenological paradigms in its acknowledgment that people with a lived experience are often the best source of expert knowledge on those experiences; and on interpretive paradigms in its emphasis on the dynamic process of research, within which the researcher plays an active role in making sense of the data (Smith, 1996; Smith & Osborn, 2007). The researcher is thus able to connect the data to existing knowledge, interpreting it in a way that can usefully inform clinical practice disciplines (Smith & Osborn, 2007).

Chapter one of this report has provided a brief introduction to this practice research project, including the aims of the study, context and an introduction to the methodology. Chapter two reviews previous research on family carers and provides a justification for the current study. This chapter gives some background information on schizophrenia and reviews the literature on carer burden, positive carer experiences (including a summary of qualitative research in the area), models of carer coping and supportive factors. Chapter three describes the methodological approach in detail, methods used for data collection and analysis, ethical considerations, as well as an evaluation of the quality and credibility of this study. Chapter four presents the findings of the analysis as themes that were identified in the data, with supporting excerpts from the interview transcripts. Finally, chapter five includes a discussion of the findings in the context of the literature. Potential limitations of this study as well as recommendations for clinical practice and future research are also addressed.
CHAPTER TWO: LITERATURE REVIEW

This chapter discusses previous research on family carers. It begins with some background information on schizophrenia and a review of the literature on carer burden, including a definition of the term, the impact of burden on caregivers and factors that affect burden. This is followed with a review of research on more positive experiences of caring, including a summary of qualitative studies, theoretical models of carer coping and supportive factors. Caregiver research in New Zealand is also reviewed in order to contextualise this research project. The chapter concludes with a summary and justification for the current study in light of the literature.

Background on schizophrenia

Schizophrenia is a major mental illness estimated to affect approximately 0.3-0.7% of the adult population worldwide, mostly in the age range of 15 to 35 years (McGrath, Saha, Chant, & Welham, 2008). Onset is typically around late adolescence and early adulthood, with an average age of diagnosis in the mid twenties (American Psychiatric Association, 2013). There have been only two studies which estimate prevalence rates in New Zealand. The Christchurch Psychiatric Epidemiology Study (CPES) estimated a lifetime prevalence 0.3% for schizophrenia, or 0.4% for schizophreniform disorders (Wells, Bushnell, Hornblow, Joyce, & Oakley-Browne, 1989). However, this survey did not sample hospitalised inpatients, therefore lower rates of schizophrenia in New Zealand may reflect a lower response rate from people with this diagnosis (Wells, et al., 1989). It is also not clear if prevalence has increased or decreased since this time (Wells, et al., 1989). A more recent study investigating prevalence of schizophrenia for Maori estimated a rate of 1%, which is more than three times higher than that for non-Maori (Kake, Arnold, & Ellis, 2008). The CPES does not provide information on ethnicity (Wells, et al., 1989).

The DSM-5 (2013) diagnostic criteria for schizophrenia describe a wide range of symptoms, classified as either positive or negative. Positive symptoms include delusions, hallucinations, cognitive disorganisation and disorganised or abnormal behaviour. Negative symptoms include diminished emotional expression, reduced motivation, anhedonia (lack of pleasure) and asociality. Cognitive deficits are also common and can persist when other symptoms are in remission, causing long-term
disability (American Psychiatric Association, 2013). The illness is typically chronic, with continuing psychotic relapses causing frequent hospitalisation (Awad & Voruganti, 2008). Around one third of individuals with the disorder will recover within a year of their diagnosis (Wells, et al., 1989). However, the majority will require ongoing daily living support and many maintain a course of progressive deterioration (Alvarez-Jiménez et al., 2012). Men are more likely to be diagnosed than women, and experience more negative symptoms and cognitive impairment, as well as poorer outcomes (Aleman, Kahn, & Selten, 2003; Alvarez-Jiménez, et al., 2012).

The illness profile and symptomology of schizophrenia has significant emotional and socio-economic costs for those with the condition as well as their families (Awad & Voruganti, 2008). Direct costs include hospitalisation and ongoing psychiatric and medical care, as well as provisions for economic and social support. Indirect costs include loss of productivity for both the individual and caregivers (Davies & Drummond, 1994). The disorder is typically managed via antipsychotic medications, which aim to reduce positive symptoms (American Psychiatric Association, 2013). However, medications have a number of well-recognised limitations, such as a range of adverse side-effects and low tolerability (Awad, Voruganti, & Heslegrave, 1995). Psycho-social support and rehabilitation are also important to address negative symptoms, although these options are frequently underfunded or not available (Awad & Voruganti, 2008). One of the challenges in management of the disorder is lack of insight in the individual with the illness, leading to noncompliance with treatments and frequent relapse (Weiden & Olfson, 1995).

**Research on carer burden**

Carer burden is a term which has traditionally been used in research to encompass the impact and consequences on family of caring full time for a physically or mentally unwell relative (Awad & Voruganti, 2008; Baronet, 1999). It encompasses the emotional, psychological, physical and economic dimensions of caring (Awad & Voruganti, 2008). Hoenig and Hamilton (1966) were the first researchers to qualify the concept of burden, dividing it into two distinctive domains – objective and subjective burden. Objective burden (OB) consists of the caregiving demands placed on family members which disrupt family life (Baronet, 1999; Samele & Manning, 2000). Subjective burden (SB) refers to the subjective experience of caring, including
psychological and emotional impacts as well as the extent to which caregivers perceive their role as burdensome (Baronet, 1999; Samele & Manning, 2000).

Dillehay and Sandys (1990) later introduced a widely adopted definition of carer burden as “a psychological state that ensues from the combination of the physical work, emotional and social pressure, like the economic restriction that arise of taking care of the patients” (p. 263). This definition includes aspects of OB such as the economic impact on caregivers, including loss of time and potential for earning, impaired social and vocational functioning, and family conflict (Awad & Voruganti, 2008). It also includes aspects of SB in regards to emotional distress, decreased quality of life and perceptions of the illness (Awad & Voruganti, 2008). Some studies which investigate burden using quantitative measures have evaluated SB and OB separately, while others use scales that evaluate both types of burden in each item (Baronet, 1999). This leads to some confusion as to what aspects of burden have been measured and makes data difficult to compare between studies.

Impact on caregivers
Studies of carer burden have risen steadily since the advent of community based care (Baronet, 1999; Saunders, 2003). This is reflected in the increasing number of quantitative measures of carer burden being used (Schene, Tessler, & Gamache, 1996). A large volume of research has shown that the burden of caring for a family member with severe mental illness is associated with reduced quality of life and has significant impacts on the mental health and functioning of caregivers (Gutierrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005). Family carers typically report experiencing considerable stress, anxiety, depression and economic strain (Addington, Collins, McCleery, & Addington, 2005). It has been estimated that over half of caregivers experience significant emotional distress, which can be enduring when the illness is chronic (Boydell et al., 2013; Parabiaghi et al., 2007). Around one third of family caregivers also report depression, trauma-like symptoms and burnout (Boydell, et al., 2013). Carers also experience feelings of loss and grief, stigma associated with having a family member with mental illness, family conflict and disruptions to work or social activities (Boydell, et al., 2013; Fang-pei & Greenberg, 2004).

Families themselves are also negatively affected by schizophrenia, with reported impacts ranging from increases in conflict, decline in family outings and social
activities, embarrassment and loss of self-esteem, to more serious issues such as substance abuse and spousal separation (Awad & Voruganti, 2008). A stressful family environment is also a strong predictor of relapse in schizophrenia, therefore burden and distress in a family can impact the course of the illness (Addington, Coldham, Jones, Ko, & Addington, 2003; Mueser & Rosenberg, 2003). Tangible costs of caring for families can include practical expenses such as transportation, food, clothing, housing, as well as loss of time and potential for earning (Awad & Voruganti, 2008). In New Zealand, a survey of 52 caregivers reported significant financial issues, with around 40% unable to engage in their usual paid employment due to their caregiving responsibilities (M-Tag, 2006). Suitable living accommodation is also an issue, with caregivers often struggling with the decision of whether or not to allow their adult children with mental illness and a history of violence to live in their homes (Copeland & Heilemann, 2011).

It is more difficult to qualify the costs of ongoing distress and stigma, which also differs across cultural contexts (Awad & Voruganti, 2008). It has been shown that in general family members caring for an individual with mental illness experience significantly more SB and lower levels of social support than those who care for a relative with an equivalent long-term physical health condition (Berglund, Vahlne, & Edman, 2003; Bradbury & Powers, 2009). This is likely due to the lack of understanding and greater stigma associated with mental disorders (Boydell, et al., 2013).

Factors which affect carer burden

There is a well-established relationship between symptoms and the extent to which family carers experience burden (Addington, et al., 2003; Martens & Addington, 2001). In general, the more severe the symptoms of schizophrenia the greater the perceived burden of caregivers (Awad & Voruganti, 2008). There is no clear agreement as to whether specific symptoms are more burdensome for caregivers than others. Some studies have found that positive psychotic symptoms cause greater distress for caregivers, while others have found that negative symptoms, such as anhedonia or social and emotional withdrawal, increase burden (Dyck, Short, & Vitaliano, 1999; Wolthaus et al., 2002). There has also been little research which investigates the impact of other symptoms, such as cognitive deficits, on caregivers. The onset of psychosis is often traumatic, both for the individual as well as their family (Addington, et al., 2005; Mueser & Rosenberg, 2003). Significantly higher rates of burden have
been observed in carers of individuals with first episode psychosis when compared with those who have been caring long-term (Addington, et al., 2003; Martens & Addington, 2001).

Higher objective burden (OB) is generally experienced as a result of an increase in tasks related to the caregiving situation, such as providing transportation, financial assistance (including help in money management), housework and cooking, and the need for constant supervision (Baronet, 1999). Lower global functioning, disability and poor quality of life in the individual with schizophrenia are also important predictors of OB (Ohaeri, 2003; Parabiaghi, et al., 2007). In contrast, higher subjective burden (SB) is reported as a result of problematic behaviours, such as high demands and dependency on caregivers, night disturbances, and embarrassing or uncooperative behaviour (Baronet, 1999). In particular, actions that may pose a threat to carer safety increase SB, such as aggression or violence, destruction of property and substance abuse (Ohaeri, 2003; Winefield & Harvey, 1993). This is significant, as the survey of New Zealand caregivers documented that 15.7% of individuals being cared for had injured a carer or someone else in the last six months (M-Tag, 2006). A further 23.5% had caused damage to property, 13.7% had self-harmed and 5.9% had attempted suicide (M-Tag, 2006).

Although there is a strong relationship between symptoms and carer burden, a number of studies have also suggested that burden is related to carer appraisals of the impact and consequences of the illness, rather than the severity of symptoms per se (Scazufca & Kuipers, 1996; Tennakoon et al., 2000). Caregivers are more likely to report greater distress when they perceive the illness as having more severe consequences, or when they believe the impact of the illness will be outside their capacity for coping (Onwumere et al., 2008).

Carer burden has also been measured with the concept of ‘expressed emotion’ (EE), defined as a caregiver’s appraisal of the quality of their relationship with the unwell individual (Scazufca & Kuipers, 1996). A high EE, represented by a high level of critical comments and emotional over-involvement on the part of the caregiver, predicts higher levels of burden and increases the likelihood of relapse (Kavanagh, 1992; Scazufca & Kuipers, 1996). This is further evidence that burden and distress in a family can have an adverse impact on recovery (Onwumere et al., 2009). However, it has also
been suggested that high EE may represent attempts on the part of caregivers to cope with and care for their unwell relative (van Os, Marcelis, Germeys, Graven, & Delespaul, 2001). Therefore, high EE may be a result of caregivers attempting to cope with a frequently relapsing illness, rather than a causal factor (van Os, et al., 2001).

**Gender**

Research on gender and caregiving shows two important factors. One is that in general caregivers report higher levels of distress when the relative with schizophrenia is male (Mors, Sørensen, & Therkildsen, 1992). This is thought to be because males exhibit more unusual and disruptive behaviours, cognitive impairment, and in general have poorer outcomes than women with this disorder (Aleman, et al., 2003; Mors, et al., 1992). It is known that dealing with these types of problematic behaviours is associated with increased burden in caregivers (Baronet, 1999). Violence and aggression in particular are associated with increased burden and these are symptoms more commonly exhibited by men than women (Aleman, et al., 2003; Winefield & Harvey, 1993). Caregivers of males with schizophrenia are also more likely experience social dysfunction and disability themselves, due to increased levels of stress (Mors, et al., 1992; Scazuflca & Kuipers, 1996).

A second factor is that the majority of studies indicate that caregiving roles are mainly filled by women. In one US community survey of 697 caregivers, 82% were female with 90% being mothers of the individual with schizophrenia (Awad & Voruganti, 2008). In addition, 70% of the caregivers were aged 60 years or older (Awad & Voruganti, 2008). In New Zealand there is limited data on the demographics of family members caring for an individual with schizophrenia. One survey of caregivers, undertaken on 52 participants mainly from the Auckland and mid-central regions, showed that 88.2% were female (M-Tag, 2006). Data on caregivers of family members with physical illness or disability is comparable, with 81% of these carers being female and 37% mothers of the individual being cared for (Jorgensen, et al., 2010). However this population of caregivers is younger, with the majority in the age range of 30-49 years (Jorgensen, et al., 2010). This is likely a reflection of the inclusion of childhood intellectual and other disabilities in this study. Carers of individuals with schizophrenia may be older as the onset of this illness is typically late adolescence and early adulthood (American Psychiatric Association, 2013). Female caregivers of individuals with schizophrenia also report generally greater levels of burden compared with male
caregivers, specifically in terms of their levels of worry and perception of the impact of the illness on the family (Boydell, et al., 2013; Tennakoon, et al., 2000).

**Ethnicity**

There is little research which has investigated carer burden in different ethnic populations. Rosenfarb, Bellack and Aziz (2006) compared African American and Caucasian American groups, finding that Caucasian caregivers in the study were significantly more likely to feel burdened and were less tolerant of disruptive schizophrenic behaviours. Another study found that Hispanic caregivers were more likely to be accepting of the illness and have more hope for the future (Guarnaccia, Parka, Deschamps, Milstein, & Argiles, 1992). Studies of caregivers in non-developed countries are also limited; one study of Chilean caregivers highlighted the support needs of carers in contexts with high rates of poverty and limited health and community resources (Gutierrez-Maldonado, et al., 2005).

Research on ethnicity and caregiving in New Zealand is also limited. One study on Maori who care for intellectually disabled family members showed that understandings of, and attitudes towards, intellectual disability differed considerably from that of New Zealand European groups (Bevan-Brown, 1989). For example, there is no exact Maori word equivalent in meaning to ‘intellectual disability’ and attitudes were influenced by a more holistic understanding of health and wellbeing (Bevan-Brown, 1989). These findings suggest that cultural attitudes towards family roles and mental illness play a role in determining perceived burden. Further research in this area is needed.

**Research on positive experiences of caregiving**

The concept of carer burden is frequently referenced in the literature, but has also been criticised. Some authors have noted that the term ‘burden’ is inherently negative, discounting any potentially positive or rewarding aspects of caregiving (Bulger, Wandersman, & Goldman, 1993; Szmukler, 1996). In addition, studies have shown that caring for a relative with schizophrenia is not just burdensome for caregivers, but can be a transformative experience (Fang-pei & Greenberg, 2004; Yamashita, 1998). Meeting the challenges of caregiving can provide carers with a sense of satisfaction and many families are able to identify the strengths that they have developed through their experiences (Greenberg, Seltzer, & Judge, 2000; Winefield & Harvey, 1993). There
have been some efforts to replace carer burden with a more neutral term, such as ‘caregiving’ (Szmukler, 1996). Szmukler and colleagues (1996) developed the Experience of Caregiving Inventory (ECI), a self-report measure which assesses both positive and negative caregiving experiences. There is evidence to suggest that the ECI is a better predictor of psychological wellbeing of carers and is more accurate than scales of carer burden (Martens & Addington, 2001). However, a number of other scales of burden are still in use.

Carer burden has also been criticised as a construct with no single and clear definition or measure, making it difficult to compare data between studies (Awad & Voruganti, 2008; Vella & Pai, 2013). In an effort to address this, some studies have adopted the stress-appraisal-coping model of Lazarus and Folkman (1984). This model suggests that the wellbeing of caregivers results from an interaction between objective or environment stressors, caregiver appraisal of these stressors, and available coping strategies (Onwumere, et al., 2008). More negative appraisals are associated with greater social impairment and disability in the individual with schizophrenia as well as smaller support networks (Addington, et al., 2003; Martens & Addington, 2001). Negative appraisals have also been found to strongly predict caregiver distress (Harvey, Burns, Fahy, Manley, & Tattan, 2001).

In contrast, positive caregiving appraisals are associated with better social functioning for the individual with schizophrenia and higher levels of social support for caregivers (Harvey, et al., 2001; Onwumere, et al., 2008). Family members who have been caring for relatives with longer illness histories also report more positive appraisals of their caregiving role (Addington, et al., 2003; Onwumere, et al., 2008). However, it is not clear whether this is due to the development of more effective coping strategies or a readjustment of expectations over time. Other theoretical frameworks for caregiving include aspects of the relationship between the family carer and individual with schizophrenia, as well as psycho-social factors (Kuipers, Onwumere, & Bebbington, 2010; Samele & Manning, 2000).

The use of more holistic conceptualisations, such as the stress-appraisal-coping model, has contributed towards a more balanced understanding of caring. However, quantitative research can be limited by focussing only on aspects of caregivers’ experiences which fit with particular measures or theoretical constructs (Rose,
Mallinson, & Walton-Moss, 2002). In contrast, qualitative research is better positioned to facilitate a more in-depth and detailed understanding by studying the caregiver’s whole experience (Muhlbauer, 2002; Rose, et al., 2002). Qualitative studies on carers have shown that in addition to negative impacts, carers also report gains such as becoming more sensitive to those with disabilities and becoming more understanding and patient people (Fang-pei & Greenberg, 2004). Other investigations have reported feelings of gratification, love and caring for the individual with the illness, as well as a sense of life lessons learned (Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Veltman, Cameron, & Stewart, 2002). Caregivers have also reported positive emotions such as pride in what they have accomplished, a sense of resiliency, a greater ability to adjust to situations and hope for the future (Mays & Lund, 1999).

Positive caregiver experiences are apparent even in studies which aim to investigate the negative aspects of caring. For example, in a mixed-methods study on burden in caregivers of individuals with chronic mental illness, it was found that carers appreciated the opportunity to talk about the rewards of caring as well as the contributions their unwell family member had made to their lives (Jones, 1996). Qualitative research has also shown the extent to which caregivers are affected by the social context of mental illness (Rose, et al., 2002). The effects of ongoing stigma and discrimination have been explored, with one study finding that efforts to create a sense of normalcy within an inherently difficult and abnormal experience are important (Rose, et al., 2002). Qualitative research also has the capacity to develop a more nuanced understanding of caregivers’ experiences. For example, in a recent study by Zegwaard (2013) it was found that perceived freedom of choice had a significant impact on the psychological wellbeing of caregivers. Caregivers who viewed their role as voluntary generally perceive more gains, while those who viewed caregiving as an unavoidable obligation perceive more losses as a result of their experience.

**Caregiver coping and supportive factors**

Lazarus and Folkman (1984) defined coping as a strategy in which individuals attempt to master, minimise or tolerate stress or conflict, in order to solve life problems. Research on caregivers has identified a wide range of coping strategies in use. Individual coping strategies include the use of cognitive techniques such as positive thinking, problem-solving and accessing information on schizophrenia and its treatment.
Cognitive coping strategies also include attitudinal changes such as acceptance of the illness, developing a better understanding of the individual with schizophrenia and maintaining hope (Sveinbjarnardottir & Casterli, 1997; Yamashita, 1998). Individual coping also includes less constructive physical strategies such as over-eating, and the use of smoking, alcohol and sedative medication to manage stress (Huang, et al., 2008; Sveinbjarnardottir & Casterli, 1997).

More problem-focussed coping strategies tend to be used by caregivers with better practical and social support as well as more professional help (Magliano et al., 1998). In contrast, emotion-focussed coping strategies are more frequent amongst caregivers with poor social support and who have been living longer with the individual with schizophrenia (Magliano, et al., 1998). There is also a difference in coping strategies used across different cultural contexts. Western populations are more likely to engage in practical and emotional coping strategies, while Mediterranean groups tend to engage in more spiritual or faith based strategies (Magliano, et al., 1998; Tennakoon, et al., 2000). Behavioural strategies, such as keeping busy, pursuing other interests and the use of relaxation exercises, are also common across different geographical and cultural contexts (Huang, et al., 2008).

Several studies have noted the positive impact of social support on the physical and psychological wellbeing of caregivers (Huang, et al., 2008; Saunders, 2003). Caregivers may seek support from family and friends, community support groups, professional services, respite and spiritual or religious groups. Social support is particularly important for family who care for an individual with mental illness, as these caregivers are often isolated due to stigma and a lack of understanding (Berglund, et al., 2003; Boydell, et al., 2013). The effects of stigma also differ across different cultural contexts. For example, a study of Taiwanese caregivers found that the stigma around having a family member with schizophrenia led many to feel ashamed and limit contact with family and friends (Huang, et al., 2008). It has been suggested that more severe symptoms or lower levels of functioning may make caregivers in general more likely to avoid social contact due to an increased fear of stigma and embarrassment (Magliano, Fiorillo, De Rosa, & Maj, 2006). There is also a well-established relationship between poor social support and increased levels of burden (Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2005). It is also possible that carers become overwhelmed by their
caregiving role and too exhausted to be actively involved in social networks (Magliano, et al., 2005).

In contrast, carers who have a person to confide in report significantly more positive caregiving experiences (Boydell, et al., 2013). Support groups have also been shown to be an effective way of reducing isolation and enhancing support for caregivers (Saunders, 2003). Additionally, participation in support groups can facilitate the sharing of strategies and skills, confidence-building and opportunities to more effectively advocate for the individual with schizophrenia (Saunders, 2003).

Mental health interventions that have been shown to be useful for family carers include those that aim to develop better communication strategies, problem solving and stress management skills (Awad & Voruganti, 2008). Support for carers from mental health professionals treating the individual with schizophrenia through psychoeducation and collaboration in the treatment process can also help families to better cope with the illness (McFarlane, Dixon, Lukens, & Lucksted, 2003). Information on managing difficult behaviours and other practical coping strategies have been shown to help increase a family’s sense of control and reduce perceived burden (Reinhard, 1994).

The positive impact of family therapy on both the individuals with the illness as well as caregivers is also documented. Family therapy interventions have been shown to effectively reduce carer burden as well as significantly reduce relapse rates for the individual with schizophrenia (Addington, et al., 2005; Berglund, et al., 2003). In addition, the positive impact of family therapy has been shown across a number of countries with different cultural attitudes, such as Japan, China and Latin American countries (Gutiérrez-Maldonado & Caqueo-Urizar, 2007; Xiong et al., 1994; Yamaguchi, Takahashi, Takano, & Kojima, 2006). However, it is not clear from these studies whether improvements for caregivers are a result of reduced relapse rates or the development of better coping skills. Despite evidence for their efficacy, many authors note that family therapy and provisions for caregivers are not widely integrated into mental health care plans (Awad & Voruganti, 2008). In New Zealand, psychosocial interventions, including family therapy, are recommended by clinical practice guidelines for individuals with schizophrenia, although it has not been determined to what extent this is routinely made available (McGorry, Killackey, Elkins, Lambert, & Lambert, 2003). Caregivers in other contexts have also report experiencing
considerable emotional stress that is frequently unacknowledged by mental health professionals (Saunders, 2003).

**The New Zealand context**

In New Zealand, the worldwide mental health consumer movement has led to the adoption of a recovery based approach by mental health services (Mental Health Commission, 1998; O'Hagan, 2004). The New Zealand Mental Health Commission (1998) defines recovery as a journey to living well, with or without the ongoing effects of mental illness. There is a focus on human rights and anti-stigmatisation in this definition, as well as a recognition of the impact of mental illness on families and the potential benefits gained from collaboration with family in treatment (Mental Health Commission, 1998). Although this recovery philosophy is now widely accepted in the mental health sector, thus far there has been little research undertaken to determine how it being implemented in service delivery or to what degree it is effective (Pearson, 2004; Weisser, Morrow, & Jamer, 2011). One study investigating recovery policy and practices indicated that both consumer advocates and policymakers lack confidence in the implementation of a recovery paradigm in the New Zealand mental health sector (Ianovski, 2009). Another has shown that mental health support workers are more successful in implementing a recovery based approach when their own values are congruent with the recovery philosophy (Bisogno, 2009). These studies highlight the need for further research on the implementation and usefulness of recovery practices in the New Zealand mental health sector.

There is also little New Zealand based research on the mental health and support needs of family carers themselves. A nationwide study of family caregivers of individuals with physical disability and chronic illness in New Zealand was undertaken by Jorgensen, Parsons, Jacobs and Arskey (2010). The study collected both qualitative and quantitative data via phone interviews and two scales measuring carer depression and stress. The findings were consistent with research from other countries, with caregivers reporting considerable psycho-social impacts and numerous practical difficulties. Two thirds of carers were suffering from depression and 59% experienced moderate to severe stress. Caregivers also reported a lack of information and support from services, a need for more financial assistance and adequate respite, reliable support workers, as well as a desire for some recognition of the often full-time caregiving role.
McPherson, Kayes, Moloczij and Cummins (In Press) completed a qualitative study on informal carers, including those who care for a family member with mental illness. The study aimed to explore the connection between informal and formal care providers in New Zealand, finding two main areas of concern for caregivers: the quality of care provided by services and the need for a greater exchange of knowledge between services and family members. The findings also reflected the constant struggle inherent in caregiving, which was contributed to by services that were often inflexible in their approach. Although these two studies offer a useful comparison, their application across different caregiver groups is limited. Family caregivers of individuals with schizophrenia in particular must cope with a wide range of symptoms and deficits unique to this disorder, stigma associated with mental illness, as well as differing support provisions and services. Further research is needed which focuses specifically on examining the experiences and support needs of this population of caregivers.

**Summary and justification for the current study**

Caring for a relative with a severe, long-term and disabling mental illness has considerable impacts and consequences for family caregivers. Schizophrenia in particular is a disorder associated with a number of difficult to manage symptoms, low global functioning and a high level of required care. The literature on carer burden has documented the significant psychological, social and economic implications on family caring for an individual with this disorder. In addition, caregiver stress is largely unrecognised and unacknowledged by mental health providers.

Carer burden is a multifaceted concept that covers many aspects of the caregiving experience. However, the concept has been criticised as it discounts any positive or rewarding aspects of caring. The majority of research on carer burden has also been undertaken on those who care for an individual with first episode psychosis and there is limited knowledge on the experience of long-term caregivers. The large number of quantitative measures of burden in use also make data difficult to compare across studies. Although research on the positive experiences of caring is growing, at present studies are few in number and based on relatively small samples. A few qualitative studies have provided a more holistic understanding of the experience of caregivers, however such research is also limited, particularly in the New Zealand context.
This study explores the experiences of parents who are providing long-term care and support for an adult child with severe and disabling schizophrenia in New Zealand. The aim of this research is to investigate both the positive and negative experiences of caregiving, in order to develop a more holistic conceptualisation of the caregiver role, as well as develop a better understanding of carer coping strategies, supportive factors, attitudes and perceptions. Qualitative methodology is used in order to develop a more in-depth and detailed understanding of caregivers’ experiences. An interpretive phenomenological analysis also ensures that the most salient factors for caregivers are taken into account, rather than attempting to fit carer experiences into existing measures or frameworks. It is hoped that the sharing of these experiences will help to increase knowledge on schizophrenia and the role of family caregivers, thus helping to reduce the ongoing stigma around major mental illness. This study also provides valuable information and awareness to mental health clinicians on the current issues for this population of family carers. Such information has important implications for developing effective intervention and support strategies that can help both families and individuals in New Zealand to better manage schizophrenia.
CHAPTER THREE: METHODOLOGY

This chapter outlines the rationale for the use of a qualitative methodology in this research project and discusses the epistemological framework used for data collection and analysis, as well as the researcher’s subjective position within the research. The research process is outlined in terms of recruitment of participants, data collection and analysis. Ethical considerations as well as quality and credibility of the data are also discussed.

Methodological approach

This research project takes the form of a qualitative inquiry. Research in the human sciences has historically been dominated by quantitative research approaches (Denzin & Lincoln, 2000; Michell, 2004). More recently there has been some debate as to whether quantitative methods are sufficient for answering all theoretical and practical questions in these disciplines (Denzin & Lincoln, 2000). Traditional quantitative research orients itself towards searching for population patterns, correlations and generalisations and away from a sense of the individual experience (Willig, 2008). Descriptive data are assumed inherently better if they represent a larger rather than smaller number of cases and in many cases only acceptable if rigid criteria are used to ensure the data gathered from all subjects are as identical as possible (although this is not true for all quantitative designs) (Willig, 2008). Because of this, quantitative data can be limited in its scope and depth (Smith & Osborn, 2007).

Qualitative methodologies are increasingly being used to produce valuable and high quality research in human science disciplines like psychology, where meaning plays an important role in behavioural processes (Michell, 2004; Smith, 2004). Psychological phenomena, such as the display of emotion, problem solving, recollection of past events and anticipation of the future, are expressed discursively and interpersonally (Harré, 2004). They can therefore be captured well by qualitative investigations (Harré, 2004). Qualitative research also has the capacity to facilitate an understanding of the meaning of the phenomena under investigation for the participants, preserve the individuality of the participants’ accounts as well as be flexible in identifying an unanticipated points raised by the participants (Denzin & Lincoln, 2000; Maxwell, 2012). For these reasons, a qualitative methodology was selected as the most suitable way to develop a more in-
depth and detailed understanding of caregivers’ experiences in the New Zealand context.

**Epistemological position**

The non-hegemonic status of qualitative studies requires a contextualisation of the research within a particular epistemological approach. This ensures that the theoretical and methodological framework that has been used for the analysis and interpretation of the data is transparent (Denzin & Lincoln, 2000). This research project uses an interpretive phenomenological analysis (IPA). Interpretive phenomenological analysis is a qualitative methodology that has become well-established in social, clinical and counselling psychology research (Smith, 2004). It represents an epistemological position, while at the same time offering a practical and accessible set of guidelines for conducting a qualitative analysis (Smith, 2004; Smith & Osborn, 2007).

Interpretive phenomenological analysis aims to explore in detail participant’s lived experiences, as well as how they make sense of those experiences (Smith, 2004). It draws from phenomenological research traditions in its focus on an individual’s perception of objects and events, aiming as much as possible to elicit an ‘insider’s perspective’ of the phenomenon under study (Giorgi & Giorgi, 2007; Smith, 1996). At the same time IPA emphasises the dynamic process of research, within which the researcher plays an active role in making sense of the participant’s personal world through a process of interpretation (Smith, 1996; Smith & Osborn, 2007). It is therefore also connected to interpretive or hermeneutic traditions (Ashworth, 2007; Smith & Osborn, 2007).

Smith (2004) outlines three basic characteristics that define IPA: it is idiographic, inductive and interrogative. Interpretive phenomenological analysis is idiographic in that it begins with a thorough and in-depth examination of each individual transcript before moving on to analysis of the next. This type of in-depth analysis facilitates the generation of important generic themes that all participants share, while still capturing something of the individual world of each of the participants. Secondly, IPA is inductive, in that researchers maintain flexibility in the research process, allowing for unanticipated topics or themes to emerge during the analysis. Interpretive phenomenological analysis constructs broad research questions, leading to the
collection of expansive and detailed data, rather than attempting to verify specific hypotheses determined prior to the investigation. Finally, IPA is interrogative. While this approach differs from quantitative studies in its epistemological assumptions and methods, it shares constructs and concepts with previous psychological research. This allows for the results of an analysis to be constructively discussed in light of existing knowledge. Smith (2007) notes that a key aim of IPA is to interrogate or illuminate gaps in previous research; this facilitates an interpretation of the data that can usefully inform clinical disciplines.

Interpretive phenomenological analysis is considered a suitable methodological approach when a research project aims to investigate how individuals perceive their particular situation and how they make sense of their personal and social world (Smith & Osborn, 2007). This research aims to explore the subjective experiences of caregivers in the New Zealand context. This includes positive and negative impacts, coping strategies, supportive factors and attitudes towards, or perceptions of, the caregiving role. Interpretive phenomenological analysis was considered to be the most appropriate methodology to facilitate this investigation. The idiographic and inductive characteristics of IPA will allow for an in-depth exploration of the subjective experience of each of the participants, while generating common themes across the dataset. Additionally, the interrogative nature of IPA enables an analysis and discussion which can draw from and contribute to existing knowledge, making this methodology suitable for a practice research project.

**Reflexivity**

Inherent in any qualitative research is the researcher’s own values, experiences and theoretical perspectives (Willig, 2008). Although both the researcher and participants are involved in data collection, the researcher’s interpretation of the data will ultimately guide the analysis (Grant & Giddings, 2002; Smith & Osborn, 2007). It is therefore important to understand and account for the researcher’s positioning in relation to the phenomenon being studied (Grant & Giddings, 2002).

As a student in a counselling psychology training programme, I appreciate the value of evidence-based practice and the importance of positivist research. However, I also identify with an interpretivist paradigm, with an interest in understanding individual
experiences and the meanings people ascribe to them (Grant & Giddings, 2002). For this reason my perspective is best described as post-positivist (Grant & Giddings, 2002). My chosen methodology of IPA reflects both my desire to understand the subjective experience of family caregivers, as well as to contextualise those experiences within an empirical basis in a way that contributes meaningfully to clinical knowledge (Smith, 2004).

When undertaking a practice-based psychology training programme, it is easy to become overly focussed on the diagnoses, assessment and treatment of mental illness. I was mindful during the research process that I would find appeal in exploring factors that may be related to the development of, or recovery from, schizophrenia. As a psychologist in training I have a bias towards the belief that family, including caregivers, can have a significant impact on the course of a mental illness. For this reason I kept in mind the aim of exploring the experience of caregiving, particularly during interviewing. Semi-structured interviews were also used in order to have on hand a guide to questioning and prevent the interviews from becoming diverted into other topics of interest to me.

**Recruitment of participants**

The participants for this study were recruited via the Auckland branch of Supporting Families in Mental Illness New Zealand (SFMI), an organisation which supports families who provide care to relatives with schizophrenia or a related diagnosis. This is done via the distribution of information, the development of peer support networks and support groups, and promotion of the rights and needs of individuals and families affected by mental illness. The Auckland branch of SFMI included an advertisement for participants in the May 2013 edition of their two-monthly newsletter, which is distributed to members via email or mail (see Appendix A). Participants were also recruited via snow-balling, as members of SFMI were encouraged to pass the advertisement on to other individuals that may be interested in participating in the research (Willig, 2008).

The selection criteria were for parents who care for an adult son or daughter with a diagnosis of schizophrenia. Participants were required to be the primary caregiver for the individual with mental illness, who could either be living with a parent caregiver or
living in the community with a parent as their primary source of support. Participants also needed to be parents of long-term mental health service users who require a high level of ongoing support, rather than parents of those who are managing their disorder independently and living integrated into the community. Only participants from the Auckland region were included in the study to ensure that face-to-face interviews were possible.

Smith and Osborn (2007) recommend five to six participants as a suitable number for student research projects, to allow for a sufficient in-depth engagement with the data. It was decided that six to eight participants would be a suitable number for a research project of this size and scope. If more than this number responded to the advertisement, the first eight participants who volunteered for the study would be selected for interview. In total ten individuals contacted the researcher with an interest in participating in the study. One did not meet the selection criteria as they were a sibling of an individual with schizophrenia rather than a parent; one further volunteer withdrew prior to the interview taking place due to other commitments. Interviews were arranged and carried out with the remaining eight individuals.

Data collection
Semi-structured interviews were chosen as the most suitable method to facilitate the collection of complex and detailed data (Willig, 2008). Semi-structured interviews are also considered to be the optimum method of data collection for IPA (Smith & Osborn, 2007). In this form of interviewing, the researcher uses a schedule of questions to guide rather than dictate the interview. The researcher engages the participants in an open discussion on the research topic, modifying follow-up questions in order to follow the participants’ interests or concerns (Smith & Osborn, 2007). During the interview, the researcher aims to understand as much as possible the psychological and social world of the participant; therefore the participant shares closely in the direction of the interview and can introduce topics not previously considered (Smith & Osborn, 2007). Participants are given maximum opportunity to tell their own story, with questions aiming to elicit further detail or explore areas of interest (Smith & Osborn, 2007). In addition, one-on-one interviews allow for the creation of intimacy and building of rapport which enable participants to share very personal information, while feeling safe and supported in the interaction (Taylor, 2005).
An interview schedule was developed from the literature on caregiving (see Appendix B). The main interview question was: “Can you tell me about your experience of caring for your son/daughter?” Follow up questions differed dependent on topics the participants discussed, but aimed to explore areas such as the impacts of caring on self and family; emotional, financial, social or other difficulties; coping strategies and supports accessed or needed; whether the role has changed over time; and any positive experiences. The schedule of questions helped to guide the interaction and cover similar areas across all of the participants. However, the interviews were largely participant-led as there were many issues and concerns which the participants considered important to discuss. The interviews ranged from an hour to an hour and a half dependent on the participant’s communication style and all were audio taped and transcribed by the researcher.

Smith and Osborn (2007) note that one of the limitations of semi-structured interviewing is that researchers have less control over the direction of the interview than in more structured methods. This drawback was experienced with one of the participants, who preferred to discuss her advocacy work in the interview. Although questions were asked in an attempt to guide the interview more towards the participant’s personal experience of caregiving, the participant would answer by relaying stories about other carers she had supported. In this case the researcher wished to maintain a respectful interaction and so did not push the participant to discuss areas which she was not comfortable with. Because the data from this interview mainly consisted of second-hand stories about other caregivers’ experiences it was deemed unsuitable for inclusion in the analysis.

In addition, another participant who was interviewed did not meet the selection criteria for the study, as her child had been diagnosed with schizophrenia the previous year and was therefore not a long-term mental health service user. This information was not discovered until the interview was underway. In order to respect the participant’s willingness to share her story and sensitive personal information a full interview was undertaken. However, because this participant met the exclusion criteria and her experience was significantly different to that of long-term caregivers the data collected in the interview was unsuitable for use in this study. Thus only six of the interviews completed were used in the analysis. However, this number meets the recommended
guidelines for IPA (Smith & Osborn, 2007). The richness of the data obtained also ensured that data saturation was reached and the results are an accurate reflection of the experience of caregivers in this particular context (Denzin & Lincoln, 2000).

**Method of analysis**

Interpretive phenomenological analysis provides a useful step-by-step guide for undertaking a thematic analysis of the data (Smith & Osborn, 2007). The assumption in IPA is that the researcher is interested in learning about the participant’s psychological and social world. The aim is to understand the content and complexity of the participants’ experiences as well as the meanings they ascribe to them. Interpretive phenomenological analysis holds that these meanings are not transparently available; rather they are obtained through a process of interpretation by the researcher (Smith & Osborn, 2007). Thus the researcher follows a process of identifying patterns or themes in the data, beginning with a thorough analysis of the first transcript and moving across the dataset, before examining and interpreting the assumptions and ideas underlying these themes in the write-up (Smith & Osborn, 2007).

This research project has closely followed the four step guide for IPA provided by Smith and Osborn (2007), described below:

**Step 1: Looking for themes in the first case**

The first stage is to become as familiar as possible with the data, taking note of what is interesting or significant about what the participant has described. The first interview transcript is read two to three times, noting each time in the left hand margin any associations or connections that are noticed, preliminary interpretations, similarities, differences or contradictions. There are no formal rules about what aspects of the data are commented on, nor is it necessarily to comment on all units of data. Rather, some aspects of the transcript will be richer than others or of more interest to the research question.

This process is continued for the entire first transcript. When no new insights are elicited on reading, the transcript is read again while documenting in the right hand margin emerging theme titles. The aim here is to transform the initial notes into concise phrases which capture the essential quality of what was found in the transcript. The
themes draw on more psychological terminology and move to a higher level of abstraction or conceptualisation, while maintaining connections to what the participant has said. Theme titles can be repeated where the underlying concepts or ideas are similar. No attempt is made at this stage to omit or select particular units of data; rather the number of themes should reflect the richness of the transcript.

**Step 2: Connecting the themes**

The initial list of themes is chronological, based on the sequence in which they were identified in the transcript. The next stage involves a more analytical ordering and organisation, as the researcher makes sense of the connections between different themes. To do this, the full list of themes is copied into another document and examined to determine which themes seem to cluster together or emerge as superordinate concepts or categories. The researcher draws on previous knowledge in order to interpret the data in a way that is meaningful for the aims of the research, while at the same time checking the interpretation against the transcript to make sure the connections work in terms of the participant’s account.

This ordering and interpretation is continued until all of the themes can be organised coherently into a table. The clusters of themes which capture most strongly the participant’s conceptualisation are named and treated as superordinate domains or categories. The table then lists the themes which come under each superordinate category and an identifier is added in order to aid in the organisation of the analysis and facilitate finding the original source during write-up. While Smith and Osborn (2007) recommend this is done by listing page numbers under each theme, in this study colour coding proved to be an easier and clearer method of identifying relevant passages in the transcripts. During this process themes which do not fit well into the emerging structure or are not very rich in evidence can be dropped from the analysis.

**Step 3: Continuing the analysis with other cases**

Smith and Osborn (2007) suggest that this stage can be undertaken in one of two ways. Either the themes generated from the first transcript can help to orient the analysis of subsequent transcripts, or each of the transcripts can be treated the same as the first, generating a table of themes from scratch. Due to the scope of the study, the first
method was applied for this analysis. The second is usually recommended for studies involving very small sample sizes (generally one to three participants).

During this stage the researcher discerns repeating patterns across the dataset, while also identifying any new themes emerging in subsequent transcripts. Each transcript was analysed, with evidence for the previously articulated themes emerging in other transcripts, helping to illustrate these concepts further. The original table of themes was modified and added to as new subthemes were generated. Once the entire dataset had been analysed a final table was confirmed, based on prevalence of the themes across the dataset as well as the richness of the data illustrating each theme. The results of the analysis respect both the theoretical convergence of high level concepts and ideas, while representing the individual idiosyncrasies of the different participant accounts.

**Step 4: Writing up**

The final stage involves the writing of a report based on the results of the analysis. Whereas the previous steps involve a reduction of the data to a table of simplified concepts, this stage involves creating a more expansive narrative which explains and illustrates the nuances of each theme. The table of themes is used as the basis for the outline of the write up and is interspersed with verbatim extracts from the transcript which support and highlight the researcher’s interpretation of the data. The table of themes and written account of the results are included in the following chapter.

**Ethical considerations**

In all research in the human sciences the rights, privacy and welfare of the participants should be respected (Berg, 2009). To ensure that the participants were able to give full informed consent, a copy of all relevant information on the study was given to each via a participant information sheet (see Appendix C). Participants were given the opportunity to read and consider the information as well as ask questions about the research, before providing written consent to participate in the study (see Appendix D for consent form).

To protect privacy and confidentiality each of the participants was assigned a pseudonym which is used to identify their data in all written reports of the research. Any information which may easily identify the participants or their family members
was removed from the interview transcripts and is not used in any written reports. The majority of the participants were female; therefore the male participant was more easily identifiable in the final report. To ensure anonymity female pseudonyms and pronouns are used for all of the participants. Although this strategy hides gendered responses, in this case confidentiality of all participants was considered to be more important.

Interviews were recorded on a digital voice recorder and audio files were stored on the researchers password protected laptop. The researcher was the only person with access to the participant consent forms, audio files and transcripts during the analysis. After the research report has been completed the audio files and typed transcripts will be transferred to a portable memory stick and stored, along with the consent forms, in a locked cabinet in the office of the researcher’s primary supervisor at AUT University. The data will be stored for a period of six years before being destroyed. The participants were provided with full information on the use and storage of their data via the information sheet.

During the design of this study it was acknowledged that the participants are likely to have felt vulnerable in their experience of caring for a family member with major mental illness and that they may discuss difficult or distressing experiences during their interview. Prior to the interview beginning, the participants were advised that they could stop the interview at any stage for a break and could discontinue at any time if they wished. The participants were also informed that they could refuse to answer any questions or remove themselves from the study completely with no adverse affects, in which case all data collected would be destroyed.

Up to three, free counselling sessions per participant were made available at AUT Health and Counselling services for any issues arising from participating in this research. The participants were given information on how to access these sessions via the information sheet. The content of these sessions would be confidential, however the researcher would be notified should a participant choose to utilise the sessions in order to verify their details. Although some of the participants discussed very difficult and distressing experiences during their interviews, none choose to utilise the counselling sessions provided. Additionally, all of the participants described feeling grateful for the opportunity to talk about their experiences and contribute to research in this area.
Quality and credibility

In quantitative research, tests of reliability and validity are undertaken to ensure that data collected is as consistent, accurate and objective as possible. Although these concepts do not translate directly to qualitative research, it is still necessarily to evaluate rigour in order to ensure the quality and credibility of the research (Davies & Dodd, 2002). Because qualitative researchers use a variety of paradigms and epistemologies, multiple standards of quality and credibility exist (Lincoln & Guba, 2000). While some of these standards are more universal across different paradigms, others are assessed on the basis of the epistemological orientation of the research and the standards of each particular discipline (Lincoln & Guba, 2000).

Morrow (2005) has suggested four criteria for assessing the trustworthiness of post-positivist qualitative research: credibility, transferability, dependability and confirmability. Based on criteria developed by Lincoln and Guba (2000) for assessing constructivist research, these are intended to loosely achieve the same purpose as measures of reliability and validity in quantitative research. They are therefore framed as ‘parallel criteria’ (Morrow, 2005). An explanation of each of the criteria and how they are satisfied by this research project follows:

Credibility is considered to be parallel to the quantitative concept of validity and refers to the idea of internal consistency in the data, as well as accuracy of the results and their interpretation (Morrow, 2005). Credibility is achieved by prolonged engagement with the participants and a thorough description of source data in the analysis (Morrow, 2005). In this study data was obtained from six participants who were interviewed on the same topic area, but asked follow-up questions dependent on their differing experiences. The interviews continued until the participants were satisfied that they had shared their complete story. This ensured that the data collected reflected the breadth and depth of the participants’ perspectives. Interpretive phenomenological analysis enabled strong links to be established between the original data and the results of the analysis, and numerous transcript excerpts are used in the write up of the results in order to highlight these linkages.

Transferability is considered parallel to the quantitative measure of external validity, or generalisability (Morrow, 2005). It refers to the extent to which the findings of the study can be generalised or applied to other contexts (Lincoln & Guba, 2000). This
criterion is met by providing information about the research context, processes and participants to enable the reader to determine how the findings of the study may transfer (Morrow, 2005). Qualitative data is not generalisable in the conventional sense; therefore it is not suggested in this study that the findings can be applied all populations or settings (Morrow, 2005). Rather the context and processes which apply to the participants has been made explicit in order to specify the areas in which these findings apply.

**Dependability** is parallel to the quantitative concept of reliability and refers to the consistency of the study across time, researchers and analysis techniques (Morrow, 2005). In qualitative research, the process of data analysis should be as explicit and repeatable as possible (Morrow, 2005). This has been accomplished by detailing the step-by-step process of conducting the research, including recruitment methods, data collection and analysis. In addition fully annotated transcripts which demonstrate the analysis process have been stored and can be examined by other researchers or supervisors in order to audit or replicate the study.

**Confirmability** is considered to be parallel to the concept of objectivity in quantitative research (Morrow, 2005). However, in qualitative research it is acknowledged that the researcher is never entirely objective (Lincoln & Guba, 2000). Rather, this criterion is met when the findings of the study represent the situation being researched as much possible, rather than the beliefs or biases of the researcher (Morrow, 2005). This was achieved by making explicit the connections between the data and findings, the analytic process, as well as reflexively reflecting on the subjective position of the researcher and any potential biases in the research. This allows for a reader to confirm for themselves the adequacy of the findings.
CHAPTER FOUR: RESULTS

All of the participants had experience of caring for a son with schizophrenia; none had a
daughter diagnosed with this illness. There were five female participants and one male,
ranging in age from 58 to 73, and all were New Zealand European. Five were married,
one separated, and one widowed. Two were a married couple who were interviewed
separately. Four participants were living with their son and providing a high level of
day-to-day care. A further two had sons who were living in the community, but still
considered themselves to be the primary caregiver, visiting frequently to take care of
basic needs. All of the participants had been providing care for their son since
diagnosis, between 13 and 28 years. The demographic information for the participants
is summarised in Table 1.

Table 1

<table>
<thead>
<tr>
<th>Pseudonym ¹</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Marital status</th>
<th>Time as caregiver ³</th>
<th>Living arrangement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anna</td>
<td>73</td>
<td>New Zealander ² (NZ European)</td>
<td>Widow</td>
<td>20 years</td>
<td>Living on own; son lives in a flatting situation with three others</td>
</tr>
<tr>
<td>Cathy</td>
<td>71</td>
<td>New Zealander ² (NZ European)</td>
<td>Married/ Separated</td>
<td>13 years</td>
<td>Living with son</td>
</tr>
<tr>
<td>Erica</td>
<td>58</td>
<td>New Zealander ² (NZ European)</td>
<td>Married</td>
<td>15 years</td>
<td>Lives in family home with son, husband and daughter</td>
</tr>
<tr>
<td>Francis</td>
<td>68</td>
<td>New Zealander ² (NZ European)</td>
<td>Married</td>
<td>17 years</td>
<td>Lives with husband and son</td>
</tr>
<tr>
<td>Greta</td>
<td>70</td>
<td>NZ European</td>
<td>Married</td>
<td>17 years</td>
<td>Lives with wife and son</td>
</tr>
<tr>
<td>Harriet</td>
<td>73</td>
<td>NZ European</td>
<td>Married</td>
<td>28 years</td>
<td>Lives with husband; son living in flatting situation</td>
</tr>
</tbody>
</table>

¹ To protect confidentiality of the male participant, all are identified with female pseudonyms.
² These participants preferred to identify their ethnicity as ‘New Zealander’
³ ie: number of years since child was diagnosed with schizophrenia.
The remainder of this chapter describes the themes generated during the data analysis. The participants were asked to talk generally about caring for their son with schizophrenia, including both positive and negative experiences, access to support, as well as their understandings of and attitudes towards schizophrenia and their caregiving role. The participants’ accounts have been organised into three superordinate categories: psychological factors, external support factors and systemic issues. See Table 2 for a list of themes generated in the analysis.

Table 2

*Themes generated by the analysis*

**Psychological factors**

- Theme 1: Emotional burden
- Theme 2: Cognitive coping techniques
  - Subtheme A: Knowledge acquisition
  - Subtheme B: Positive thinking

**External support factors**

- Theme 3: The importance of communication and collaboration with mental health professionals
- Theme 4: The importance of group and peer support
- Theme 5: Family support and family conflict

**Systemic issues**

- Theme 6: Lack of resources and support for caregivers

**Psychological factors**

Psychological factors included the cognitive and emotional aspects of caregiving discussed by the participants. Two themes were identified in this area: 1) emotional burden and 2) cognitive coping techniques. The latter included two subthemes: 2A) knowledge acquisition and 2B) positive thinking.

**Theme 1: Emotional burden**

This theme contains the participants’ descriptions of the emotional impact of caring for a family member with a severe and ongoing mental illness. The term ‘burden’ was not used by the researcher during the interviews, rather the participants were asked to
describe in their own words their experience of caring for their son with schizophrenia.
The participants primarily talked about the negative emotional impact of the experience, including feelings of distress, stress, confusion, helplessness and loneliness. Because these feelings fit within the concept of carer burden as described in the literature, but are related primary to the emotional impacts of caring, this theme has been named ‘emotional burden’.

Most of the participants began by describing their feelings of distress, loss and grief upon finding out their son had a diagnosis of schizophrenia and their early experiences of coming to terms with the severity of the illness. Some of the participants shed tears when describing how the illness developed, further communicating the depth of their distress at this time.

_Greta: I guess it’s something we never prepared for, we didn’t sign up to. It took a long time to sort of accept the diagnosis, a long time, it was really, really difficult, and I felt so sorry for him._

This sense of emotional burden also included stress associated with managing the ongoing symptoms of the illness, such as dealing with spontaneous, bizarre and sometimes violent behaviours. Some participants also described the difficulty inherent in dealing with someone who is exhibiting symptoms of paranoia and mistrust, as well a lack of insight into the illness or refusal of help from mental health services. Anna’s description of dealing with a recent episode of self-harm captured many of these difficulties:

_Anna: Umm six months ago it escalated and he started hearing voices, and he took a table knife to his ear to try and get rid of them...but that was the first time he’d ever harmed himself, and umm and he was just trying, he was talking about, he told the doctors that that umm Maori gangs were talking to him and he wanted to get rid of him, he didn’t want to take any notice, he wanted to get rid of them. So umm I don’t know where that comes from, he’s paranoid, he umm and that’s difficult to deal with, I find it hard to avoid words that trigger his anger. Umm you can’t use the word mental, or illness...the big problem is that it’s always hard to detect that he’s getting unwell again, you know. I don’t know whether he can recognise it._
Like Anna, most of the other participants talked about finding it hard to avoid certain words, phrases or actions that could ‘trigger’ anger or aggression. There was a sense of ‘walking on eggshells’ and a constant emotional effort expended in trying to maintain a calm environment.

_Cathy_: That’s very, when you’re living with somebody like this you, you just basically have to accept everything. Because, and you’ve got to be so careful about what you say because it can be the slightest thing that can suddenly umm you know…. you’re sort of almost, you’re just sort of floating on a particular level, and you’ve got to stay on that level because if you drop below it or go above it, it creates problems.

_Greta_: I need to be a little bit more, much more sort of umm go with the flow sort of thing. Like rather than kicking back and saying no that’s not right, no do it this way or whatever, better to sort of agree with him, so you don’t sort of rock the boat, and sometimes I find that quite difficult…you can’t really be honest.

This was also combined in some of the participants with a fear for their personal safety.

_Francis_: Umm at times we’ve felt ever so slightly unsafe, because of all of this. We are subject to verbal abuse, haranguing, umm we have to support but we can’t umm you know it’s certainly not, like asking him to put his beer bottles out you could be seen to be buying a fight, if you were, so we’re having to be very careful.

Others expressed fear for the safety of their son. Anna continued on to describe her ongoing worry that the incidents of self-harm may eventually result in suicide:

_Anna_: Mostly because my daughter lived next door to a chap who was schizophrenic, and he started hearing voices and he committed suicide. So when I told her that umm my son had put the knife up under his ribs umm she was heartbroken, you know. All she could imagine was that he was trying to kill himself. I don’t know if that was his intent. Umm and of course once they’ve
done it once, it’s not so hard to do it twice is it? That’s where my heads been going this last week or two.

Erica also spoke about her distress in having to manage her son’s suicidal and self-harming symptoms when he first became unwell:

Erica: Just talking him down all the time I think was the hard part [tearful]. So it was a very dark, dark time... then there was a stage where the two of us did a suicide watch. Between the two of us, so you couldn’t go anywhere... so that went on for probably couple of years, yeah.

Most of the participants described their emotional experience as cyclical; they experienced more stress and negative affect when symptoms were worse, and less when they were improved. Four of the participants felt that this cycle had an overall downward trajectory, with symptoms becoming worse over time, escalating their distress.

Anna: He’s definitely getting worse, because these two physical incidents to my mind are really a step that’s frightening... I sense we’re going to continue on this rollercoaster as we have done, umm but it’s getting worse, the dips are long and it’s harder to climb out.

Both Harriet and Erica felt that there had been a slow improvement in symptoms over time, and Erica felt that her son would eventually completely recover. Although these two participants described experiencing less distress, there was still a sense of the constant emotional effort expended in order to maintain a high level of support.

Erica: It’s almost like having a toddler, and everywhere you go you’ve got this person with you, and they’ll wake up in the morning you know and say “Well what are you doing today?” Because they’ve got nothing to do themselves. And you know I don’t want to leave him in the house by himself because that’s when he goes downhill... it’s incredibly draining and very tiring.
The emotional experience of caregiving is multifaceted and the participants found many aspects of their role distressing and difficult to cope with. This included coming to terms with the diagnosis, dealing with ongoing symptoms of the illness, fears for personal safety, and dealing with self-harm and suicidality. It is clear from the participants’ descriptions that there is a considerable emotional burden associated with caring for a family member with severe schizophrenia. This theme lays the foundation for consideration of other aspects of the caregiving experience.

**Theme 2: Cognitive coping techniques**
This theme describes the cognitive coping techniques that the participants used as a way of managing their emotional distress and sense of burden. It contains two subthemes: 2A) knowledge acquisition and 2B) positive thinking.

*Subtheme 2A: Knowledge acquisition*
The participants described how they coped with some of the difficulty of their experience by learning as much as possible about schizophrenia. This was epitomised by comments such as: “Oh yeah, I’ve done a huge amount of research”, “Yes, yes I’ve read a lot of books now” and “I’m an expert on it these days”. The participants had accessed information via the internet, books, research articles, conferences, support group meetings and by sharing knowledge with other parents caring for sons or daughters with schizophrenia.

Their research provided the participants with more information on the causes and symptoms of schizophrenia, which facilitated a better understanding of the symptoms exhibited by their own child. Developing their understanding in this way seemed to help the participants to feel more empathy for their sons and lessen their sense of burden.

*Harriet: So I think, it was my purpose to go and learn about schizophrenia, so I read a lot of books to get a sort of an idea on umm symptoms, family reactions, umm and I feel that umm we’re all probably, well we all have a level of umm the degree of sanity, and something sometimes can tip you over.*
Greta: Yeah I cope with it better from the point of view of the fact that I suppose I’ve got a bit more of an understanding of what’s going on for him.

Knowledge acquisition also served to equip the participants with skills and strategies to use in dealing with the difficult behaviours which are symptomatic of the illness. For example, Cathy said: “It’s got easier for me to cope with because I’ve learnt what I have to do.” Harriet also described how learning about schizophrenia helped her to better manage her son’s symptoms:

Harriet: I went into a caring education course, which educated me on schizophrenia, umm the responsibilities of care, getting help all this sort of thing. I’ve learnt to say, from education learnt to say well I know you think like that but I don’t feel like that, I think it’s such and such and so and so, and that seems to work.

The participants had also done research on the mental health system and recommended treatments for schizophrenia. This allowed them to better comprehend the efficacy and side-effects of medications being administered to their son and in some cases have more input into medical management of the illness. Erica discussed how she was able to advocate for changes to her sons antipsychotic medication:

Erica: So I was very, I did a lot of homework on the medication, did a lot of talking with the psychiatrist... umm so I said to [the psychiatrist] I told him he was umm old-fashioned, and he needs to try one of the new drugs.

By doing this Erica was able to have her son transferred to newer medication, which she attributed to the dramatic improvement in his symptoms. Erica took great pride in being able to influence her son’s recovery in this way and it contributed to her sense of agency and control over a situation that was often overwhelming.

The participants also recognised knowledge as something beneficial that had come from their experience. For example, Harriet said: “I think we’ve all gained, we haven’t just lost.” Despite the struggles that they had been through, the participants described feeling grateful for the learning and personal development that being in a caregiver role had facilitated.
Erica: Knowledge. Incredible knowledge…huge knowledge about umm about all different areas. Yeah just, yeah huge knowledge that I would never, ever, ever have experienced. So I think I’ve learned a lot, yeah I’ve learned a lot.

Francis: There’s a lot of learning and if one needs to develop oneself through experience then this is a wonderful A-grade lesson.

The subtheme of knowledge acquisition contained two aspects. Primarily, researching and learning about schizophrenia was a cognitive coping strategy which helped the participants to better understand and manage their son’s illness. This helped to empower them in their role as a caregiver and increase their sense of control over their experience. A second aspect was the attitudes of caregivers towards their learning. All of the participants talked about their knowledge of schizophrenia as a beneficial outcome, which contributed to their personal development. These two factors helped to balance some of the distress and emotional burden of being a caregiver.

**Subtheme 2B: Positive thinking**

A second, smaller subtheme of positive thinking was identified as a cognitive coping technique used by two of the participants. As an extension of the sense of being grateful for their new-found knowledge, Erica and Harriet also described how they had deliberately cultivated a more positive attitude towards their situation.

Erica: So and you’ve got to look on the positives, ’cause there were so many dark horrible times that were before, and you know I watch, I go to these groups and some of the, one woman, so angry because her husband, her son has been trying to hang himself. She rang the crisis team and the crisis team said they wouldn’t come, they had to get the police, and oh and I just watched her, and her anger, so much anger. And I can understand her anger, but such a negative thing and you know? It’s so negative.

Both participants assessed their situations in comparison to that of other caregivers, or to an earlier time when they had experienced more distress. By becoming aware that things could be (or had been) much worse, they were able to feel more positive about
their current situation. Harriet also found herself re-evaluating her situation in light of the minor difficulties and stressors that other people may experience:

Harriet: Like I think I had a neighbour who was really stressing, she changed her kitchen three times, and stressing about the tiles and things, and I thought oh! Gosh why doesn’t she just go eanie-meanie-miney-moe? There’s nothing really life threatening with that is there! You either like it or you don’t. So I think it’s helped balance things in life umm in a way.

Both Erica and Harriet felt that a negative attitude would only serve to amplify their sense of burden and difficulty coping. They also expressed appreciation that their situations had become more manageable over time. This may suggest that caregivers can only engage in positive thinking as a cognitive coping strategy once the more severe symptoms of schizophrenia have improved. This method of coping may be more difficult when caregivers are experiencing a high degree of distress and emotional burden.

**External support factors**

External support factors included the participants’ experiences with mental health services and community based support, as well as the impact of schizophrenia on family relationships. This area included three themes: 3) the importance of communication and collaboration with mental health professionals, 4) the importance of group and peer support, and 5) family support and family conflict.

**Theme 3: The importance of communication and collaboration with mental health professionals**

All of the participants had ongoing contact with mental health professionals who were providing treatment and care for their sons. They consisted of crisis teams, psychiatrists, psychologists and psychotherapists, doctors, key workers and community support workers. The participants spoke about the importance of communication and collaboration between these professionals and family caregivers. For some, the refusal of treating professionals to provide information to them had negatively impacted on their ability to provide support for their sons. In many cases, mental health
professionals cited their client’s right to privacy as the reason to not maintain open communication with the family.

Anna: The thing that made me angry, well not…yeah angry I suppose, or upset, was that the mental health or the privacy act had stopped any communication with me whatsoever. He had isolated himself and he’d probably said to them you know, don’t tell my mother. Umm and so from their point of view they rightly or wrongly, they didn’t.

Cathy also described her struggle in trying to access information from mental health professionals treating her son:

Cathy: The family, we were totally shut out from him and I could not find out anything about him, he shifted house I couldn’t find out where he was, they wouldn’t tell me anything…then I had a meeting with the doctor and we basically sat in a room like this and I tried to say “look, he’s struggling by himself you know, I’m his mother, I want to help him, can’t we do…”, “No, no we can’t you know unfortunately, the privacy, privacy”. Every time I turned around I hit the privacy thing.

The participants found this justification frustrating and difficult to understand: “I can’t imagine any family you know wanting anything other than the best for their, you know their child. So that didn’t make sense to me.” In their view, a lack of collaboration with family who were providing a high level of care for an individual with schizophrenia did not benefit either the individual or the family.

Francis also reported negative experiences with mental health services. At the time of the interviews, her son was becoming increasingly aggressive and she was seeking an appointment with a psychiatrist in order to discuss a change in medication:

Francis: We are still desperately trying to speak to the psychiatrist who seems too busy, or unwilling to see us, I don’t know whether as concerned or at least involved parents we’re seen as a problem. Their view seems to be that they deal with the adult client and not with the caregiver, which is just ludicrous because
the adult client’s opinion is important, but it is not the reality of the lived experience, and they need to talk to caregivers.

Greta also expressed her frustration with the lack of collaboration between family and mental health services, describing it as: “an absolutely illogical, woeful, lack of reasonable collaborative consultation with people who are caregivers.”

The participants felt that as family caregivers they had a greater degree of knowledge and understanding of symptoms and level of functioning than treating professionals. For example, Anna noted: “I don’t know whether the medical staff have the time you know to get to know him, and to really ask those questions, and to get good answers.” Some also expressed concern that the information provided to services by their son may not be entirely accurate due to symptoms such as lack of insight, paranoia or delusions. The participants were frustrated that they were not used as a source of information or consulted on treatment plans, despite providing a high level of day-to-day support for their sons.

Harriet and Erica reported more positive experiences with mental health services. They described the professionals that they had contact with as more willing to listen and collaborate with them as caregivers.

Harriet: Yes, and the psychiatrist that he had when he first went, he’s had all the time, and she’s excellent. She asked his perspective on this or that, how’s he been doing, and then she would say how do you feel Mr and Mrs. Harriet about something, and umm another meeting we’ve been to recently, well when he was being discharged from hospital, they had [my son] in first and talked to him. Then they asked him to go out and talked to us.

Erica was the only participant who was financially able to access private treatment for her son. This had allowed her to avoid many of the issues with privacy:

Erica: Every time [my son] had his appointment with the psychiatrist my husband and I were in, or me, were in the appointment with him. So we didn’t have the problem that most of them have with the privacy act, where they, and their kids won’t tell them what medications they’re on, the psychiatrist can’t tell
them, umm they don’t even know if they’re taking their meds, all that sort of thing, well we didn’t have that.

Erica’s situation was unique as the treating psychiatrist for her son was also a trained psychotherapist. Erica and her son would see this practitioner together during appointments for medication and general advice. Erica also maintained fortnightly appointments with the same practitioner separately for personal therapy, with a focus on developing skills to aid her son’s recovery.

_Erica:_ So I was seeing him once every two weeks as well, and what he was doing, he was doing psychotherapy through me, and I diluted it through to [my son]. ‘Cause he couldn’t do it because of the schizophrenia…yeah, yeah and then I’d go and talk to him and tell him what [my son] had said or whatever, and he would tell me how to handle it. Umm and it seemed to work.

Through this unique situation, Erica was able to better process her own experience as well as provide information on her son’s condition and receive advice to aid in management of the illness. She attributed the quality of her experience, as well as her son’s recovery, to this greater degree of transparency and collaboration:

_Erica:_ I’m pleased we went the private way and that we got continuity and the same psychiatrist every, umm and I could do what I did, tell them I want, I couldn’t have done that if we were in the public system, I couldn’t have got his drugs changed over. I wouldn’t have been even allowed in with him, into his session.

All of the participants noted the impact of open communication between mental health services and family providing care for the individual with mental illness. In many cases, the participants viewed themselves as an untapped resource of information for treating practitioners. In the participant’s view, the benefits of collaborating with family caregivers outweighing concerns around client privacy. The frustration around the lack of communication and inability to have input into treatment plans further contributed to the stress of their role as caregivers. Erica was able to achieve greater transparency and collaboration through private treatment and felt that this contributed towards her son’s
recovery. However, this option was not financially viable for the other participants in this study.

**Theme 4: The importance of group and peer support**

Mental health services mainly provided support to the individual with mental illness rather than family. Because of this, all of the participants had sought community based support specifically for family caregivers. This was mainly accessed through monthly local support groups run by Supporting Families in Mental Illness (SFMI), which was expected given that the participants were identified via this organisation. Some of the participants also utilised one-on-one peer support.

The participants described SFMI support groups as most useful early on in their experience of caregiving, as this was the time of greatest distress and difficulty. This was also when the participants lacked the knowledge and skills that they would later develop through experience and their own research.

Anna: The umm family support group, I went to one for a couple of years. I found it very useful, and that was when I first found out that he was mentally ill and umm the people there... I found there was so many commonalities, that I learned from them in some ways you know, just umm their attitude to their child or their sibling, and how they coped with all of these things.

Most of the participants described how valuable these groups were in terms of sharing their story and receiving support from other caregivers. As Greta said: “The best person to speak to is somebody who has been through it themselves.” The non-judgemental understanding by other members of these groups was highly valued in light of the ongoing stigma and discrimination around mental illness in the community.

Anna: Just the way they talked about what was happening, and the fact that you could have a giggle about it, that was great. You know, I’d be able to say “Well this month...” [laughs] umm whereas that’s not the sort of conversation you have with your family or your friends. So you’re in a group of people who are in similar circumstances and there was no judgement.
Francis also spoke about how much she valued the sense of belonging in the groups she attended:

*Francis: It's really umm nice to be with fellow travellers on the journey of mental health caring...hearing their stories, just being together with some sort of sense of solidarity, being understood, the mutual understanding that we can all share is a really, a really good thing.*

Within these groups the participants were able to share coping skills and strategies for managing difficult situations, thereby learning from each other’s experience. Support groups also served as a source of knowledge via the sharing of useful resources and information. This was something not provided by mental health services, highlighting the valuable role these groups played in equipping the participants with the information and skills needed to navigate their role as a caregiver.

*Anna: It helped me tremendously, because I was really floundering around. There was no umm, in fact I think these are the things that the hospital could do. That they could recommend you to those sort of groups or you know, where you could get some sort of help or websites you know, a list of useful websites. I know it’s asking a lot because they’re just focussed on their patients, but I mean it only has to be compiled once, and you hand it out. It’s just information that just helps you to learn and understand what it’s about.*

Half of the participants no longer attended support group meetings regularly. They described how over many years it became more difficult to make it to meetings that had changed time or location, or that they had less of a need for these groups once they had developed better coping skills and support networks. However, most maintained connections with SFMI and would attend groups or other activities irregularly.

*Anna: I no longer go to it. Because the woman that was running it, she moved away, she went out and over to [area] and it seemed to just sort of collapse. I’m on their database because they invite me to the Christmas party, umm so I go to the Christmas party and meet up with some of those people again.*
Although she had attended some meetings, Cathy felt that the SFMI groups were unsuitable for her due to cultural practices that she felt were at odds with her own values: “I have strong objections to walking into a room full of people and suddenly having a Maori person sit up and start going off in Maori….it was this Maori greeting that meant nothing to me.” However in the absence of regular support group meetings Cathy had accessed one-on-one peer support via Caring for Carers, an organisation which provides peer support to parents who care for a family member with a long-term mental, physical or intellectual disability. Although she could no longer access their service due to the need to work, she had found it useful early on in her experience: “I did miss that, because that was a good one.”

Greta also found one-on-one peer support to be more useful than the SFMI groups, although she still attended them. She had established a relationship with another caregiver via a support worker for her son:

_Greta: Our support worker was kind enough to give me a couple of people to ring. She gave me about three people to ring, I rang three of them, and this one particular lady sang the same tune as what I did. In other words she felt the same about psychiatrists as I did, she felt the same way about drugs, she felt the same way about alternative therapies. We speak the same language. And that’s been a relationship that’s been ongoing…and I think that umm sort of should be encouraged._

Most of the participants described support groups as a valuable source of emotional and practical support for caregivers. The groups provided a non-judgemental space in which the participants could share their experiences and in return receive understanding and support that helped to decrease their emotional burden and isolation. Support groups also played an important role in enabling the sharing of skills, information and resources that helped caregivers to better cope with their situation, particularly early on in their experiences. While two of the participants preferred one-on-one peer support to attending support groups, it was clear that maintaining connections with others in a similar situation was important. The fact that information and resources were not provided to the participants by mental health services highlights the importance of support groups and peer support as an external supporting factor for these caregivers.
**Theme 5: Family support and family conflict**

All of the participants described their son’s diagnosis as having a significant impact on family relationships. While some family members were supportive, in many cases there was ongoing conflict and tension that occurred as a result of issues surrounding the individual with schizophrenia.

Some of the participants talked about the impact of their son’s symptoms on other children living in the family home around the time of diagnosis. Although these siblings were not in a caregiver role, having to cope with the difficult and extreme behaviours of their brother resulted in a degree of emotional burden similar to that experienced by their parents. For example, Harried noted: “It can’t be nice for them, either, when all our family lived at home, and umm all his bizarre things going on. It spoilt family relationships in a way”. The participants also found that the need to prioritise their unwell child led to some resentment and tension in their relationships with their other children.

*Erica: Someone with a mental illness in your house it affects everyone. Umm them emotionally being upset with what they hear and see and umm it has a huge effect...I think they think it’s all about them [the unwell individual], which in lots of ways it is. Umm so they feel like they're sort of left out, yeah.*

In many cases family members had found it difficult to come to terms with the illness, or distressing to associate with the unwell family member. This led to some family choosing to distance themselves and have limited contact with both the individual with schizophrenia and their parent caregiver.

*Anna: My daughter is finding it difficult...she goes over to see him and they last time she came back very distressed, and she said “There’s no connection any more. We’ve got nothing to talk about. I tell him about the kids and what they’re doing and what I’ve been doing, and he’s got nothing to say ‘cause he’s not doing anything.” My daughters husband, I don’t think has any realistic idea of what schizophrenia is like, so he keeps away, umm the children have only seen him probably when the youngest daughter was about seven or eight, and she’s now coming up to seventeen, so ten years. So they’ve not had any real contact with him.*
While other family members were described as more sympathetic, there was a lack of understanding of schizophrenia and its implications: “I do sometimes wonder whether they recognise that mental health isn’t like a cut finger, you know it just doesn’t go away.”

In some cases the need to prioritise care for their child with schizophrenia had led to a permanent disruption to family relationships. Cathy in particular had become isolated from almost all family, including separating from her husband, due to her son’s illness.

_Cathy: My daughter, my younger daughter...she doesn’t speak to me these days, she will not have anything to do with me. She’s got three children umm she blames me for [my son]. Umm I’m not, I don’t handle it properly, I don’t get the doctors at the right time, umm you know Umm my sister I don’t see any more, she has nothing to do with me, umm because she just got sick of me saying oh we’ll get, no I won’t meet you today I’ll get home [my son] is waiting for me. And she would just you know, the last time she just threw her hands up in the air, drove off down the drive in her flash car and went home to her flash house and her husband._

Francis and Greta had both had an experience in which their son’s had become aggressive around family members, which had led to a permanent disruption to relationships:

_Francis: He can be confrontational and angry, and he was like that on father’s day last year, and our son-in-law couldn’t take it and marched him outside forcible, forcibly, and there was a dreadful altercation in the drive, and that was the last time the grandchildren were allowed on our premises. That was the last time our family visited us._

Although both participants expressed an understanding of their family’s reaction, they also felt disappointment that they were no longer close with some family members. Greta noted: “It’s been a bit of a handbrake on us from the point of view of enjoying our uh grandchildren and children.”
While Harriet and Erica also reported family conflict, particularly around the time of diagnosis, they also spoke about the support provided to their unwell child by their siblings:

*Erica: Oh yeah no they’re very, umm my kids are amazing, the three girls are really, [my one daughter] not so much, she’s had a lot of anger towards [my son] because she’s had to live through it, lots huge anger. But the other two sisters are very, very supportive, umm my mum’s amazing. My sister and yeah they’re all, no they’re all really, really supportive of it.*

Harriet in particular spoke about the benefits of family-wide education in enabling her other children to be more understanding and supportive:

*Harriet: But his brothers have been supportive but umm they’ve been supportive in offering him work, umm cigarettes [laughs] that sort of thing, and understanding that. But we did have to have a session quite a few years ago about educating the family... so despite all the ups and downs, we’re still close, he’s still close with the family.*

It is clear that schizophrenia has an impact on families that extends beyond the burden felt by parents as the primary caregiver. A lack of understanding about schizophrenia and the need to prioritise their son’s care often led to tension, conflict and in some cases a complete fracturing of family relationships. The sense of emotional burden experienced by parent caregivers was often felt by other family members, particularly siblings. However in some cases siblings were also a significant source of support. The participants who described better family relationships are also those who reported an improvement in symptoms, less burden and stress, better cognitive coping strategies and more support from mental health services. It is likely that these factors contributed to improved family relationships, and vice versa.

**Systemic issues**

Systemic issues discussed by the participants were contained in one theme: 6) lack of resources and support for caregivers. This included issues such as a lack of financial
aid, respite and residential care, and support with day-to-day practical problems which arise when caring for a family member with schizophrenia.

**Theme 6: Lack of resources and support for caregivers**

All of the participants discussed the lack of resources and support available to them as caregivers. Although mental health services provided medical care for their sons, the participants described a lack of wrap-around services offered in the community for families coping with schizophrenia, such as counselling, respite, residential care and community support workers.

*Erica: There’s no help. I mean if you go through the public system you get a key worker, I gather they’re like the doctor or the nurse whatever, and then you get a peer support worker as well, umm but even that as I say isn’t there, it’s not really...they haven’t got enough. They haven’t got enough, it’s just not enough at all. There’s way more support needs to be there, because it’s just a nightmare.*

A primary concern for all of the participants was the lack of suitable accommodation for their sons. In most cases the individual with schizophrenia had a relatively low level of functioning and required a high level of day-to-day support with basic needs, such as cooking, cleaning and managing medication. The participants described living with their son as the only suitable option due to the lack of residential facilities that could provide this level of support.

Anna’s son had been placed in a flatting situation, although she often worried about his ability to live independently. She described feeling frustrated at the lack of options available and her son’s standard of living was an ongoing concern:

*Anna: They eventually found him this place where there’s three other people living, and it’s a house umm none of them do any housework. I hate going there, it’s filthy... I’ve spoken to his community carer, and he agrees it’s not the most idea situation. And he said “We can’t find anywhere else, we don’t quite know...” There’s no supervision, there’s no one there to make sure they’re eating. There’s no one to get them organised for cleaning.*
Harriet was the only participant who was able to access long-term residential care for her son. She described the availability of this option as a “blessing” in that it allowed her to be free from the day-to-day stress of caring for her son without fear or concern for his well-being. This enabled family relationships to become re-established, and she was able to bring her son home for short periods to also reconnect with family.

Harriet: Then about nine years ago [my son] was offered oh ten years ago, they said at hospital there was a place at a residential house….and he went into that, and that worked well. The family life settled down, but by that time too the boys were leaving home. But I guess for my husband and I it was a time we could consolidate, and we would visit [our son] and it was a controlled thing, and he would come home for so many days and then have to go back.

Many of the participants drew similarities between their situation and that of parents caring for children with a physical or intellectual disability. The participants were aware that community based supported living facilities were available for this population and expressed a need for a similar option for those with severe and long-term mental illness.

Anna: I don’t know, I’d love to see something like what the IHC have got, something that…just something that was clean and comfortable and yet not taking their independence away. But there’s nothing for the mental health patients, nothing.

Greta and Francis had both sought temporary care facilities for their sons, but had found those they had seen to be of poor quality. For example, Greta said: “There’s a huge issue from our point of view, is respite care. The lack of respite care, the lack of quality respite care.” On one occasion Francis had paid a nurse to care for her son when she needed to travel and support other family members. However, this option was not something she could financially support on a regular basis.

Francis: The only way we felt that we could achieve respite that offered any sort of reasonable care for our son, didn’t totally disconnect him from his environment, was to find a nurse which we could hire and which, because I’m still working, we could afford to pay out of my wages...So we did that, umm and
we paid her mileage...we paid for absolutely everything we could to try, at least while we were away for five days, give him some quality of care, nutrition, circumstance and known-ness. That was really the only time we’ve had a major break I guess you could say in 17 years.

Most of the participants were of retirement age and struggled financially in their current situation. This was highlighted throughout the interviews by comments such as, “We’re not very well off at all.” and “Who can afford that?” Most of the participants mentioned that personal counselling was another resource that was unaffordable, while some saw this as less useful than practical support:

_Cathy_: It’s very hard to give support to this situation because you, I mean no disrespect you can sit and you can talk, you can listen to half a dozen people, but when it actually comes to actually trying to help you can’t, because you’re not there, you’re not doing it.

However not all participants agreed with this view and Erica found her ongoing psychotherapy to be a significant supporting factor.

The participants also identified a need in terms of reconnecting their son back into the community. Recovery was seen not just as an improvement of symptoms, but as the ability for their son to re-engage with others in work and social activities. While community support workers provided some social contact, the participants again described this resource as not being “enough” to achieve meaningful community integration.

_Erica_: How you get them back out into society? How do you do that? That’s why I’m stuck, that’s like this big stuck bit. Yeah and it’s actually just as hard in some ways as when they’re really, really ill, because you feel like you’re just stuck here, and there’s no, they’re not ready to work, they need help to just transition. But there’s nothing there...So there’s a really big gap for that, when people do get well, a very big gap.

The participants discussed several significant gaps in systems that support individuals with severe and ongoing mental illness, as well as their families. Primarily the
participants described a lack of suitable respite and residential care facilities. Living with and providing a high level of care for an individual with schizophrenia was associated with ongoing stress and emotional burden. The participants felt that both permanent and temporary supported living facilities would relieve a significant amount of this burden. Financial aid was also viewed as important, as it would enable caregivers to access additional support such as counselling, private care for their son and respite for themselves. There was also a need for support to better engage the individuals with mental illness in the community. This would further help to alleviate caregiver burden and stress. Overall, there were a number of areas in which the participants expressed a lack of support and resources for family caregivers.
CHAPTER FIVE: DISCUSSION

Summary of the research findings
This research has explored the experience of parents who are providing long-term care for an adult child with schizophrenia in New Zealand. Using an interpretive phenomenological analysis, the research aimed to investigate both the positive and negative experiences of caregiving, as well as coping strategies, supportive factors, attitudes and perceptions of caregivers. Six themes were identified within the participants’ stories of their experiences, which were organised into three superordinate categories: psychological factors, external support factors and systemic factors.

Within the category of psychological factors two themes were identified, 1) emotional burden and 2) cognitive coping techniques. The latter contained two subthemes, 2A) knowledge acquisition and 2B) positive thinking. Three themes were identified within the category of external support factors: 3) the importance of communication and collaboration with mental health professionals, 4) the importance of group and peer support, and 5) family support and family conflict. Systemic issues were contained within one theme, 6) lack of resources and support for caregivers. The remainder of this chapter discusses the findings of this study in light of the literature previously reviewed. The chapter concludes with limitations of the current study and recommendations for clinical practice as well as future research.

Psychological factors

Emotional burden
One of the most salient aspects of the participants’ experiences of caregiving was emotional burden. Although the participants did not use the term ‘burden’, it was clear from their descriptions that they experienced significant worry, distress, fear, helplessness and frustration in their role as caregivers. The term ‘carer burden’ has been criticised for discounting any of the positive aspects of caregiving (Szmukler, 1996). While this may be the case when the term is used to refer to the entirety of caregivers’ experiences, it is also true that caregivers experience significant negative feelings (Boydell, et al., 2013; Parabiaghi, et al., 2007). Caregiver experiences are best represented on a continuum from positive to negative; therefore ‘emotional burden’ was
used to reflect the dimension of negative emotional impact and consequences for these caregivers.

The participants’ descriptions of emotional burden were consistent with other research on caregiving (Awad & Voruganti, 2008; Baronet, 1999). In particular, studies have shown significantly higher rates of distress and trauma in carers of individuals with first episode psychosis (Addington, et al., 2003; Mueser & Rosenberg, 2003). This was reflected in the participants’ descriptions. While the caregivers in this study described feelings of loss and grief as they came to terms with their sons’ diagnoses, they did not report any experiences of depression, anxiety or substance abuse. These secondary mental health effects are known to be common amongst caregivers (Awad & Voruganti, 2008; Boydell, et al., 2013). This may either be because these issues did not affect this group of caregivers, or the participants were unwilling to disclose such information in the non-anonymous setting of a face-to-face interview. The significant level of stress described is consistent with research on other caregivers in New Zealand, suggesting that this is a common issue across different carer populations (Jorgensen, et al., 2010).

The degree to which the participants experienced feelings of emotional burden strongly corresponded with the severity of symptoms in the individual with schizophrenia. A number of other studies have documented the relationship between symptoms and burden (Addington, et al., 2003; Martens & Addington, 2001). For two participants, an improvement in symptoms over time had alleviated a considerable amount of the distress they had experienced as caregivers. These carers also utilised an additional cognitive coping strategy of positive thinking and had a greater degree of professional and family support. Improved symptoms, particularly social functioning, and higher levels of social support have previously been associated with more positive caregiving appraisals (Harvey, et al., 2001; Onwumere, et al., 2008). It is likely that these factors have led to a more positive outlook and a reduction in stress for these two caregivers.

Correspondingly, four of the participants reported increasing emotional burden over time as a result of a continuing deterioration in symptoms. These carers also had more negative appraisals of the impact of the illness, more difficulty accessing appropriate support from mental health services, and increased family conflict. It is likely that a combination of deteriorating symptoms and lack of support resulted in more negative appraisals and increased burden. The findings of this study are not consistent with
research which shows that long-term caregivers tend to report more positive appraisals of their role (Addington, et al., 2003; Onwumere, et al., 2008). Rather, these results suggest that caring may only become easier over time in situations where symptoms improve and caregivers can access adequate social and professional support. It may be the case that carers in previous studies have experienced a reduction in symptoms and increase in supports over time, thus enabling a more positive view of caring. It is also possible that this may be the result of a selection bias, as carers whose situations have improved may be more willing and able to participate in research. However, the findings of this study indicate that carer situations do not necessarily become easier over time in situations where symptoms and supports continue to deteriorate. This was the case for the majority of the participants in this study.

The participants experienced the greatest distress in response to behaviours that were difficult to manage, including aggression, violence, self-harm and suicidality. Other studies have also shown that caregivers experience higher subjective burden as a result of problematic behaviours, in particular those that pose a threat to carer safety (Ohaeri, 2003; Winefield & Harvey, 1993). In addition, the survey of New Zealand caregivers showed that a substantial number had experienced injury or damage to property in the last six months (M-Tag, 2006). Self-harm and suicide attempts were also common (M-Tag, 2006). This was reflected in the participants’ accounts and contributed considerably to burden and distress. The prevalence and impact of these behaviours is a significant issue for this population of caregivers.

The participants also spoke of the difficulty in maintaining a calm home environment, in order to avoid perpetuating anger, violence or other symptoms that were difficult to deal with. These fears are not unfounded, as it has been shown that a stressful family environment and a high level of expressed emotion are predictors of relapse in schizophrenia (Kavanagh, 1992; Scazufca & Kuipers, 1996). Unfortunately, the constant effort expended in order to avoid escalating distressing situations only added to the degree of burden experienced by these carers. Even in situations where symptoms had improved, there was considerable burden involved in maintaining a high level of day-to-day care for an adult with low functioning.
Cognitive coping techniques: Knowledge acquisition

Caregivers in other studies have exhibited a wide range of coping strategies. There were two main coping techniques used by this group of carers. Knowledge acquisition was used by all of the participants as a way to cope with some of the emotional burden of their experience. Through their own research on schizophrenia and its management, the participants were able to develop skills that were useful in dealing with difficult symptoms and behaviours as well as increase their understanding and empathy. Increasing their knowledge of the mental health system also enabled caregivers to better advocate for themselves and their sons. It is known that increasing information on managing difficult behaviours and other practical coping strategies helps to increase caregiver’s sense of control and alleviate burden and stress (Reinhard, 1994).

In addition, the participants recognised their learning as beneficial and something which they had gained through their experiences. This is supported by other qualitative research that has noted that caregivers are able to describe many gains from their experience (Fang-pei & Greenberg, 2004). In particular, this theme was consistent with the sense of life lessons learned and a greater ability to manage difficult situations in life documented in other studies (Mays & Lund, 1999; Veltman, et al., 2002). Research in New Zealand has also emphasised the importance of access to adequate information in enabling caregivers to better cope with their role (McPherson, et al., In Press). This strategy has been documented in a variety of countries, further supporting the findings of this study that knowledge acquisition is an important coping strategy for caregivers across different contexts (Huang, et al., 2008; Sveinbjarnardottir & Casterli, 1997).

Cognitive coping strategies: Positive thinking

Only two of the participants used positive thinking as a coping strategy. Both of these carers had more positive appraisals, expressed as a sense of being grateful that their situation had improved over time and was not currently as difficult as that of other caregivers. A reduction in symptoms, adequate mental health support for their sons and improved family relationships were also important factors for these two participants that are likely related.

There are two possibilities to explain the use of positive thinking as a cognitive coping strategy by only two carers in this study. One is that the use of positive thinking created better circumstances for these participants, by helping to improve family relationships.
and enabling a greater ability to access adequate professional support. The second is that positive thinking is a result of an improvement in these caregivers’ situations, which came about as a result of the re-establishment of supportive family relationships, access to adequate mental health services as well a reduction in schizophrenia symptoms. The second hypothesis is more likely, as both of these carers reported experiencing significantly fewer issues in accessing appropriate support from mental health services than the other participants. Therefore positive thinking may be more difficult to use as a coping strategy when carers are experiencing a high degree of distress and lack of support.

One of the participants who used positive thinking was financially able to access professional services privately, while the other was the only participant able to access long-term residential care. It is likely that these two situations contributed to an improvement in symptoms and helped to alleviate carer stress. While it is difficult to determine the significance of positive thinking in each of these situations, it is clear that both of these caregivers were able to maintain more positive appraisals of their role. Both caregivers also attributed their attitudes towards the level of professional support accessed, indicating that the material circumstances of caregivers’ situations are difficult to separate from their perceptions of the caregiving role.

Both of these participants also had greater access to professional support for themselves and family through psychotherapy and family counselling. This helped to improve family relationships and increased family support, another important factor in reducing relapse rates as well as burden (Addington, et al., 2005; Berglund, et al., 2003). The findings of this study highlight the importance of access to appropriate support from mental health services in alleviating caregiver burden and distress, enabling a more positive outlook for both of these carers.

**External support factors**

*The importance of communication and collaboration with mental health professionals*

All of the participants spoke about their experience accessing mental health services, predominantly on behalf of their sons. In particular, the participants’ descriptions highlighted the importance of communication between services and family in helping to
alleviate some of the stress of caring, as well as to improve support for the individual with schizophrenia. Many of the participants talked about the refusal of mental health services to provide information based on privacy. This significantly impacted on the participant’s ability to care for their sons and resulted in feelings of stress and frustration. The findings of this study indicate that carers would benefit from information regarding their ability to access their family member’s health information under the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Health Information Privacy Code (Mental Health Commission, 2009).

Research on other carer groups in New Zealand has shown that the ability to obtain adequate information from services is a significant issue (Jorgensen, et al., 2010; McPherson, et al., In Press). Carers have also noted the importance of their personal knowledge being respected and considered by services in regards to treatment plans (McPherson, et al., In Press). These were also concerns for the participants in this study, who felt that as carers providing the majority of support, they were an expert source of knowledge on the mental health and day-to-day functioning of their sons. In most cases however, they were an underutilised resource in treatment and support planning, and many of their concerns were not given consideration. This is particularly concerning in situations where symptoms, particularly aggression and violence, were escalating.

One participant attributed the improvement in her circumstances and the recovery of her son to her ability to access private mental health treatment. This raises questions of equitability, as access to quality mental health services should not be dependent on financial ability. In this situation, the carer was also able to experience a greater degree of input and transparency via a psychiatrist/psychotherapist who provided therapeutic intervention to both herself and her son. However, there are potential ethical and client confidentiality issues for clinical service providers who treat both the individual with mental illness and their caregiver. Despite this, these unique circumstances facilitated a significantly better outcome for both the participant and her son. This was likely to be due to the increased degree communication and collaboration, as well as the ability of this caregiver to access a continuing high level of support from services.

It has also been documented that for all groups of carers in New Zealand, engaging with services is a constant struggle (Jorgensen, et al., 2010; McPherson, et al., In Press).
Carers must advocate for themselves as well as the individual they are caring for, often at a point of crisis when they feel most vulnerable (McPherson, et al., In Press). The carers in this study and in other groups have described the lack of flexibility in services, which contributes considerably to the difficulty of their experience (McPherson, et al., In Press). In New Zealand, a recovery based approach in mental health care emphasises the impact of mental illness on families and the potential benefits gained from collaboration with family in treatment (Mental Health Commission, 1998). However, the findings of this study and others suggest that services often fail to meet this standard. These results also suggest that psychosocial interventions, including family therapy, are not routinely made available to individuals with schizophrenia and their families.

The importance of group and peer support

A number of studies have noted the positive impact of social support on the physical and psychological wellbeing of caregivers (Fang-pei & Greenberg, 2004; Huang, et al., 2008). Carers in this study accessed social support via Support Families in Mental Illness (SFMI) support groups, as well as one-on-one peer support. The participants described support groups as a useful way of connecting with other caregivers and helping to alleviate feelings of burden, stress and isolation. The participants who accessed peer support described these relationships as serving a similar function. Carers who have a person to confide in generally report more positive caregiving experiences (Boydell, et al., 2013). Additionally, participating in support groups facilitated the sharing of useful skills and knowledge, enhancing the participant’s ability to cope with the many difficulties of their role. Support groups also provided opportunities to build confidence and enabled the participants to better advocate for themselves and their sons (Saunders, 2003).

Other authors have noted that family who care for an individual with mental illness can become socially isolated due to stigma and a lack of understanding (Berglund, et al., 2003; Boydell, et al., 2013). It has been documented in other studies that carers are sometimes prevented from accessing social support due to fear of embarrassment (Huang, et al., 2008; Magliano, et al., 2006). While the participants did not describe stigma directly as a barrier to social support, it was clear from their accounts that group and peer relationships were important due to the greater degree of non-judgemental understanding offered by other carers. Many of the participants also experienced a
considerable degree of family conflict, which impacted on their ability to access support from family. This study and others have shown that group and peer relationships are an effective way of enhancing emotional and practical support for this population of caregivers (Saunders, 2003).

This support was particularly important around the time of diagnosis, when caregivers had the greatest need for information and practical coping strategies. It was not clear from the participants’ accounts whether they had accessed SFMI groups independently, or whether they were directed to this service by clinicians and mental health workers. Of those who accessed peer support, one connection was made through a community support worker and one through a peer support organisation. It is important for clinicians and support workers to connect caregivers to these networks where possible, particularly around the time of diagnosis.

**Family support and family conflict**

Another area of concern for the participants was the impact of schizophrenia on family relationships. While some experienced family members as supportive, most described considerable conflict, tension and fracturing of relationships. Family conflict and disruptions to relationships are known to be common in families coping with schizophrenia (Boydell, et al., 2013; Fang-pei & Greenberg, 2004). The participants in this study noted that siblings of the individual with the illness experienced a considerable degree of distress and difficulty, particularly when living in the same home. It was clear that siblings shared in the feelings of emotional burden even when not providing care themselves. These findings emphasise the impact of schizophrenia on whole families, with burden and distress extending well beyond the primary caregiver (Awad & Voruganti, 2008).

Siblings were also described as providing a considerable amount of support by two of the participants. These carers were also the only two who were able to access family counselling, psychotherapy, and long-term residential care. The participants with a greater degree of family conflict described a lack of understanding from other family members as the cause of tension in relationships. It is likely that family counselling and therapy facilitated a greater understanding of schizophrenia for those with access to it, further emphasising the benefits of family-wide psychoeducation (McFarlane, et al., 2003). This helped to alleviate the burden felt by family members as well as reinforcing
support for the carer. In one case, long-term residential care for the individual with the illness granted family members the opportunity to re-establish more positive relationships. The family members were also able to meet with the individual with schizophrenia in a limited and controlled way, which enabled them to maintain family connections without becoming overwhelmed by the impact of the illness.

The participants described extended family relationships in similar terms. Some noted the desire of extended family to be supportive and helpful, but this was combined with a general lack of understanding of the illness and the responsibilities of the caregiver. In other cases, aggression and violence from the individual with schizophrenia had led to a complete fracturing of family relationships. This demonstrates that behaviours which pose a threat to safety are not only the most difficult for caregivers to cope with, but also have a considerable impact on families (Ohaeri, 2003; Winefield & Harvey, 1993). This can also serve to further isolate caregivers from family support. The general lack of understanding of schizophrenia demonstrates the need for a greater degree of public education around this disorder. In addition, suitable respite and residential care has the capacity to provide caregivers with greater opportunities to reconnect with family and facilitate much needed support.

**Systemic issues**

*Lack of resources and support for caregivers*

The distinct lack of resources and support available to the participants was prevalent throughout their accounts. The majority of support provisions were for the individual with mental illness; almost no resources were provided directly to caregivers by mental health services to assist with the caregiving role. Some of the participants were able to access a community support worker for an hour once a week or fortnight. One participant was also able to access limited family counselling, while another maintained a high level of support by paying for private mental health services as previously discussed. There were no other supports formally made available to carers.

The main concern of the participants was a lack of suitable residential care for the individual with schizophrenia. Because of this, the participants found that they were unexpectedly required to take on the responsibility of providing shelter, financial support and a high level of day-to-day care and supervision for their unwell son.
Additionally, the participants were provided with little information or support to help manage deteriorating symptoms and serious issues such as aggression, violence and self-harm. Concern for the well-being of their son and the desire to provide the best possible care often conflicted with fears for their own safety. Other research on mothers who care for adult children with mental illness and a history of violence has described this situation as “choosing the best of hells” (Copeland & Heilemann, 2011). Either parents must take on the responsibilities of caring and risk their own safety and wellbeing, or they can choose not to provide accommodation and support, thus risking the safety and wellbeing of their offspring (Copeland & Heilemann, 2011).

The participants felt that much of their burden and stress would be alleviated by the availability of temporary and permanent residential care facilities, including respite. The only carer who was able to access long-term residential care described a number of benefits from this situation, including reduced emotional burden, more positive family relationships as well as ongoing high quality mental health support for her son. Other participants had sought temporary respite but found a lack of quality services available. Other research on carers in New Zealand has shown that lack of adequate respite is a common concern (Jorgensen, et al., 2010). It is clear that making such facilities more widely available would alleviate a considerable amount of burden across carer populations.

The participants also described a need for increased financial aid. This has also previously been documented as a need of carers in New Zealand (Jorgensen, et al., 2010). Additional supports such as counselling, private mental health care and respite could not be accessed by most of the participants due to a lack of financial ability. In addition, it has been shown that nearly half of this group of carers cannot continue full time work due to the requirements of the caregiving role (M-Tag, 2006). This was supported by the participants’ accounts, with most having to restrict their amount of work in order to care for their son. They were also coping with ongoing costs such as food, transport, clothing and medical care. As a result, many were working past retirement age in order to cover these expenses and experiencing considerable financial strain, adding to their feelings of stress.

In New Zealand, the Funded Family Care policy was recently introduced to allow adults with significant disability to employ a family member to provide some or all of their
allocated paid support (Ministry of Health, 2013). Previously, the Ministry of Health’s policy was that this funding could not be used to employ family members. In 2010 the High Court declared that the Ministry’s refusal to pay family who support their disabled relatives was a breach of the New Zealand Bill of Rights Act (1990), which dictates that it is illegal to discriminate against someone in employment on the grounds of family status (Ministry of Health v Atkinson, 2010). In addition, the Court noted that caring for full-time for an adult child who is disabled is considered to be well beyond the duty of “natural support” which parents owe their children (Ministry of Health v Atkinson, 2010). While this policy took a number of years to change, this new legislation provides hope for parents caring for adult children with mental illness. Although the participants did not discuss this case directly, it is possible that continuing advocacy in this area may eventually enable these carers to access a similar type of funding.

Limitations

There are several limitations identified in the current study. Generally, small sample sizes are not considered to be a drawback for qualitative studies as they do not aim to collect expansive data that is representative of whole populations (Morrow, 2005). However, it must be acknowledged that qualitative studies are therefore limited in their generalisability. This study was undertaken with a small group of New Zealand European parents who are providing long-term care for sons with severe and disabling schizophrenia. The findings of this study may not be representative of carers from different populations, different ethnicities or those residing outside of the Auckland region. The study also contained only one male participant and is therefore biased towards female experiences of caring. While women make up the majority of the caregiver population, it is likely that men have different experiences, perceptions and coping strategies that are not represented by this study. It is also possible parents of females with schizophrenia may have to deal with different issues and stressors, such as sexual exploitation, contraception and reproductive health issues.

Another area of potential limitation is that the participants were self-selected through a carer support and advocacy organisation. This may mean that the carers in this study represent those who have experienced the most difficulty and are more invested in contributing to research, or advocating for change in this area. Because of this, the data may be biased towards capturing negative rather than positive caregiving experiences.
However, this is somewhat mitigated by the fact that two of the participants reported situations of considerably less stress and greater support. Another restriction when undertaking face-to-face interviews is that the participants may withhold parts of their experience that they feel uncomfortable sharing in a non-anonymous setting. While the participants were assured that their privacy and confidentiality would be respected, it is possible that certain issues that were more difficult to share in this setting were not captured by this study.

It is also important to acknowledge the role of the researcher within a qualitative study. As a student in a psychology training programme, the researcher is interested in understanding issues in clinical practice and this is reflected in the focus of this practice research project. In order to mitigate any potential bias on the part of the researcher, the research design and interview questions were based on the existing literature of caregiving. In addition, each step in the analysis was documented thoroughly and the themes examined reflexively to ensure credibility of the findings. Many of the themes are supported by the research literature which demonstrates that there is strength in the findings of this study.

**Conclusions and recommendations**

This research demonstrates that caring for a son with schizophrenia is a complex and multi-faceted experience, within which contextual factors play a significant role. The participants were faced with the difficult role of providing a high level of care and support for a family member with severe and disabling mental illness; a role which they initially undertook with little information, resources or support. Knowledge and information have a powerful role to play in equipping caregivers with the skills and understanding needed to cope with the many difficulties they face, as well as providing them with a sense of control in an often unpredictable situation. This can also be facilitated by greater collaboration and communication between family carers and mental health services, something which is emphasised by a recovery based approach in mental health care. Clinicians must walk a fine line between maintaining client privacy whilst respecting the role that family caregivers play in supporting those with severe mental illness.
The SFMI support groups also provide useful practical and emotional support for caregivers, particularly as stigma and a lack of understanding of mental illness are still significant issues for this population of carers. It is clear that schizophrenia has an impact on whole families and, where tensions can be resolved through increased understanding, families can also provide much needed support. There are many significant systemic and contextual issues faced by family who are coping with the impact of schizophrenia, and little financial or practical support available to caregivers, other than that provided by non-government organisations like SFMI. De-institutionalisation has been prioritised in the mental health sector; however sufficient resources and support must be made available to caregivers in order to truly achieve a model of ‘community-based’ care.

This study can suggest a number of recommendations that may be useful for mental health clinicians who are working with individuals with schizophrenia and their families. The involvement of caregivers in a ‘care plan’ would help to formalise the interaction between services, clients and family as well as acknowledge the role and knowledge of family carers. This could include the creation of a safety plan for carers to use in crisis situations. Psychoeducation for family is also important to facilitate an increased understanding of the illness as well as to suggest strategies that may be useful in dealing with difficult behaviours. Other useful information, such as details of community based support services, legal information, and other available resources should also be routinely given to family carers.

Psychosocial interventions and rehabilitation for individuals with schizophrenia could be made more widely available. This would facilitate increased functioning and ability in these individuals as well as help to alleviate some of the stress of day-to-day support provided by caregivers. A greater degree of community based resources, including crisis management teams, support workers and suitable respite and residential care facilities are also needed, as is financial support. It would also be useful to make counselling and family therapy routinely available to families coming to terms with the impact of schizophrenia; this would also benefit the individual with mental illness. In New Zealand, the Like Minds, Like Mine public awareness campaign has worked to reduce stigma and discrimination via television advertising, education resources and the use of well-known spokespersons (Vaughan & Hansen, 2004). There is evidence to suggest that Like Minds, Like Mine has increased awareness and improved attitudes
towards those with mental illness in New Zealand (Vaughan & Hansen, 2004). The findings of this study indicate that carers would benefit from the continuation of such campaigns to reduce stigma and facilitate greater support for family carers.

Considerably more research on the experiences and needs of caregivers in the New Zealand context is needed, particularly those caring for individuals with long-term and severe mental disorders like schizophrenia. Research on the role of culture and ethnicity in caring is also needed; this is particularly important within New Zealand’s ethnically diverse population. This information would also be useful in designing culturally appropriate intervention strategies. The variety of coping strategies and supportive factors used by carers could be further explored and helpful in facilitating the use of such strategies. There has been little research thus far on the positive aspects of caring and this study demonstrates that this area is worthy of further exploration. In particular, what types of circumstances, coping strategies and supports contribute to the more positive aspects of caring and help moderate carer stress. Further research on the economics of caregiving in New Zealand, like the survey undertaken on mainly Auckland-based carers, would also serve to bolster advocacy for greater funding of carer resources and supports (M-Tag, 2006).

This study has provided some useful insights into the unique experience of parents who are providing long-term care and support for an adult child with schizophrenia in New Zealand. Both positive and negative experiences were found, as were a range of coping strategies, supportive factors and systemic issues. The emotional burden and difficulties experienced by family caring for an individual with schizophrenia are extensive. Although the significant impact and consequences on family carers is well documented, the current research shows that carers continue to struggle in accessing adequate support for themselves and for the individual they are caring for. Although social support via SFMI support groups and peer relationships help to alleviate some of the stress felt by carers, the illness continues to have a significant impact on families, particularly in situations where symptoms are deteriorating. A greater degree of input and acknowledgement of family carers by mental health services is needed via increased communication and consideration of family knowledge, as are specific supports and services that help families to cope with the many practical and emotional challenges of caring for an individual with major mental illness.
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APPENDICES

Appendix A: Advertisement for participants

Advertisement for research participants

“Caregiver experiences of parents who support sons or daughters with schizophrenia”

The aim of this study is to explore the experience of parents who care for an (adult) child with severe, long-term and disabling schizophrenia. This includes both positive and negative experiences, access to support, as well as understandings of and attitudes towards mental illness.

It is hoped that this study will contribute to a more detailed understanding of the experience of informal caregivers of relatives with major mental illness in New Zealand.

There are very few documented narratives from New Zealand caregivers and the sharing of these experiences may help to reduce the ongoing stigma around severe mental illness, as well as help to improve services and support in this area.

We are looking for participants to interview who:

- Have an (adult) child with a diagnosis of schizophrenia or related disorder, who is a long-term mental health service user and requires significant ongoing support. They may or may not still be using mental health services and recommended treatments.

- Are the primary care-giver for the individual with mental illness (either living with you or living in the community with you as their primary source of support).

- Are over 45 years old.

- Are New Zealand residents, speak English fluently and currently reside in Auckland.

If you meet these criteria and you would like to share your story, or you would like more information about what is involved, please contact the researcher directly at barbara.j.pike@gmail.com or on 021 146 1379 with your best contact details. Recruitment is open until the end of June 2013.

Please feel free to spread this advertisement through your networks or invite any family or friends you know who meet these criteria and would be interested in participating.

Approved by the Auckland University of Technology Ethics Committee on 26 April 2013. AUTEC Reference number 13/67.
Appendix B: Interview schedule

Indicative questions for semi-structured interviews

Introduction:

- Self-introduction and brief information about the project.
- Work through Participant Information Sheet and Consent Form with participant. Ask if there are any questions regarding the research. Obtain informed consent prior to interview and recording.

“Today is about having a chat about your experiences of caring for an (adult) child with schizophrenia. I’ll be guiding this interview with a few planned questions however if you feel uncomfortable at any time please let me know and we can skip that question. As you know we are recording the interview and I may make some notes to assist me later.

Although there are a few specific questions for me to ask, I am interested in your experiences, so if you have some information you feel is important or things you wish to bring up, please let me know.

If at any time you feel as though you need a break, or you want to stop the interview for any reason, please let me know.”

- Make sure the participant is comfortable and ready to begin.
- Collect basic demographics and details of the participants situation: age, gender, ethnicity/cultural background, marital status, family/living arrangement

The interviews are “semi-structured” and will start with a general question about the experience of caring for an (adult) child with schizophrenia. The following questions will be used as a guide, however the participants will be encouraged to elaborate and describe experiences in their own words. The goal is to elicit the participant’s subjective experience and the aspects of this that they see as most important.

Some suggested questions are as follows:

- Can you tell me about your experience of caring for your son/daughter?
  - How did the problem develop?
  - What was the diagnosis/first access to mental health services experience like?
  - What are the difficulties you experience caring for your son/daughter? Eg: emotional, financial, social, etc.
  - How does this situation impact on your family?
  - Have things changed for you over time? How?
  - What support do you access/have you used in the past? Eg: mental health services, community services, family/social support etc.
  - Are these supports useful?
  - What supports are needed?
  - Are there any benefits or rewards you think come from this situation?
  - Do you experience any stigma or discrimination?
  - What do you think recovery would look like for your son/daughter?
- What would be helpful for recovery/management of the disorder?
- What would be helpful to you as a caregiver?

- One 10-15 min break after approx 45 minutes
- Draw the interview to a close after 1.5-2 hours of talking
- Thank participant for sharing their time and story, offer Koha of $20 petrol voucher
- Close interview
Appendix C: Participant Information Sheet

Participant Information Sheet

Date Information Sheet Produced:
1 April 2013

Project Title
Informal caregivers: narratives of parents who support (adult) children with schizophrenia

An Invitation
My name is Barbara Pike and I am a student completing a Master of Health Science in Psychology at AUT University. As part of my Master’s thesis I am working on a research project which aims to explore the experiences of parents who care for (adult) children with severe, long-term and disabling schizophrenia. I would like to invite you to participate in this research.

Participation in this study is voluntary and you may withdraw at any time prior to the completion of data collection. Although you may be a member of Supporting Families in Mental Illness (SFMI), taking part in this study will not advantage or disadvantage you in any way in terms of the support you receive from SFMI or any other organisation.

What is the purpose of this research?
The purpose of this research is to develop a deeper understanding of the complex experience of caring for a relative with severe mental illness. This might include both positive and negative experiences, access to support, as well as understanding of and attitudes towards mental illness.

In exploring these areas, this study will contribute to a more detailed understanding of the experience of informal caregivers in New Zealand.

It is hoped that this research will be published in an academic journal and will be presented to appropriate academic, mental health and community groups where suitable. A copy of the research report will be provided to SFMI, which they will upload onto their website.

How was I identified and why am I being invited to participate in this research?
You are being invited to participate in this research because you have emailed me your contact details in response to an advertisement placed in the SFMI newsletter, and you meet the research criteria as follows:

- You are the parent of an (adult) child who has a diagnosis of schizophrenia or related disorder.
- You are the primary care-giver for the individual with mental illness, who may either live with you or live in the community with you as their primary source of support.

- Your (adult) child is a long-term mental health service user who requires significant ongoing support; they may or may not still be using mental health services and recommended treatments.

- You are over 45 years old.

- You are an Auckland based, New Zealand resident and speak English fluently.

**What will happen in this research?**

This research will consist of a one-off interview session that will last around 1.5 to 2 hours. I will ask you some questions to give the interview a loose structure, but you will also be given the space to talk about which aspects of your experience you view as most important. The interview will be recorded to ensure accurate documentation and will be transcribed by me for analysis.

The questions will be focussed around the difficulties you experience as an informal caregiver, any benefits or rewards you gain from the experience, what support services you access and whether they meet your needs, and your understanding of and attitude towards mental illness.

The interview sessions will take place in a location we agree upon. I am able to book rooms at the Psychology clinic at AUT Akoranga Campus, Youthline in Ponsonby or Manukau, or SMFI Auckland in Grey Lynn. I am also able to drive to other places if you have another preference. It is important that the interviews are undertaken at a location we both find comfortable.

**What are the discomforts and risks?**

Although it is not anticipated that you will experience discomfort or risk by taking part in this interview, you may discuss extremely difficult experiences in relation to caring to a family member with schizophrenia. This may be uncomfortable or distressing for you.

**How will these discomforts and risks be alleviated?**

You are encouraged to choose the level of disclosure you personally feel comfortable with. Your privacy and confidentiality will be respected in order to protect you from any stigma around disclosing your experience with mental illness.

You will be able to stop the interview at any stage for a break or discontinue the interview if you wish. You may withdraw from the study at any time, in which case any information collected from you will be destroyed.

AUT Health and Counselling service also offers up to three free counselling sessions per participant. The counselling will be provided by professional counsellors and must be sought in relation to issues arising from your participation in this research. If this service is required you can contact the AUT Health and Counselling centres at WB219 or AS104, or phone (09) 921 9992 City Campus, or (09) 921 9998 Akoranga Campus to make an appointment.

You will need to let the receptionist know that you are a research participant and provide my details. You can find out more about AUT counsellors and the option of online counselling on their website:
http://www.aut.ac.nz/students/student_services/health_counselling_and_wellbeing.
What are the benefits?

This research will benefit me by helping me to obtain a Master of Health Science in Psychology, as well as increase my understanding of current issues in mental health.

You may benefit from the experience of sharing your story and contributing to research which intends to help improve support provided to informal caregivers.

The wider community will benefit from the sharing of stories of families who experience schizophrenia. There are very few documented narratives from New Zealand caregivers and the sharing of these experiences may help to reduce the ongoing stigma around severe mental illness, as well as help to improve services and support. SFMI may also use the report of this research to help further their advocacy and support activities.

How will my privacy be protected?

Your privacy and confidentiality will be respected with no identifying information present in the data or report; a pseudonym will be used to identify your data.

You will also be given the opportunity to review the transcript of your interview to check that all the information I have collected is accurate. You may also request any changes if you feel there is some information that may easily identify you.

You should be aware that confidentiality will be breached if you disclose information about activities which may cause harm to yourself or others.

What are the costs of participating in this research?

The interview will take approximately 1.5 to 2 hours, plus travel time. You will be required to travel to the interview location at your own expense. There are no other costs for participating in this research.

What opportunity do I have to consider this invitation?

Your participation in this study is completely voluntary and you have until the end of June 2012 to consider this invitation. If you require further information or want to ask questions about this research please contact me via email. If you would like to discuss the requirements please email me with a suitable time and I will call you.

How do I agree to participate in this research?

If you would like to participate in this research please contact me and we will arrange an interview time and location. You will also need to sign a Consent Form, which I will bring to the interview. We will go through this form and make sure you have a chance to ask questions before you sign it.

Will I receive feedback on the results of this research?

You are invited to receive a summary report of the research once completed. Please tick the appropriate box on the consent form if you wish to receive one.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Daniel Shepherd, daniel.shepherd@aut.ac.nz, 921 9999 ext 7238.
Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Dr Rosemary Godbold, rosemary.godbold@aut.ac.nz, 921 9999 ext 6902.

Whom do I contact for further information about this research?

*Researcher contact details:*

Barbara Pike, barbara.j.pike@gmail.com, 021 146 1379

*Supervisor contact details:*

Primary supervisor: Dr Daniel Shepherd, daniel.shepherd@aut.ac.nz, 921 9999 ext 7238

Secondary supervisor: Kate Diesfeld, kate.diesfeld@aut.ac.nz, 921 9999 ext 7837

Approved by the Auckland University of Technology Ethics Committee on 26 April 2013. AUTEC Reference number 13/67.
Appendix D: Consent Form

Consent Form

Project title: Caregivers experiences of parents who support sons or daughters with schizophrenia

Project Supervisors: Dr Daniel Shepherd and Kate Diesfeld

Researcher: Barbara Pike

☐ I have read and understood the information provided about this research project in the Information Sheet dated 1 April 2013.

☐ I have had an opportunity to ask questions and to have them answered.

☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

☐ I agree to take part in this research.

☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

Participant’s signature: ..........................................................

Participant’s name: ..........................................................

Participant’s Contact Details (if appropriate):

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..........................................................................................

Date:

Approved by the Auckland University of Technology Ethics Committee on 26 April 2013.
AUTEC Reference number 13/67.

Note: The Participant should retain a copy of this form.