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who cares for people with schizophrenia: family carers' health, circumstances and adjustment

SUNNY COLLINGS
SOCIAL PSYCHIATRY & POPULATION MENTAL HEALTH RESEARCH UNIT
UNIVERSITY OF OTAGO WELLINGTON

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EXECUTIVE SUMMARY

Family carers of people with schizophrenia are an important part of the mental health sector landscape, yet there are few studies of representative samples to inform policy and service development. Traditional psychiatric research has investigated carers' characteristics in relation to the recipients of care, and has paid little attention to aspects of the family caregiver experience other than burden. This cross-sectional study describes the experiences of family carers of people with schizophrenia in Wellington, New Zealand, paying attention to their socio-demographic profile, their health, the context within which they provide care and how they cope with and adjust to their situation. There were three areas of investigation, selected on the basis of the literature and a preliminary qualitative study. These areas were the carers' health status, burden, coping and adaptation; experiences of mental health services; and social support. Family carers of people with schizophrenia wanted their whole experience as carers reflected in the research, rather than simply represented by the extent to which they were not coping or were ill themselves.

Firstly, the study identified a representative sample of 96 carers of people in the Wellington region diagnosed with schizophrenia for between one and six years, and described the socio-demographic profile of both the people with schizophrenia and family carers (93 carers were family members and three had other relationships to the index consumers). Secondly, the health status, psychological adaptation and social experience of the carers were described, with a focus on potential systematic differences between carers of different sexes, socio-economic status, ethnicities and relationships to the index consumer. Data from structured measures of psychosocial characteristics of carers were complemented by responses to additional questions devised for the study.

The study shows that family carers of people with recent-onset schizophrenia in New Zealand are a diverse group with multiple social roles. They rate their own general health as satisfactory, but more commonly have more mental health problems than the general population of New Zealand. There is no sex or ethnic difference in the frequency of current mental health problems among the carers. Rates of hazardous alcohol

consumption are the same as for the general New Zealand population. There is also an unmet need for help for carers' own mental health problems. Their satisfaction with mental health services is high in general, but there is a trend for Māori and Pacific Island carers, and carers with less education, to be less satisfied. Over half of carers are not satisfied with their level of involvement with the mental health service. Parents are dissatisfied in more domains than any other subgroup of carers. Carers' knowledge of schizophrenia is consistent with the psychiatric illness model. There is some variation between subgroups in attribution of symptoms and behaviours – for example, parents commonly attribute self-harm to personality problems rather than illness, whereas non-parent carers do not. It was surprising that carers did not name illness-monitoring as a prominent aspect of their caring role.

The majority of carers enjoy good social support, but a poor sense of attachment is associated with recent-onset poor mental health as measured by the GHQ-28^a. Those who reported positive experiences of care-giving had good social support, a wide repertoire of coping strategies and additional carer roles.

Negative experiences of caregiving are associated with inadequate social interaction and enduring poor mental health, and also with involvement in advocacy organisations and greater satisfaction with services. Carers with the widest range of coping styles are those who live with the index consumer. The majority of carers have a high degree of commitment to the caring role, and all carers have experienced some enhancement to their relationship with the care recipient because of the caring role.

Eminent psychiatrist John Wing said in 1978 that “the relatives of schizophrenic consumers are nowadays the real primary care agents”.¹ Psychiatry has long acknowledged the importance of family carers in schizophrenia, but from a narrow perspective, and largely on its own terms. As mental health consumers have done, family carers are asserting themselves on the political and health services landscape. Psychiatry as a discipline needs to develop the capacity to respond in this complex social system. This study suggests that the ‘traditional’ approach taken by academic psychiatry to the study of carers, which considers the situation only from the perspective of burden, has

^a GHQ-28 = 28 item General Health Questionnaire refer to Appendix on page 45

constrained our understanding of the characteristics of the carer population and of the caregiver experience. The contemporary context of psychiatric practice and mental health policy demands an enhanced response to carers, especially those of people with serious enduring mental illnesses such as schizophrenia. The

first part of developing this response is to know the characteristics of the local carer population. This study makes a major contribution to this understanding in the New Zealand setting, and provides some additional information about the relationship between carers' adaptation and mental health status.

1. FAMILY CARE IN MENTAL ILLNESS

1.1 Introduction

1.1.1 Informal care: a useful way to think about family care

Providing care and support for a family member may extend beyond what would normally be expected as part of our usual routines, but the term ‘family carer’ does not make this obvious. In the research literature, various terms are used to mean ‘family care’. One such term, ‘informal care’, provides a useful way of thinking about family care by emphasising particular characteristics. Informal care is a term used to distinguish carers who are family and friends from professional carers. Support for family and friends is a usual part of family and community life. However, informal care provided by family members extends beyond the scope of this simple support. People who provide such care readily distinguish it from ordinary family or friendship responsibilities.² Informal care is therefore ‘extraordinary care’ which is outside the boundaries of usual care,³ but is embedded in ordinary relationships as an everyday activity. Thus, informal care is distinct from ‘formal care’, which is care provided by qualified people in a professional capacity,⁴ working within bureaucratically structured organisations.⁵

Most psychiatric research has implicitly constructed family care as informal care: as support given by family members for those who are sick or dependent. Schene provides an explicit example. He described informal care in mental illness as taking place in the context of a “relationship between two adult individuals who are typically related through kinship”,⁶ where one person takes on an unpaid, unanticipated responsibility for the other person, and where the reciprocity usually associated with adult relationships is not present.

Other disciplines have taken other perspectives: in the discipline of sociology, for example, the distinction between formal and informal care was first made some 50 years ago. The perspectives of political economy, social context, gender and the identity and characteristics of the carers have all received attention from the sociological perspective. Such considerations

of informal care emphasise the social and relational basis of the phenomenon and the transactions involved, and have tended to differentiate between the affective and other components of family care, such as ‘caring about’ somebody and ‘caring for’ them.⁷ Self-identity among family carers themselves is important. Once carers consciously regard themselves as such, they become both more demanding of services and more accepting of support,⁸ adopting a position between that of a naive layperson and that of a professional carer.⁹ In addition, there is some evidence that carers who identify as such (whatever definition they use) may be more able to increase their sense of mastery, and to make more space in their lives for their own needs outside the caring role.¹⁰ These adaptations in turn may lead to better health and wellbeing for carers.

Although this is a study of family carers, from a research perspective it was important to adopt an explicit theoretical frame which could support the interpretation of the results. The notion of informal care was appropriate for this. Opinion about the ‘best’ definition of informal care varies to some extent according to discipline. The working definition of informal care used in this study is that the care takes place in a relational context of commitment and attachment, and provides emotional, practical or financial support, accompanied by a feeling of responsibility, by people without a professional background in caregiving. This working definition captures the relational, affective and behavioural aspects of informal care, which is considered to demand “both love and labour, both identity and activity”.¹¹

In this report, the terms ‘family care’ and ‘carer’ have been used in place of ‘informal care’ and ‘informal carer’. This reflects better the relational commitment and attachment in the contemporary New Zealand context of an extended family or whānau, beyond the nuclear or even intergenerational social systems. However, it is important to remember the special characteristics of informal care, as it is this kind of family care that is described in this study. Although participation in the study was open to any carers, 93 of the 96 participants were family members. The terms ‘index consumer’ and ‘consumer’ are used to mean the person with schizophrenia who is the recipient of the family care.

1.1.2 Rationale for this study

This study is important for three reasons. Firstly, the societal context of family care is changing with the significant social and demographic changes that have occurred in the past 25 years. Decisions made by individuals about how to provide care, either in family or extra-family settings, are inevitably shaped by the positions of the individuals within wider social structures. In the face of this, remarkably little is known about those who commence providing family care for people with schizophrenia in the contemporary setting, either overseas or in New Zealand. Secondly, the key tenets of traditional psychiatric interventions with families and other family carers of people with severe chronic mental illness are based on the assumption that burden and coping are the most appropriate constructs to use. However, psychiatry has struggled to develop a meaningful approach to partnership in its

relationship with family carers.¹² Few new interventions have been developed on the basis of a more contemporary theoretical understanding of family carers' experiences – that is, what was once viewed as 'pathology' is now thought of as 'adaptation'. Thirdly, in New Zealand there has been no formal investigation into who provides family care for those with severe and enduring mental illness. New Zealand's unique social fabric, culture, service structure and patterns of clinical practice may influence outcomes for consumers and family carers, meaning the findings of overseas studies may not describe our situation.¹³ If there are differences between patterns of family caring and associated carer factors between New Zealand and other countries, it is important to explore the sociological, cultural and political influences on this pattern, and use the results to inform policy and service development.

2. GENERAL BACKGROUND

2.1 New Zealand literature on carers of people with mental illness – research, inquiries and advocacy

2.1.1 Research

Few quantitative studies of New Zealand informal or family carers of people with mental illness have been published. A report based on a service audit¹⁴ was published in 1990, and a study of carers of people with obsessive-compulsive disorder¹⁵ in 1999. In 2002, Laidlaw et al published a further study describing caregivers' stress in shared and non-shared households.¹⁶

The first study had a number of methodological flaws, which make it difficult to accept the reported findings with any confidence. The second briefly reported on carers' mental and physical health, though these were not among the stated aims and how they were assessed is not described. The Laidlaw study is the most robust. It found that, in a clinic sample, 65 percent of the carers were women, and 68 percent were parents of the consumers. However, few other socio-demographic characteristics were described, and it was not clear how representative the sample was. There were no differences between carers who lived with the index consumer and those who did not in terms of stress levels or mental health status.

In addition to these quantitative studies, there are two New Zealand qualitative studies of those caring for people with schizophrenia.^{17, 18} Wheeler's study described several key themes in family care for mental illness: fear; uncertainty; disruption; powerlessness; and sometimes relief. The second study described the importance of communication, services, relationship, legislation and stigma.¹⁷ These related mainly to carers' experiences of mental health services, which appeared to lay the foundation for the rest of their experience.

2.1.2 Inquiries and advocacy

The lack of New Zealand research means that what is known is still largely drawn from formal inquiries and information-gathering strategies used by advocacy groups and monitoring agencies like the Mental Health Commission. During the 1990s there were a number of inquiries prompted by tragedies involving mental health services.¹⁹ The reports generated by such inquiries and

by monitoring agencies are not research in the strict sense, but they do provide important information. Such reports have highlighted the legislative environment and mental health services themselves as major sources of stress for family carers.¹⁹⁻²² For example, the constraints of the New Zealand Mental Health (Compulsory Assessment and Treatment) Act (1992) impinge on family carers by requiring that treatment be delivered in the least restrictive environment conducive to safe recovery. In addition, many carers perceive New Zealand's strict privacy legislation as working against their need for information about the person they are caring for.²¹ This is a particular problem in relation to information about medication or potential risk,²³ despite the fact that these domains are covered by a permissive code of practice for health practitioners about the handling of information about consumers.²⁴ Official inquiries have also revealed that family carers are generally still not regarded as a critical part of the health-care delivery system. The distribution of services responsive to them remains patchy, and it has been asserted that "in no other sphere of health services are (carers) so completely divorced from dialogue with health professionals".²⁵

2.2 Important methodological issues

2.2.1 Study design

In order to select relevant background studies from the vast international literature on family carers, a classification of studies was developed. Type A studies are population-based, mainly quantitative studies, where care-recipients are loosely defined. They are uncommon because population-based studies are large and expensive, and are not a cost-effective method for sampling carers of people with a low-prevalence illness like schizophrenia. Despite a lack of consistent method and intent, Type A studies do present a picture of informal care as a social process occurring in a substantial number of households, with carers as a socio-demographically diverse group of predominantly women, most commonly with familial ties to the care recipient. However, associations between characteristics of carers – such as whether they share the household with the recipient – are non-uniform. This suggests that such associations may be influenced by broader contextual factors like community attitudes to the role of family carers.

Type B studies use convenience samples, where carers are selected because the care-recipients are known

to the researchers. This study type is the one most commonly found in the psychiatric literature, and it has important limitations and implications. Firstly, findings may have limited external validity with respect to more general populations. The characteristics measured are usually related to a narrow focus of study, although opportunistic collection of broad descriptive data sometimes occurs. Selection of carers is inevitably biased by consumer-selection factors, and often this bias is not accounted for in the interpretation of the findings, which may be over-generalised. The second issue follows from the observation that many assumptions about family carers of people with schizophrenia have developed on the basis of Type B studies designed to answer clinical questions about mental health consumers. This fosters a view that carers' characteristics are the result of consumers' characteristics. Some family carers have rejected this one-dimensional portrayal of their experience.²⁶ The third issue relates to the tendency of psychiatry (and, by extension, the Type B design) to construct family carers' responses to the caring situation as either pathological or not.^{17, 23, 27, 28} Because of these issues, carers themselves have objected to the importance placed on this type of study.

In Type C studies, carers are found through carer-advocacy groups rather than through care-recipients. Type C studies often use samples that are small and again highly selected by particular attributes of carer or consumer.²⁹ Family carers who are engaged with a support or advocacy group are already selected for the characteristics that caused them to join a group in the first place. Nonetheless, Type C studies have been instrumental in prompting psychiatric researchers in particular to adopt a broader perspective, and in supporting attempts to re-orientate mental health services to a more carer-responsive position.

This study is a Type D study: a geographical administrative sample of care-recipients were approached, and carers were contacted through them. In order to do this, a case register of all mental health consumers with the problem of interest who use services in a defined region must be constructed. Because it is possible to obtain a representative sample of highly specified care recipients, study Type D has the potential to yield descriptive findings that can be easily generalised *and* to provide the opportunity to test hypotheses about social and psychological factors

in carers and care-recipients. This design makes it possible to assess the utility of psychological constructs and associated interventions in 'real-world' samples of consumers and family carers.

2.2.2 Family carer ascertainment

Carer ascertainment is a summary phrase that includes the definition, identification and recruitment of carers. These steps vary greatly between studies. Many studies involving family carers do not define carer status or do not indicate how they were defined and identified or recruited, although often this can be inferred. Traditionally, family carers of the mentally ill are defined and identified by mental health professionals³⁰ or by researchers. Other potential sources include clinical records and mental health consumers themselves. Different ascertainment methods may identify different individuals as family carers, and therefore determine the applicability of research findings.

2.3 The characteristics of family carers of people with schizophrenia

2.3.1 Socio-demographic description

Representative demographic and social descriptive data on carers is important for two reasons. Firstly, it has relevance for the enhancement of local clinical and social policies and services.³¹ Secondly, it allows comparisons across countries, cultural groups and services. Differences shown by comparisons can highlight issues that may otherwise not be noticed. In the case of family carers, this is because of the likely influence of local cultural and social factors on who adopts family carer roles, the effects on families and individual carers of the configuration and quality of local mental health services, and higher-order contextual factors such as the adequacy of social welfare benefits and social and cultural expectations.

2.3.2 Mental health of family carers of people with schizophrenia

Psychological health is commonly used as an outcome measure in studies of family carers, as it can be considered a general indicator of their wellbeing. Studies of carers' mental health are of two types: those that use standardised self-report instruments to measure psychological symptoms; and those that use diagnostic assessments to detect cases of mental

illness in carers.^{31, 32} Most studies report on carers' mental health in schizophrenia as an incidental finding rather than as an outcome of interest. No systematic population-based study of the mental health of family carers of schizophrenia was found in the literature search. However, the literature appears to support the 'clinical wisdom' that family carers of people with schizophrenia are at increased risk of common mental disorders, especially at the time of role-change and adjustment. Evidence of variation among carers by socio-demographic and psychological characteristics, and some aspects of the index consumers' characteristics, is inconclusive.

2.3.3 Physical health of family carers of people with schizophrenia

The physical health of family carers of the mentally ill has been studied less frequently than has their mental health.^{12, 33} However, the causal links between stress and physical ill-health are now well established.³⁴ It has been suggested that in situations where the carer is chronically stressed, emotional distress surfaces first, and if the stress persists, it may contribute to deterioration in physical health.³⁵ It is reasonable, therefore, to hypothesise that family carers of those with severe and enduring mental illness would have an increased risk of suffering physical and mental health problems.^{36, 37}

2.3.4 Alcohol use among family carers

Between 20 and 34 percent of family carers in general have been reported as using alcohol to cope with stress.³⁸ There are no research reports of the patterns of alcohol use among family carers of people with schizophrenia. Given that alcohol use is almost ubiquitous in New Zealand society, and that the prevalent social mores condone its use to relieve stress, it is reasonable to hypothesise that family carers may be at higher risk of alcohol abuse than the general population.

2.4. Psychosocial aspects of family care-giving

Attempts to characterise and explain the experience of family caring are the dominating feature of the care-giving literature. The three main strands to this work can be summarised as the concept of burden (its definition, measurement, predictors and subjective

accounts); carers' appraisal and attribution of index consumer problems (and its relationship to burden and coping styles); and coping (coping styles and their prediction of burden).

2.4.1 Experience of care-giving: burden

The study of burden was profoundly shaped by the findings of a landmark study in 1966, in which it was claimed that the burden construct comprised distinct subjective and objective elements.³⁹ *Objective burden* was "any type of abnormal behaviour in the consumer which was likely to be disturbing to others"³⁹ and the observable costs or disruptions to daily life associated with this, whereas *subjective burden* was the carer's own view of the extent to which they were burdened, and his or her emotional reactions to care-giving.³⁹

Until recently, the validity of this dichotomy has been assumed in most studies of family carer burden.⁴⁰⁻⁴⁵ Some common themes have emerged.³³ They include the association of overall (that is, subjective and objective) burden with negative symptoms of schizophrenia, with the family carer's coping style and with poorer social networks. However, more recently some researchers have criticised this reliance on the notion of burden to describe the experience of family carers, arguing for a full exploration of the experience of caring and how it relates to carers' distress.^{35, 36, 46}

2.4.2 Experience of care-giving: contemporary developments

2.4.2.1 Appraisal and attribution

Appraisal and attribution are related to burden. This is because burden comprises two elements: firstly, the disruption to the carer's life and their psychological response to this (their appraisal of the stress and whether it is manageable or overwhelming); and secondly, the attribution of the disruption to the consumer's illness.⁴⁷ Situations of low predictability and high uncertainty, said to be characteristic of the experience of carers of the severely mentally ill,⁴⁸ are more likely to be perceived as outside the control of the stressed individual. Further, the negative symptoms of schizophrenia – which overlap more with normal behaviour than do positive symptoms – have been said to pose more of a burden because family carers are more likely to attribute them to the consumer's character than to the illness.⁴⁹

2.4.2.2 Coping

Coping is another construct relevant to the experience of burden. The coping strategies adopted by family carers are highly varied and are arrived at by trial and error rather than through seeking or receiving information or through clinical or social interventions by care professionals.⁵⁰ Coping effectiveness has been associated with emotional mastery of the situation, as well as cognitive skill and being able to fulfil the needs of the carer through caring and other means.⁵¹ Coping strategies are also context-dependent – they relate to the unpredictable nature of mental illness, the involvement of different mental health services and the cultural context of the consumer-carer relationship.⁵²⁻⁵⁶ Family carers' adaptation and experience can be meaningfully understood only in terms of the lifestage, economic, cultural, social and mental health service context within which it occurs.^{36, 46, 47}

2.5 The context of caring – social support and mental health services

2.5.1 Social support

Social support comprises two relatively well-accepted main elements: structural and functional support.^{57, 58} Structural support relates to the social network of the individual and is essentially the context in which the functional support occurs.⁵⁹⁻⁶¹ Functional support includes the quality of support and the supportive acts themselves.^{60, 62-64}

There is consistent evidence that social support is associated with psychological health and adjustment among family carers, and that the effects of social support are influenced by other contextual factors such as the nature of the care being given, and stigma. The mechanisms of this interaction are poorly understood and progress has been hampered by the persistence of the outdated concepts of burden discussed earlier.

2.5.2 Experience of services: the formal care sector

There is essentially no theoretical basis for the investigation of family carers' satisfaction with formal care, as only two things can be captured: events, such as failure of services to respond in a crisis; and carers' opinion about quality, such as information provided or the attitudes of staff. The interpretation of family

carers' experience of services cannot be divorced from the complexities of the relationship between them and the formal sector. However, it is useful to examine the differences between the types of care, and aspects of the relationship between the two parties, as contextual information.

There are three important differences between formal and family care. Firstly, family care occurs primarily in the context of a personal relationship, whereas formal care occurs in a professional relationship shaped by a professional code of conduct.⁶⁵ Secondly, unlike family care, the labour and skill of formal care are almost always exchanged for a defined monetary reward. Thirdly, family care commonly involves emotional support, direct service provision, liaison with formal services and financial assistance.⁶⁶ Formal carers are more likely to specialise in a restricted range of caring activities.⁶⁷

A number of important aspects of the relationship between formal and family carers of people with mental illness have been described in the literature.^{17, 68} Firstly, the relationship is triangulated – although the direction of care from formal and family caregivers is towards the consumer, the situation is complicated by the needs of family carers themselves. Secondly, the relationships are dynamic because the psychological and adaptive states of the parties are not fixed. Thirdly, there is an imbalance of authority and power between the parties. Family carers are readily relegated to a position where they perceive they have little importance in the relationship with the mental health system.¹⁷ The fourth issue is that mental health professionals too often consider that they know what family carers need, which may not be the case.⁶⁹ The fifth issue relates to the distribution of knowledge: professional carers have a professional knowledge base, but family carers now have access to an unprecedented amount of information via the internet and often believe that their intimate knowledge of the consumer is not sufficiently recognised by professionals. Finally, it is important to acknowledge the increasing complexity of the relationships in which family and professional carers are engaged at the level of health care delivery and policy. The growth of 'consumerism' in health, and especially mental health, has meant that there have been attempts to "incorporate consumers and carers into the ideological apparatus of health care services".⁷⁰

3. METHOD

3.1 Design, setting and sample

This is a descriptive cross-sectional study⁷¹ based on an administrative sample of people who have had schizophrenia for fewer than six years, and their nominated principal family carers.

3.2 Setting and sample

The study took place in the Greater Wellington region. This includes the cities of Wellington, Lower Hutt, Upper Hutt, Porirua, the Kapiti Coast and the Wairarapa. Participants were the principal family carers of all the people in the Greater Wellington region who had been diagnosed with schizophrenia or schizoaffective disorder (without manic episodes) for between one and six years.

3.3 Family carer identification process

Carers were selected in partnership with the consumers, not medical professionals or researchers. This mirrors what is increasingly happening in clinical work, where consumers identify their important support people.⁶⁹

3.4 Sampling frame

A case register of people with schizophrenia was constructed especially for this study, using a procedure adapted from a study of schizophrenia in five European countries.^{72, 73}

The case notes of all 215 consumers on the case register were then inspected to ensure that DSM-IV diagnostic and duration criteria were met. Seventy-six were ineligible for participation in the study, which left 139 potential index consumers in the sampling frame who could be approached for recruitment.

TABLE 1: Data domains in study of family carers

Participants	Level of enquiry	Data domains
Index consumers	Individual descriptors	Socio-demographic data Current symptom severity Current social functioning
Family carers	Social and individual descriptors	Socio-demographic data Physical health status Mental health status Alcohol use Health service use
	Contextual factors	Day-to-day life context of family care Engagement in other caring activities Social support (network) Experience of mental health services Index consumer contact with NGOs and other services
	Individual psychological factors	Knowledge of and attributions about schizophrenia Psychological adaptation Coping strategies Social adaptation Appraisal of caring role Carer involvement with support/advocacy organisations

After the data domains were fixed, each needed to be investigated using study instruments. A mixture of self-report and interviewer-administered measures was used. Each data domain used a separate study instrument. Details are available in the full research report: <http://www.uow.otago.ac.nz/academic/dph/research/socialpsychiatry/publications.html>

3.4.1 Family carer identification

Family carers were identified in partnership with the consumers.

3.5 Recruitment

All 139 eligible consumers were asked by letter to consider taking part in the study and then contacted, by phone or in person, a few days later to request a meeting. Family carers were recruited in a similar way,

although the first point of contact was a telephone call to the number provided by the consumer.

3.6 Interview procedure

Data were gathered via face-to-face interviews for both consumers and family carers. Consumer interviews were up to 90 minutes long and family carer interviews up to 135 minutes. Pairs of index consumer and carer interviews were carried out within a two-week timeframe to minimise the likelihood of a change in consumers' clinical status.

Interview schedules included structured questionnaires and open-ended questions where the data were recorded by the researcher, self-reported data recorded directly onto paper by the participant, and for family carers, a brief interview recorded onto audiotape.

4. RESULTS

4.1 Response rates

Sixteen of the 139 potential index consumers were ineligible for participation because they lacked sufficient fluency in English or because they were too unwell. One hundred and twenty three index consumers were thus eligible to participate. Ninety-nine of the 123 eligible consumers were willing to participate, giving a response rate of 80 percent. Three carers declined to take part. The response rate for carers who were approached was 96.9 percent. There were 96 participating consumer-carer pairs.

4.2 Index consumers

4.2.1 Socio-demographic characteristics

Ethnicity was classified hierarchically, whereby those claiming any Māori ethnicity were classified as Māori; of those who remained, people claiming Pacific Island ethnicity were classified as Pacific Islander; and all others were classified as non-Māori non-Pacific. Māori comprised 26 percent of the sample of consumers, Pacific people 12.5 percent and non-Māori non-Pacific contributed 61.4 percent. Table 2^b shows the sex-wise and whole-group proportions of the socio-demographic characteristics in the index consumer sample.

TABLE 2: Socio-demographic characteristics of index consumers

Characteristic	Women n=27	Men n=69	All n=96
Age	Years		
Median	30	24	25
Civil status	Percent		
Currently married/living as married	18.5	8.7	11.5
Not currently married/living as married	81.5	91.3	88.5
Ethnicity	Percent		
Māori	37.0	21.7	26.0
Non-Māori non-Pacific	59.3	62.3	61.5
Pacific	3.7	15.9	12.5
Education	Percent		
No formal qualification	33.3	36.2	35.4
Secondary school qualification	44.4	37.7	39.6
Trade certificate	18.5	17.4	17.7
University degree	3.7	8.7	7.3
Sources of income	Percent		
None	3.7	0.0	1.0
Any welfare benefit	40.7	44.9	43.8
Wages or self-employed	48.2	52.2	51.0
Other (eg investments/money from family)	7.4	2.9	4.2

^b Italic type in tables indicates a statistically significant difference. Details of statistical testing can be found at: <http://www.uow.otago.ac.nz/academic/dph/research/socialpsychiatry/publications.html>

Weekly hours of work	Percent		
None	66.7	52.2	56.3
1–30	14.8	28.9	25.0
> 30	18.5	18.8	81.5
NZDep96 quintile	Percent		
Deciles 1 & 2 (wealthiest)	14.8	20.3	18.8
3 & 4	22.2	23.2	23.0
5 & 6	25.9	15.9	18.8
7 & 8	7.4	13.0	11.5
9 & 10 (poorest)	29.6	27.5	28.1
Living arrangements	Percent		
Alone	7.5	4.3	5.3
With others	92.5	95.7	94.7

4.2.2 Consumers' ethnicity

The distribution of index consumers' socio-demographic characteristics by ethnicity is shown in Table 3.

TABLE 3: Socio-demographic characteristics of index consumers by ethnicity

Characteristic	Māori n=25	Non-Māori Non-Pacific n=60	Pacific n=11
Median Age	Years		
	25.0	25.0	24.5
Civil status	Percent		
Currently married/living as married	8.0	13.3	9.1
Not currently married/living as married	92.0	86.7	90.9
Highest qualification	Percent		
No formal qualification	48.0	25.0	63.6
Secondary school	36.0	45.0	18.2
Trade/diploma	16.0	18.3	18.2
University	-	11.7	-
Sources of income	Percent		
Benefit, none, other	60.0	38.3	63.6
Wages or self-employed	40.0	61.7	36.4

Weekly hours of work	Percent		
None	64.0	50.0	72.7
1–30	28.0	25.0	18.2
> 30	8.0	25.0	9.1
Living arrangements	Percent		
Alone	12.0	1.7	9.1
With others	88.0	98.3	90.9
NZDep96 quintiles ^b	Percent		
<i>Deciles 1&2 (wealthiest)</i>	4.0	26.6	9.1
<i>3 & 4</i>	24.0	25.0	9.1
<i>5 & 6</i>	20.0	20.0	9.1
<i>7 & 8</i>	8.0	8.3	36.4
<i>9 & 10 (poorest)</i>	44.0	20.0	36.4

4.3 Family carers

4.3.1 Socio-demographic characteristics of family carers

The family carers were a socio-economically diverse group. The proportion of Māori was similar to that for index consumers, and men were a significant minority. Female carers had a wider age range, with all nine carers aged 60 or older being women. Two-thirds had regular jobs they had worked in during the week before being interviewed, with the women having significantly fewer paid work hours per week than the men. Approximately half the carers were married or living as married, and these carers had significantly lower deprivation scores than those who were not married or living as married. Māori carers were significantly over-represented among those with lower educational attainment, and had significantly higher deprivation scores than non-Māori non-Pacific carers, although this was not translated into any differences in income bands between Māori and non-Māori non-Pacific carers.

4.3.1.1 Parents compared to non-parents

Sixty-three percent of the family carers were parents of the index consumer. Of the parent carers, 81.9 percent were mothers. Spouses or partners made up 10.4 percent of the carers, children or siblings

represented 14 percent and 12.5 percent were friends or other relatives. Of the Māori carers, 69.5 percent were parents of the consumers, compared to 50 percent of the Pacific carers and 63 percent of the non-Māori non-Pacific carers.

4.3.2 Self-reported physical and mental health status of family carers

Family carers' health status was characterised in four ways. The GHQ-28 was used as a measure of general mental health and the AUDIT indicated the extent of alcohol-related problems. Physical health was assessed using the somatic subscale of the GHQ-28 and the single self-rated health question.

A significant minority (33 percent) of family carers had poor current mental health as shown by the GHQ-28, and 14.6 percent had problematic drinking on the AUDIT scale. Of all carers 14.6 percent rated their overall health as poor. There was a borderline significant difference between proportions of women and men over the threshold for enduring mental health problems, with fewer men than expected meeting the criterion. Older carers were significantly less likely to have problematic drinking scores on the AUDIT. There were no associations between ethnicity and health-status measures. However, carers with poor self-rated health had significantly higher median NZDep96PC1 scores (ie lived in more deprived small neighbourhood areas)

^b Italic type in tables indicates a statistically significant difference. Details of statistical testing can be found at: <http://www.uow.otago.ac.nz/academic/dph/research/socialpsychiatry/publications.html>

than those with good self-rated health. There were no significant differences between parent and non-parent carers for the main health-outcome measures GHQ-28 and self-rated health, but significantly fewer parents scored over the threshold for problem drinking. In terms of mental health problems of longer duration, parents were significantly more likely than non-parent carers to have a persistent mental health problem. There was no difference between the proportions of parent and non-parent carers who rated their overall health as good: these were 82 percent and 91.4 percent respectively.

4.3.3 Self-reported use of health services by family carers

In addition to questions about their health, family carers answered questions about their visits to primary care and specialist doctors and alternative health practitioners, and nights in hospital in the previous 12 months. Visits relating to pregnancy and childbirth were excluded. Carers were asked about whether they had ever had treatment of any kind for a mental health problem themselves.

More than three-quarters (77.1 percent) of carers had visited their GP in the previous year and almost 30 percent had had four or more visits. In the previous year, 29.1 percent had visited a specialist for a non-pregnancy reason and 8.3 percent had visited a specialist four or more times. Almost one-third of family carers reported having made high use of the GP in the year prior to the survey, and increasing socio-economic deprivation was associated with a higher number of GP consultations. Māori ethnicity was associated with a lower rate of seeking help for mental health problems. Close to one-third (32.3 percent) of family carers reported having had treatment for a mental health problem themselves at some time in the past.

4.3.4 Household and day-to-day life context of family care

Family carers were asked a series of general questions on their day-to-day experience of the caring role. This included household configuration, extent of contact with the index consumer, travel required for carer and consumer to see each other, other caring, paid work experience, volunteering, other known sources of support for the consumer and their own social support (social interaction).

Male carers were more likely to live alone, and Māori and Pacific Island carers more commonly lived in extended family arrangements. Half of all carers shared the household with the index consumer. Family carers who did not live with consumers had significantly higher NZDep scores. More deprived carers had more contact hours with index consumers. Parents did not report spending significantly more time in face-to-face contact with the consumers. A significantly lower proportion of non-Māori non-Pacific family carers provided childcare in their household, compared to Māori carers, and those who did so had significantly higher deprivation scores. Twenty-eight carers (29.2 percent) had provided such childcare. Of the Pacific Island carers, 62.5 percent had provided childcare, compared to 43.5 percent of Māori and only 20 percent of non-Māori non-Pacific.

4.3.4.1 Household configuration

Details of the household configurations are shown in Tables 4 and 5.^c The category definitions are:

- A. Family carer lives alone.
- B. 'Nuclear family': these households consisted of carers living with any combination of their own children, and/or their own spouse or partner. If there was also a lodger living with the family, the nuclear family classification was retained.
- C. 'Extended family': family carer lives with their own parent, plus or minus any other people; or lives with any other combination of family members other than the carer's children. If a lodger is present, this combination is still classified as an extended family.
- D. 'Flating': family carer lives with lodger or flatmates and no others.

These groupings were then used to create a second household classification in which the presence of the index consumer in the carer's household unit was accounted for. It can be seen that if male carers lived with index consumers it was more likely to be in an extended family context, and that Māori and Pacific Island carers more commonly lived in extended family households. About half of all carers shared a household with the index consumer.

^c Statistical testing was not done as cell sizes were too small.

TABLE 4: Associations of carer’s household configuration with carer’s sex

Characteristic	Women	Men	All carers
Carer’s household unit	Percent		
Alone	2.7	22.7	7.3
Nuclear family	75.7	54.6	70.8
Extended family	14.9	18.2	15.6
Flatting	6.8	4.6	6.3
Carer/patient household unit	Percent		
Separate	50.0	45.5	48.9
Together nuclear	43.2	40.9	42.7
Together extended	6.8	13.6	8.3

TABLE 5: Associations of carer’s household configuration with carer’s ethnicity

Characteristic	Māori	Non-Māori Non-Pacific	Pacific
Carer’s household unit	Percent		
Alone	8.7	7.7	0.0
Nuclear family	47.8	80.0	62.5
Extended family	30.4	7.7	37.5
Flatting	13.0	4.6	0.0
Carer/patient household unit	Percent		
Separate	52.2	47.7	50.0
Together nuclear	30.4	49.2	25.0
Together extended	17.4	3.1	25.0

4.3.4.2 Work, volunteering and other care roles

As expected, carers who worked fewer hours per week had higher deprivation scores. Over 60 percent of male carers worked more than 40 hours per week in paid work (Table 6). Almost one-third of family carers had performed some voluntary activity in the previous month, and this was evenly distributed between the

sexes and ethnic groups and by deprivation score. Women carers were significantly more likely to routinely provide family care for a person other than the index consumer, most commonly an elderly person. Almost all carers knew of at least one other person providing support for the index consumer, most commonly a family member.

TABLE 6: Association of carer's weekly hours worked with socio-demographic characteristics

Characteristic	Hours			Significance			
	0 – 20	21– 40	> 40	Test	df	Value	p
Carer's sex	Percent						
Female	47.3	37.8	14.9				
Male	22.7	45.5	31.8	χ^2	2	5.31	0.07
Carer's ethnicity	Percent						
Māori	36.8	47.4	26.0				
Non-Māori non-Pacific	33.9	43.6	22.6	* χ^2	2	0.41	0.81
Pacific	62.5	25.0	12.5				
Carer's deprivation	Median						
NZDep96PC1 scores	1025.0	991	919	Kruskall			
(95% CI)	957,1060	952,1027	895,1006	Wallis	2	7.04	0.03

* Comparison between Māori and non-Māori non-Pacific.

Whether carers had engaged in any helping activity for anyone outside their household without pay in the four weeks before being interviewed, was investigated. Such activities could include childcare, housework or gardening, shopping, coaching, administration or meetings and fundraising. Twenty-eight of the carers

had been engaged in such voluntary activity. Table 7 shows how this activity was distributed by sex, ethnicity and deprivation. Of the men, 48 percent had done voluntary work outside the household in the preceding four weeks, whereas only 24 percent of the women had.

TABLE 7: Association of carer's volunteering with socio-demographic characteristics

Characteristic	Volunteered	No volunteering
Carer's sex	Percent	
Female	62.5	81.9
Male	37.5	18.1
Carer's ethnicity	Percent	
Māori	25.0	20.8
Non-Māori non-Pacific	63.9	79.2
Pacific	11.1	0.0
Carer deprivation		
NZDep96PC1 scores	994.0	970.5
(95% CI)	957,1022	933,1040

Carers were also asked how many people (other than the index consumer) they routinely provided care or support for. Women were more likely than men to report this, with 45.8 percent of the carers indicating that they did. The most common kind of additional care was care of an elderly person, followed by care for mental health issues. There was no association between providing care for additional people and family carers' ethnicity (Māori vs non-Māori non-Pacific) or carers' deprivation according to the NZDepPC1 score.

4.3.4.3 Other sources of support for index consumers

Carers could name up to five people who they knew also provided support to the index consumer; all carers responded to this question.

Table 8: Other people known to carer for providing support

Number of people named	Relationship category: frequency mentioned			
	Any other person*	Family	Other*	Friend
0	3	14	89	55
1	21	27	2	27
2	30	30	5	9
3	14	14	-	2
4	12	6	-	3
5	16	5	-	-
Cumulative frequency	96	96	96	96

*'Any other person' means any person other than themselves; 'other' included mental health service staff and church members.

4.3.5 Mental health service experience and NGO support context

Overall satisfaction with mental health services was high, with 94.7 percent of carers reporting being at least moderately satisfied according to the dichotomised overall satisfaction scores. For more than half of carers of both sexes, the degree of their involvement was a source of concern. High proportions of all three ethnic groups reported satisfaction with the skills and behaviours of the mental health service staff. However, almost 90 percent of Pacific Island carers were not satisfied with the information they

received. Lack of satisfaction with carers' involvement was not associated with carers' ethnicity. There was no significant association between carers' deprivation and satisfaction in any dimension.

4.3.5.1 Parents compared to non-parents

Twice as many non-parents as parents (42.9 percent vs 21.3 percent) rated access to services as poor – a significant difference. Also significant was the fact that 19.7 percent of parents and 54.3 percent of non-parents rated service efficacy as good. Only 25.7 percent of non-parent carers rated carer involvement as good, compared to 45.9 percent of parent carers; this difference was on the margin of significance.

4.3.5.2 Other services and supports available to family carers

Family carers were asked what they knew of organisations and services that provided support and care to the index consumer. Carers could name any number of options ranging from the GP through secondary mental health services to NGO and government-sector support agencies. All carers could name at least one agency or service that was involved with the index consumer. Community mental health teams and GPs were the most common, being named by 84.4 percent and 32.3 percent of carers respectively. Inpatient units and supported accommodation were the next most commonly mentioned, at 19.8 percent and 17 percent. Fewer than 10 percent of carers named drop-in centres, work programmes, churches or spiritual organisations, consumer advocacy or respite or day services.

Forty-six family carers responded to an open question to elicit information on what additional services they believed would benefit the index consumer. Responses were grouped into themes, with availability, type and configuration of services being mentioned most commonly (30.4 percent). Specific issues about services included the need for more intensive treatment services tailored for the individual, early intervention services for all ages, readily accessible respite for carers, inpatient and day services with a therapeutic community ethos, more available subspecialty services outside main centres and specialist inpatient facilities for women. Over a quarter of carers wanted intensive rehabilitation (28.2 percent), and 21.7 percent wanted occupational counselling and placement. One-fifth (19.6 percent) wanted continuing support at home but

without pressure to improve. Over half (53 percent) of carers did not see a need for additional services.

4.3.6 Carers' knowledge of schizophrenia

Seventy-six carers attributed the consumer's problems to a 'mental illness'. Family carers were asked either to name the illness they thought the index consumer had, or to give their alternative explanation for the index consumer's difficulties. Table 9 shows the frequency of responses in each category.

Table 9: Family carer explanations for index consumer's illness

Carer believes consumer has mental illness	% of 76	n
Carer's name for illness		
Schizophrenia/psychosis	72.4	55
Depression/anxiety/bipolar	5.3	4
Drug-induced	1.3	1
Not named/don't know	11.8	9
Lay term, eg breakdown	5.3	4
Other*	3.9	3
Carer does not believe consumer has mental illness	% of 20	n
Carer's explanations**		
Laziness/apathy/low motivation	15	3
Lonely/isolated	10	2
Brainwashed/possessed	10	2
Emotional/family problems	5	1
Low self-esteem	15	3
Drug-related	20	4
Recovered/recovering	15	3
Anxious/depressed	10	2

* 'Head injury'; 'low self-esteem'; 'low motivation'.

** Multiple options permitted.

A list of 28 potential 'problem' symptoms and behaviours (from the family carers' perspective) had been compiled on the basis of findings from the qualitative study. Family carers considered both negative and positive symptoms and behaviours lying

within the negative symptom domain to be among the most worrying. Of 28 problem symptoms and behaviours, carers nominated 'talks of suicide' and 'episodes of self-harm' in sixth and seventh place in terms of frequency. Eighteen and 19 carers respectively nominated episodes of self-harm and talk of suicide as problems. Of these, seven were concerned about both behaviours.

Among parents, 38 percent of those who mentioned 'lacks energy and drive' as a major problem attributed it to illness, compared to non-parents, of whom 64 percent did so. However, 28 percent of parents attributed it to drugs or alcohol, compared to none of the non-parent carers. Similar proportions of these groups attributed it to medication (parents, 17 percent; non-parents, 14 percent). 'Hearing voices' was attributed to illness by 70 percent of parents and 91 percent of non-parents who nominated it. Of parents who mentioned 'talks of suicide', 92 percent attributed it to the illness, along with 83 percent of non-parent carers. However, when it came to self-harm episodes, 42 percent of parents invoked illness and 16 percent personality, whereas 83 percent of non-parent carers attributed it to illness, and none to personality. Avoiding social contact was attributed to illness by 80 percent of parents and 28 percent of non-parents, who more commonly attributed it to personality (43 percent) or family, social or cultural causes (29 percent).

When carers were grouped into those sharing and those not sharing a household with the index consumer, key aspects of the pattern were that 31 percent of those who did share attributed 'lacks energy and drive' to drugs or alcohol, compared to none of those with separate households. Those who shared a household rated illness less frequently as a cause (31 percent) than those who did not share (71 percent). Hearing voices was attributed to illness by 79 percent of those sharing a household and the same proportion of those not doing so. Avoiding social contact was attributed to illness by 78 percent of carers sharing a household and 54 percent of carers not doing so. Of the latter, 31 percent attributed this to personality, whereas none of those sharing a household did so. All carers who shared a household with the index consumer and who were concerned about talk of suicide attributed this to the illness, compared with 80 percent of those not sharing the household, of whom the remaining 20 percent attributed it to personality.

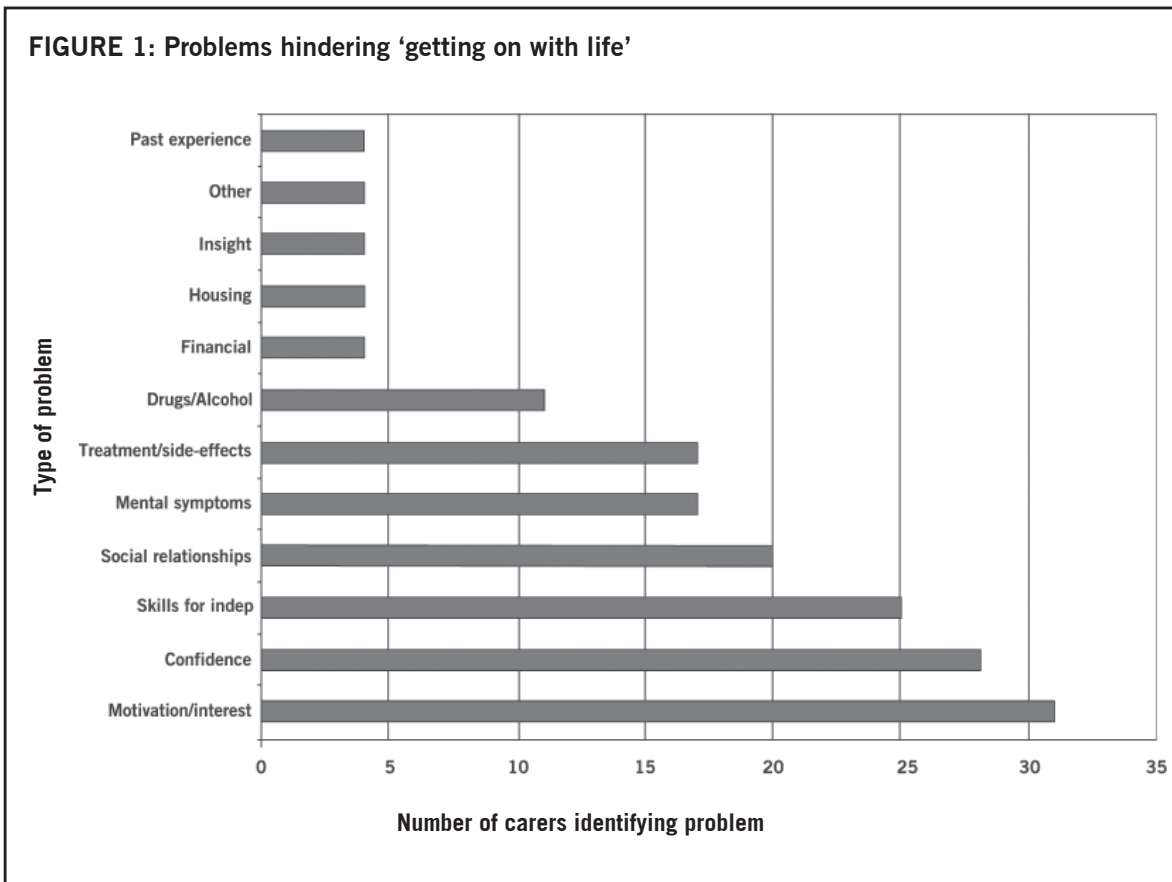
There was variation across the three ethnicity groupings for the importance of illness as a cause of 'lacks energy and drive', with 58 percent of Māori carers who named it attributing it to illness, compared to 43 percent of non-Māori non-Pacific carers, and 25 percent of Pacific carers. None of the Pacific Island carers attributed 'avoids social contact' to illness; rather, it was attributed equally to personality and cultural, social or family factors. Among Māori carers who were concerned about extent of social contact, 43 percent attributed this to illness; for non-Māori non-Pacific the proportion was 85 percent. Hearing voices was attributed to illness by 86 percent of Māori carers who were concerned about it, by 50 percent of Pacific carers and 79 percent of non-Māori non-Pacific carers. Pacific Island carers did not attribute any of their 10 most concerning problems to drugs or alcohol. Talk of suicide was attributed to illness by 80 percent of Māori and 93 percent of non-Māori non-Pacific who identified it as a problem; however, it did not rank among the top 10 problems

of concern for Pacific Island carers. Episodes of self-harm were attributed equally to personality and drug or alcohol problems by Māori carers, equally to illness and medication by Pacific Island carers and to illness by 64 percent of non-Māori non-Pacific carers.

4.3.6.1 Barriers to recovery

Family carers were asked to cite up to three problems they considered stopped the index consumer from 'getting on with life'. Only three carers claimed there were no issues preventing the index consumer from getting on with life, and only four named issues across more than three themes. Thirty-six mentioned one theme, 31 mentioned two and 18 mentioned three.

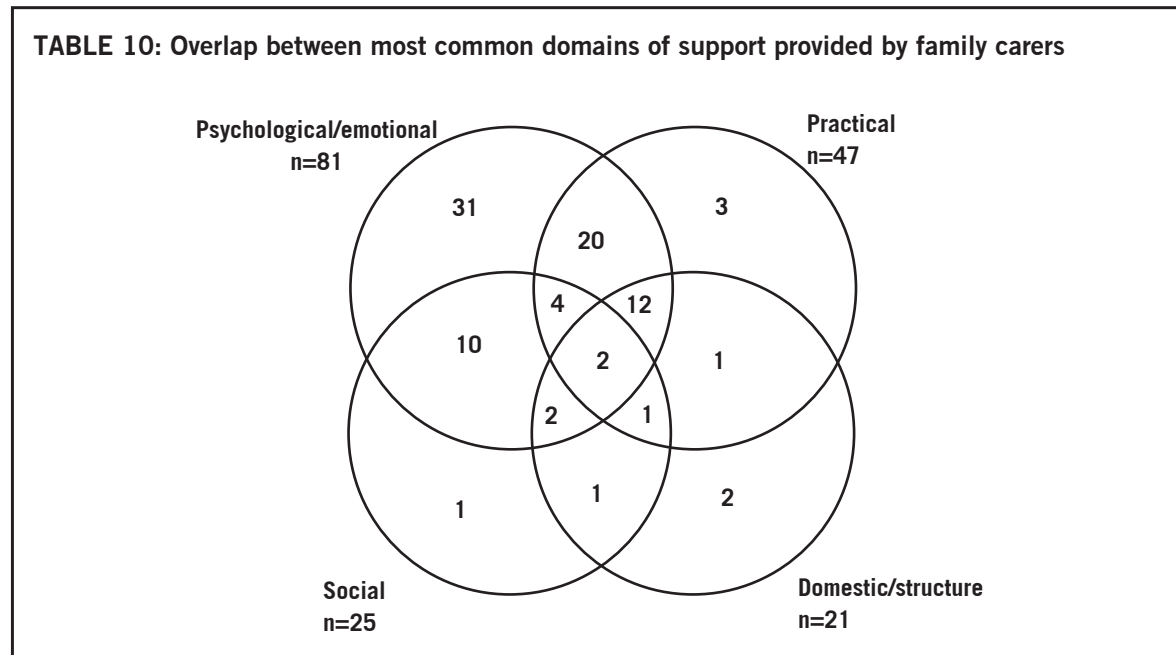
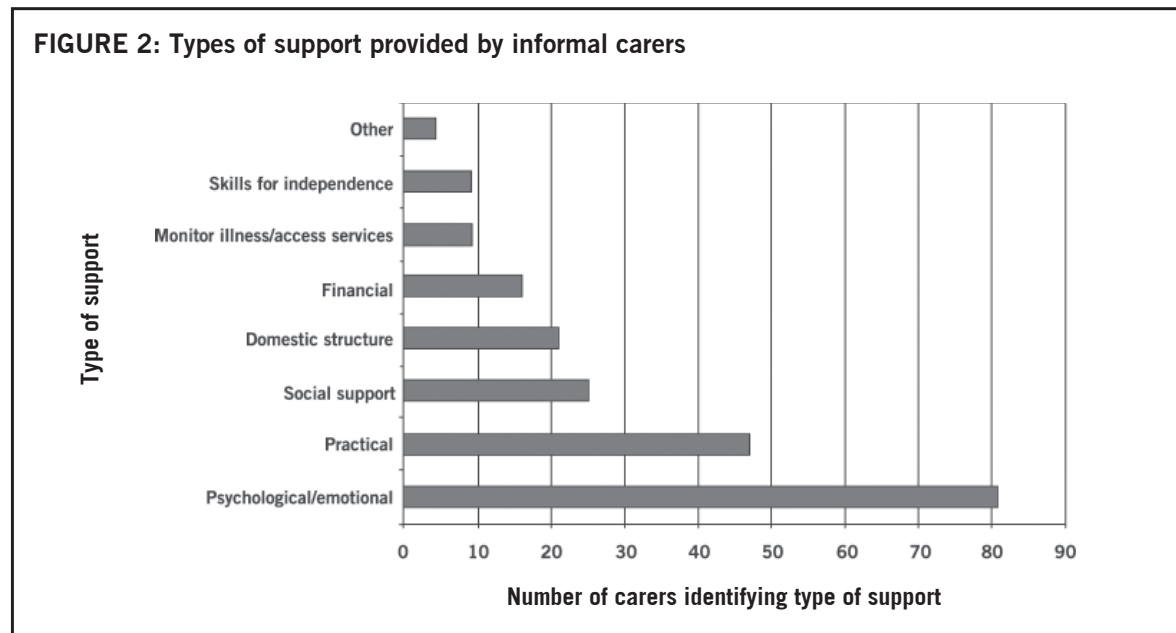
The majority of problems were broadly illness-related, but lack of confidence was noted by a significant number of carers. Problems in the social relationships sphere included social withdrawal and limited capacity to be active in social relationships.



4.3.7 Domains of support provided by informal carers

Figure 2 shows the frequencies of each support theme as mentioned by carers. Illness-monitoring was not prominent, whereas the emotional and

social relationship was of key importance. All carers mentioned at least one support role, with 25 percent naming one, 35 percent naming two, 33 percent naming three and six percent mentioning four or more.



4.3.8 Patterns of psychological and social adaptation among carers

Overall, 70 percent of the sample reported adequate attachment relationships. Nearly three-quarters (74 percent) of female carers reported adequate attachment relationships compared to 55 percent of male carers; this difference approaches statistical significance. Of the GHQ-28 recent-onset cases (traditional scoring), 59 percent reported inadequate social attachment, compared to 16 percent of those who were not recent-onset GHQ-28 cases. Regarding availability of attachment, 68 percent of the whole sample considered the availability of attachment adequate; 40.9 percent of the male family carers reported inadequate availability of attachment, compared to only 12.2 percent of the women – a significant difference.

Enduring and recent-onset psychological caseness (ie reaching the threshold to be regarded as a case) according to the GHQ were both associated with carers rating their attachment relationships as inadequate. Men were more likely than women to consider availability of attachment lacking.

Positive experiences of caregiving for the carers were not associated with any demographic descriptors, such as sex, ethnicity, education level, deprivation, relationship to the consumer, consumer functioning or weekly contact hours with the consumer. However, positive experiences were associated with the availability of attachment and interaction in social support.

Carers who reported inadequate social interaction had higher negative ECI scores, as did carers who reached the cGHQ threshold for caseness for enduring psychological problems.

Regarding coping styles, faith or hope was associated with three socio-economic variables, with people from less advantaged social positions having higher scores. Carers who shared a household with the index consumer had higher scores for all coping subscales, including faith and hope, but this was not statistically significant. Only the contextual measures of social support had any association with coping styles. These were, interestingly, those most likely to be associated

with relational transactions. All WOC domains were positively correlated with both ECI subscales.

There was less of a pattern in the relationship between health-status indicators and WOC, although higher emotional coping scores were associated with overall health and both recent-onset and enduring mental health problem 'case' status.

TABLE 11: Family carers' rating of their importance to index consumers

	%	(n)
Not at all important	-	-
Somewhat important	5.2	5
Reasonably important	17.7	17
Very important	77	74

Carers' appraisal of their importance to the consumers was shown to be independent of markers of their own psychological health and other characteristics, as shown by the following tests of association.

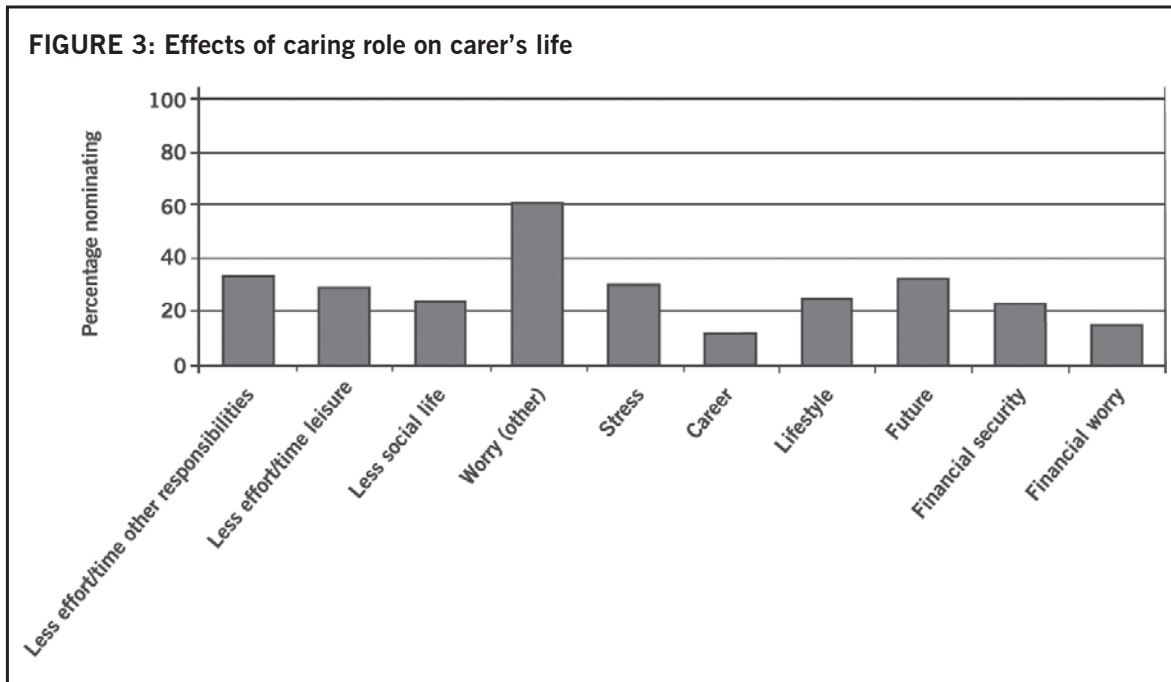
Most carers considered their role greatly important to the index consumer. This was independent of other carer variables. Caring for additional care-recipients was weakly associated with higher positive ECI scores. Carers working at jobs for more than 30 hours per week were more likely to have had fewer visits to specialists and GPs in the past year. Two-thirds of carers considered themselves the 'last port of call' for the index consumer.

Carers generally held the view that they themselves reaped benefits from filling the carer role – particularly those who saw the family-care role as 'natural'. There was a suggestion that because of Māori social and familial ties, Māori experience caring more as an integral part of life rather than as something to be adjusted to, although Māori carers were also more likely to report their overall experience as a carer as burdensome. All the carers had been able to name at least one positive aspect of the caring role, and 14.6 percent of carers did not mention a negative aspect.

4.3.8.1 Impact on carers' lives

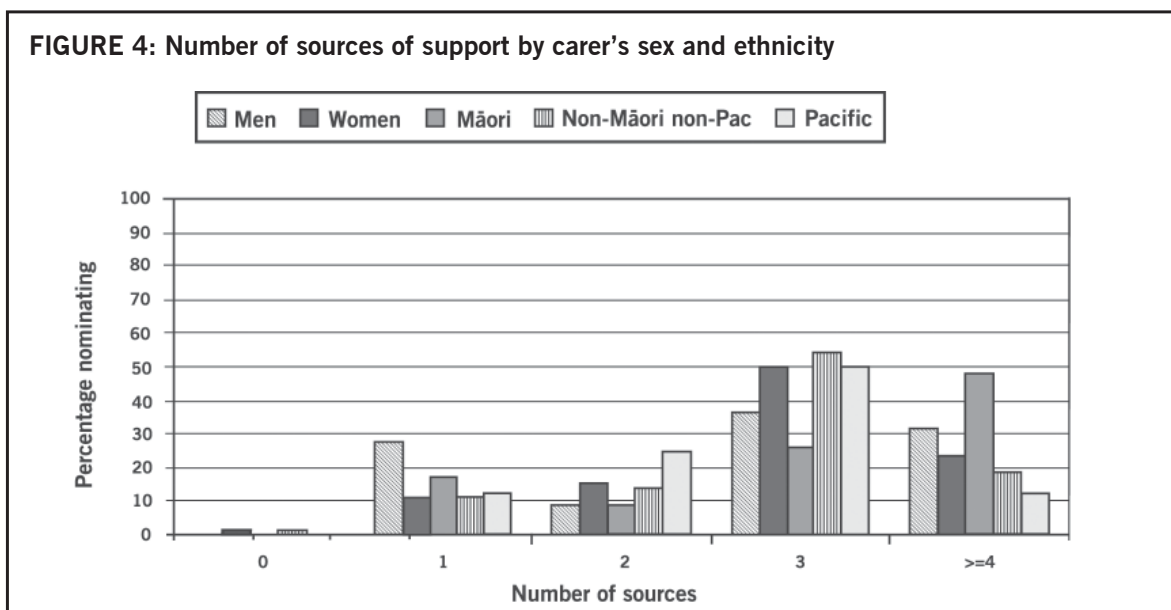
Carers were also asked to select from a list of 10 ways in which assuming a caring role could affect their ability to

live their own lives. These categories were also obtained from the qualitative study. Figure 3 shows the frequencies with which carers endorsed the 10 categories.



Carers were asked what their own main source of support was, and about their involvement in support or advocacy organisations. Figure 4 shows the

proportions of carers, grouped by sex and ethnicity, that claimed each number of sources of support.

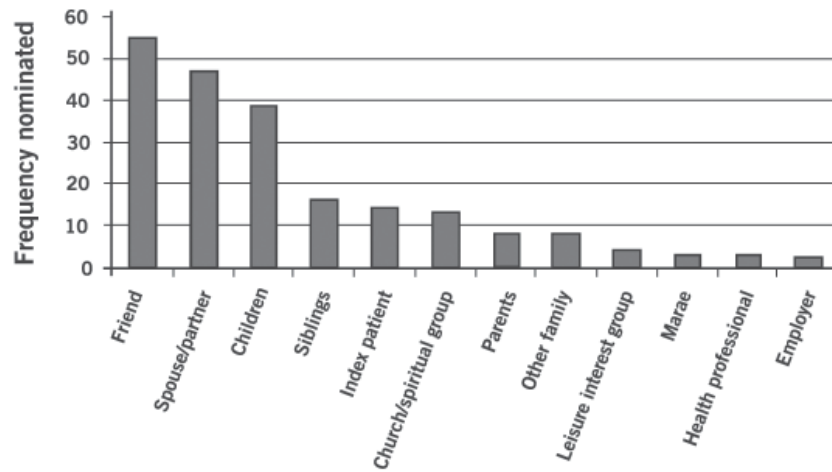


Māori family carers had more sources of support to draw on, with 74 percent having three or more. Twenty-seven percent of male carers had only one source of support, and 36 percent had two or fewer. Among women, 26 percent had two or fewer supports and 50 percent had three. For groups other than Māori, three was the most frequent number of supports.

Carers obtained support from a variety of sources (Figure 5), with a higher proportion of Māori carers

having more sources of support than non-Māori non-Pacific carers. One-third of the men had two or fewer sources of support, compared to one-quarter of the women. A quarter of carers were involved with support or advocacy organisations, and they were more likely to have higher cGHQ scores and more negative experiences of caring. Three-quarters of carers considered they did not get a ‘fair deal’ from society in respect of their role, with half considering that the Government should shoulder more responsibility.

FIGURE 5: Carers’ main source of support



4.3.8.2 Carers’ involvement with support or advocacy organisations

This study examined carers’ involvement with support or advocacy organisations by asking them to name any organisations with which they were involved. Only 21 (21.8 percent) of all carers were involved with organisations that might provide information and support. The most frequently mentioned was SF (now Supporting Families, formerly Schizophrenia Fellowship), named 16 times. The other organisations were Pablo’s Art Workshop, Victim Support, Early Intervention Service and Urban Vision, each named once. A consistent pattern emerged – those involved with support organisations had significantly higher scores for persisting mental health problems and negative experiences of care-

giving. Further analysis revealed no association between satisfaction with mental health services and engagement with support or advocacy organisations.

Carers were also asked for their opinion about where the primary responsibility for caregiving should lie – with family, community or government. Ninety-two carers responded, with 34 believing the family should be responsible, 12 believing it should be the community and 46 saying it should be a government responsibility.

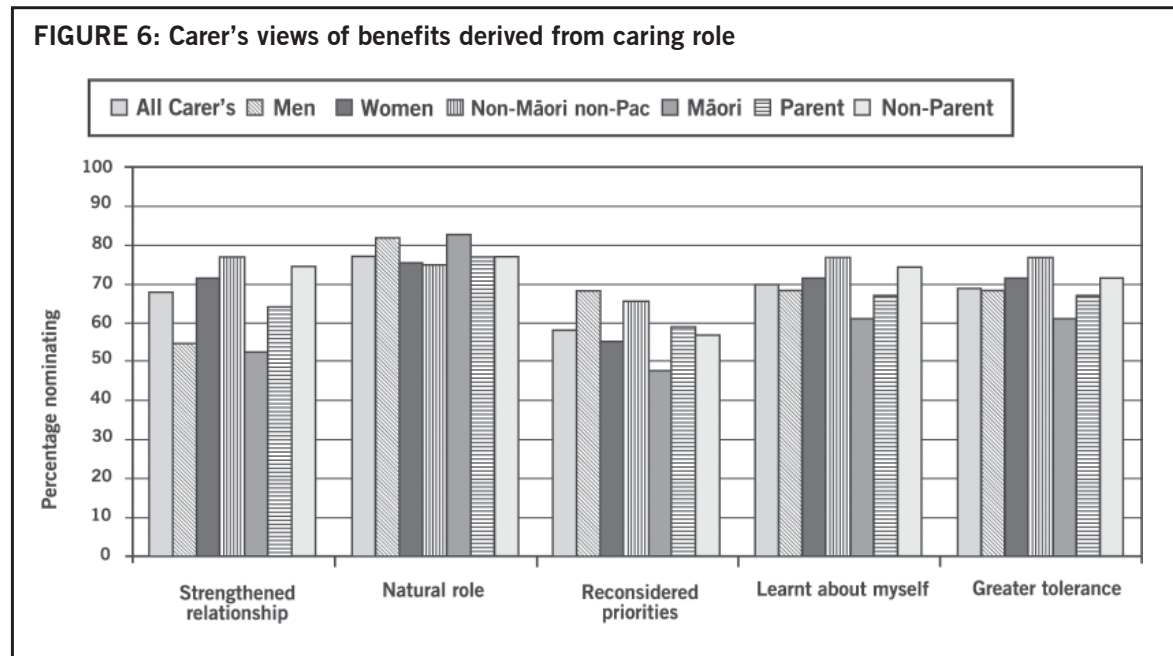
Only 22 carers believed that they got a ‘fair deal’ in society. These carers did not differ from those who considered that carers do not get a fair deal in terms of index consumer’s total social functioning scores, sex or ethnicity, whether the carer was the index consumer’s parent or service satisfaction scores.

Among the 92 respondents to the question “If all else fails, who could (index consumer) turn to for help?” 61 nominated themselves, and 18 the mental health service. The remainder nominated another informal carer, supported accommodation provider and ‘other’ which included parents, church and general practitioners.

4.3.9 The role of positive experiences of caring

As indicated in the literature review and the investigator’s own work, family carers value positive

aspects of the caring role, but these are commonly paid little attention by researchers. A reduced series of regression analyses was carried out to provide some information about the relationship between positive experiences as measured by the ECI positive subscale, and cGHQ score. The observation that positive experiences of caregiving have a different kind of relationship to carers’ enduring mental health status is important (Figure 6), and is explored further in Section 5.



5. DISCUSSION

5.1 Review and evaluation of key findings

5.1.1 The socio-demographic characteristics of family carers

5.1.1.1 Effects of index consumer and carer sampling and recruitment on external validity

The Type D (administrative prevalence sampling) design used in this study relies on the identification of the relevant population suffering from a mental illness or disability, and then the recruitment of their family carers. This 'double sampling' leads to methodological issues that could result in sample-selection bias.

5.1.1.2 Sampling and recruitment of index consumers

Sample-selection bias among index consumers in the present study is most likely to have favoured the inclusion of people with more severe illnesses but without prominent suspicion, and who are not socially excluded because of language barriers or suffering from complex syndromes with schizophrenia-like features. Māori may be minimally over-represented.

5.1.1.3 Sampling and recruitment of carers

The present sample is likely to be highly representative of the carers associated with the index consumers recruited, although this group may have a small bias towards those with more severe illness.

5.1.1.4 Selection of family carers: match between clinicians and index consumers

In just under 50 percent of cases there was disagreement between the index consumers and a clinician who knew them well, about the identity of the key family carer. However, it is unlikely that mental health professionals would have nominated people who had no supportive role. This disagreement therefore supports the claim that the idea of a single key carer is questionable.¹²

5.1.2 Self-reported physical and mental health status of family carers

The international literature has generally supported an association of family caring for people with schizophrenia with poorer mental health in carers relative to local community norms. This study tested this proposition with a robust study design in the

New Zealand setting, though it could not provide evidence of an excess of mental illness among carers – only a likely excess of common psychological symptoms. Carers' self-ratings of their overall general health were in line with those of the general population, though the consequences of common symptoms may depend on their context (the pre-existing psychological vulnerability and social context of the carer) as well as their extent.^{74, 75}

This study also raises an interesting hypothesis about the relevance of socio-cultural context to the experience of family caregiving. Participating Māori carers appeared to be no more likely to suffer psychological symptoms than non-Māori non-Pacific carers, though statistics from the general population predict higher levels of those symptoms. Given that Māori and non-Māori non-Pacific family carers differed in several other respects, including a higher proportion of Māori carers living in extended family households, and that there was a trend for Māori carers to more commonly consider family care as a natural role, it may be that the psychological impact of family care varies according to social and cultural values and practices.

Finally, this study has provided the first report of alcohol use among this specific group of carers, and has observed that they do not use alcohol to a hazardous extent.

5.1.3 Family carers' use of health services

Most family carers had visited their GP in the previous year, in a proportion congruent with that shown in the New Zealand Health Survey.⁷⁶ However, this study found a strong association between socio-economic deprivation and higher frequency of GP visits – in distinct contrast to the New Zealand Health Survey, which did not find an association between carer deprivation and visits to the GP. It is possible to hypothesise that this discrepancy reflects a tendency of poorer carers to respond more urgently to their own health needs.

The clear association between GP visits and poor self-rated health contrasted with the lack of association between enduring mental health symptoms and a history of seeking help for them. This is consistent with other New Zealand evidence observing that, for a variety of reasons, people who need mental health treatment do not always seek it.^{77, 78} Attitudes to mental illness are known to be influenced by a complex array of factors.⁷⁹⁻⁸¹ Might carers of people with schizophrenia be expected to have greater mental health literacy,

or conversely might they be more sceptical about the effectiveness of treatments for mental health problems because of their experience? Reluctance to acknowledge psychological distress or to seek help for it could also reflect a stigma, or a fear of what the carer has come to believe about mental illness through their experiences of caring for it.⁸²

5.1.4 The day-to-day life context of family care

5.1.4.1 Household situation

The day-to-day life context of family carers was diverse. Just over half the carers lived in the same household as the index consumer. Although statistical testing was not done, a pattern was apparent in which a higher proportion of Māori and Pacific Island family carers lived in extended family groups, which more commonly included the index consumer. Carer and index consumer having separate households was associated with higher deprivation scores for the family carers. Few carers lived alone but most who did were men. Carers with higher deprivation scores were more likely to have fewer weekly hours of face-to-face contact with the index consumer, and there was a trend towards Māori family carers having fewer such hours than carers of other ethnicities.

5.1.4.2 Care of children

Another issue recognised in the qualitative study was that of additional caring for children in the carer's own household, the concern being that carers had experienced difficulty finding immediate short-term care for children when they needed to respond to an emergency with the index consumer. The present study found that just over one-quarter of carers also cared for children in their own household, and that this was significantly more common among Māori carers. The significant association between deprivation of area of residence and care of children may reflect the over-representation of Māori and Pacific Island carers in poorer neighbourhoods.

5.1.4.3 Activity outside the home

Almost one-fifth of the family carers – predominantly males – worked more than 40 hours per week, potentially causing them significant strain. However, post-hoc analyses revealed that those in the study who worked very long hours did not have poorer mental health status or more negative experiences of care-

giving. Schofield et al speculated that paid employment is associated with additional stress for carers when there is strain or conflict between work and caring roles.⁸³ In this study the ability of some carers to work very long hours may indicate that there is little or no such conflict for those particular carers, and it may indicate that lack of such conflict may mitigate the effects of any additional strain associated with working long hours.

5.1.4.4 Social integration as context

Social integration – the contextual element of social support – was not associated with carers' age, sex, ethnicity or deprivation score, or with parental status. Social networks are important mediators of the effect of the caregiving role on coping style and the caregiving experience. For instance, relatives with poor social networks more commonly use emotion-focused coping,^d and those with supportive networks are more likely to use problem-focused strategies⁵⁶ – although this may be determined by cultural context. However, social networks themselves are shaped by context, and they also vary by type of index consumer illness.

This study found that family carers in New Zealand are a heterogeneous group, commonly managing multiple roles and demands in multiple contexts. This heterogeneity is likely to be an accurate reflection of the main family carers for people with schizophrenia in contemporary New Zealand.

5.1.5 Experience of mental health services and NGO support

Although levels of satisfaction with mental health services were high overall, there was cause for concern in two areas. There was a trend towards Māori and Pacific Island carers being less satisfied with the information they received, and for carers with degree-level education being more satisfied. More than half of carers were dissatisfied with the extent to which mental health services involved them. The trend in the present study may reflect an underlying inequality of access to services or aspects of services for index consumers, as well as inequality for carers. These suggestive results are, however, consistent with the assertion by Māori and Pacific Island mental health consumers and their families that mainstream mental health services do not cater well for their needs.

^d People using emotion-focused coping tend to invest more in noticing and managing their emotional responses, whereas problem-focused coping is more about identifying what needs to be done to improve the situation and putting things in place so this can happen.

When asked open questions about additional services that would be helpful, carers gave varied responses, emphasising a desire for re-orientation of service to the needs of index consumers as seen by carers. Interestingly, carers suggested that there was value in services that provided support without too much pressure on the service consumer to improve. This suggests that some carers (and consumers) may experience the therapeutic enthusiasm encouraged by mental health professionals as stressful or naïve.⁸⁴

5.1.5.1 Key carer groups

Parents as carers

When parents are the key family carers of people with schizophrenia, the relationship between carers and mental health professionals tends to have particular characteristics, as does the carers' adaptation. This is because of the nature of the relationship between parent and offspring, and the important psychosocial developmental tasks contained in this relationship during late teens and early adulthood, when onset of schizophrenia is most common.

In this study, there were few differences between parent and non-parent carers in terms of socio-demographic and health status. Parents were older, and, perhaps as a result, tended to be more affluent and drank less alcohol. Despite being more likely to share their households with index consumers, they did not spend more time per week with index consumers. However, parents were more dissatisfied with the efficacy of, access to and engagement with services. This pattern was not seen in any other subgroup of carers. It may have been due to higher parental expectations of services, and the degree of parental investment in improvement or recovery. It is also possible that parents are more persistent in seeking information.

Māori as carers

The over-representation of Māori in the sample has already been addressed. All Māori carers were nominated by Māori index consumers. Māori carers were economically poorer than non-Māori non-Pacific carers, and tended towards lower educational attainment, living alone and being on a social welfare benefit. The current clinical state of Māori index consumers was also different: they had more positive symptoms and higher general psychopathology scores.

There was disagreement about the identity of the key family carer in almost one-third of cases, and this was associated with index consumers being of Māori or Pacific Island ethnicity. Although not investigated further in this study, this observation supports claims made by Māori and Pacific Island people that mainstream mental health service staff have a poor understanding of the importance and functioning of family and wider social groups. It is also consistent with accumulating anecdotal and substantive evidence that health and social systems respond differently to Māori with mental illness.⁸⁵⁻⁸⁸

Māori carers had the same health status as non-Māori non-Pacific on all measures. This is surprising for two reasons. Firstly, given the association between poorer self-rated health and socio-economic deprivation in this sample, the expectation would be that as Māori ethnicity was strongly associated with deprivation, there would be at least a statistical trend towards overall self-rated health-status inequality. Secondly, it is known that Māori have poorer objective overall health status than non-Māori non-Pacific people.⁸⁹ However, these results are consistent with the New Zealand Mental Health Survey results for Māori, where once socio-economic status, education, income and age were accounted for, there was no significant difference in the 12-month prevalence of common mental disorders.⁹⁰ Māori carers reported less use of health services. They were less likely to have sought help for mental health problems, and there was a trend towards Māori having fewer GP visits in the previous year.

Regarding the context of care, it appeared that a meaningfully higher proportion of Māori than non-Māori non-Pacific carers lived in extended family situations that included the index consumer, and fewer lived with the index consumer in nuclear family units. On the basis of the observation that Māori carers tended to spend fewer hours per week with index consumers, it could be hypothesised that Māori might have a better overall experience of caregiving as a result of sharing the caring role.

Men as carers

Systematic comparisons of men and women as carers for people with schizophrenia are scarce. The majority of studies report the proportions of men and women participating, then go on to control for sex in analyses without reporting associations with sex in detail. The

men in the study were as involved in the caring process as the women, and had a similar or slightly greater extent of additional social-role commitments when longer paid working hours were taken into account. Differences in satisfaction with services may reflect services being less engaged with male carers. For example, it is plausible that because the men worked longer hours, it was more difficult for them to meet with professional care staff, although the difference could also be attributed to differences in expectations. These results can only be seen as suggestive, and differences between male and female carers of people with schizophrenia in New Zealand require further investigation. However, if these differences are real, then there may be a need for a re-orientation of the thinking of clinicians and guidance to services, as male carers are a substantial minority.

5.1.6 Family carers' knowledge of schizophrenia; attributions about symptoms, behaviours and recovery; and views of their own role

5.1.6.1 Knowledge and attributions

Carers' overall knowledge of the index consumers' illness was congruent with the psychiatric model of schizophrenia.⁹¹ This claim is supported by the carers' frequent attribution of index consumers' common behaviours and symptoms to illness, and the common recognition that the index consumers' problems in 'getting on with life' were illness-related. Carers appreciated that the illness-related problems they were most concerned about were not readily within the index consumers' control. Although rankings of symptoms and behaviours of concern were virtually identical across subgroups of carers, attributions of cause varied. This indicates that different subgroups of carers may have different perspectives on the illness, which in turn may have implications for interactions with the index consumer and the adjustment of the carer. For instance, stark contrasts were found in relation to concerns about talking of suicide and episodes of self-harm, where parents more commonly attributed self-harm to personality than did non-parent carers, who never did so.

Three key points arise from these observations. Firstly, the observation that parents were more likely to attribute self-harm to personality demonstrates the importance of a focus on self-harm and suicide risk when working with family carers of people with

schizophrenia, given that self-harm is known to predict an increased risk of suicide.⁹² Parental response to self-harm could act to increase or decrease the risk of future self-harm or actual suicide.

Secondly, these observations remind us how important it is that clinicians ask carers about their beliefs and assumptions about symptoms and behaviours. Having explored the carer's beliefs and attributions, the choice then is whether to work with the carer to validate his or her views by making further enquiry of the index consumer; to validate their experience (which is not the same as agreeing with their appraisal); or to work towards educating the carer. This demands a flexible approach to working with carers, particularly as simply educating people does not guarantee a change in their attitude or behaviour.

Finally, the probable patterning of carers' attributions suggests that clinicians should be alert to possible variation in attributions of symptoms and behaviours on the basis of carer subgroup, should these findings be replicated in the New Zealand setting. Particularly important is the possibility that Pacific Island carers may be more reluctant to acknowledge suicide as a potential problem, which is consistent with what is understood about current cultural practice about speaking of mental illness and suicide.⁹³

5.1.6.2 Role perception

Unexpectedly, this study found that carers did not rate illness-monitoring particularly high among their roles. The few carers who mentioned illness-monitoring did not mention any other roles for themselves. A possible explanation is that carers use their knowledge of consumers' current clinical state as 'currency' in their relationship with clinicians, as they assume or hope that clinicians will value such information, rather than giving it particular importance in terms of their own relationship with the consumer. In contrast, carers clearly emphasised more 'ordinary' aspects of their care and support roles, supporting the suggestion that it is important for clinicians to be as responsive to these aspects of the caring role, and what they mean for carers, as to the illness-management aspects.

5.1.7 Psychological and social adaptation

5.1.7.1 Social support – attachment

Two-thirds of the sample had adequate attachment relationships and the same proportion rated the

availability to them of attachment as adequate. Availability of attachment was not associated with demographic or health-status measures.

5.1.7.2 Experience of caregiving

More positive experiences of caregiving were associated with availability of interaction and attachment, and with provision of family care for someone other than the index consumer. Interestingly, positive experiences were not associated with self-appraisal of importance to the index consumer, or with any aspect of satisfaction with services.

Negative experiences of caregiving had a broader pattern of associations. They were associated with inadequate social interaction, enduring common mental disorder 'case' status, carers' involvement in support or advocacy organisations and with satisfaction with access to services and types of intervention.

These findings raise two points. Firstly, some of the observed associations appear to be counter-intuitive. The finding that carers with more negative experiences were more satisfied with access to services is difficult to explain. It could be a chance finding or alternatively it could possibly mean that these carers are receiving more attention from services as clinicians are responding to what they interpret as greater need for support. It could also suggest that carers with especially adverse experiences were particularly grateful for any intervention or support, and they appreciated even limited success.

Secondly, the experience of caregiving appears to be distributed not according to socio-demographic characteristics of carers, but according to various contextual, social and psychological factors.

5.1.7.3 Mastery

Mastery was associated with a number of socio-demographic variables. Age and educational attainment may confer a greater sense of being able to influence one's life. However, parents had significantly lower mastery scores than non-parent carers, despite the fact that they were older. This is consistent with reports of a high degree of helplessness among parental carers of people with schizophrenia.^{94, 95} Higher scores on all four social support subscales were associated with a greater sense of mastery, as were better mental health and general self-rated health.

5.1.7.4 Ways of coping

The high degree of correlation between the four WOC subscales and total WOC score indicates that carers who used a number of coping methods within one domain also used more coping methods from other domains. Such people have a more adaptive style of coping. The pattern of distribution also suggests that carers who experience more general life adversity may use faith- or hope-based coping strategies more than other carers. Further, there is a stronger suggestion that carers who live with index consumers call on a wider range of strategies than carers with a different living arrangement. Thus, it appears that the immediate caring context does influence carers' coping responses and experience. The use of emotional and detached coping styles was both associated with perceived unavailability of social support and with inadequate interaction. Emotional coping was the style most consistently associated with health-status measures, with poorer health being associated with more use of this style.

5.1.7.5 Caregivers' appraisal of relationship

Carers' appraisal of their importance to the index consumer was considered in the study to be an aspect of their psychological adaptation. The majority of carers thought their role very important, and they were highly committed to the caring role. Commitment to caring has not previously been investigated, although it had been suggested that it may mediate the effect of actual caregiving activities on caregivers' reported experience.⁹⁶ This could not be investigated further in the present study as too few carers in the sample had a low degree of commitment.

All carers could name at least one way that being a carer had enhanced their relationship with the index consumer, the most common being that it was a natural role to fulfil and the awareness of this enhanced their experience of the relationship. Worry was the only negative effect to be endorsed as frequently as any of the positive effects.

Taken together, these findings refute the notion that it is either accurate or sufficient to construct the experience of a family carer as entirely negative and burdensome. It is also inaccurate to assume that index consumers could not also support the family carer, which was the case for 14 percent of carers.

That carers who provided care for people other than the index consumer had higher positive ECI scores may simply mean that those who have positive experiences of caring are more likely to take this role on for others. The group of carers who had paid work for longer than 30 hours per week and cared for a person other than the index consumer were of particular interest, because it could be hypothesised that they might be more likely to have negative experiences or experience poorer health, but this was not the case.

5.1.7.6 Key carer groups

Parents as carers

Comparison between parents and non-parents revealed a striking finding that contrasts with much of the research in this area. In this study, parents did not differ in terms of any markers of adaptation or response to their situation, including items such as being the 'last port of call' for support. This finding suggests that it may be less important for services and clinicians to differentiate between parent and non-parent carers in respect of carers' behavioural adaptation and response to their situation. Although this contrasts with the earlier suggestion that there may be some utility in differentiating between these carer groups on the basis of their knowledge of and attributions and attitudes to the illness, together these observations and inferences signal the importance of getting to know carers as individuals rather than as types.

Māori as carers

There were only isolated associations of adaptation with the carers' ethnicity, in contrast to the clearer pattern of differences in socio-economic status and health-service use described earlier. Māori carers scored higher on the faith and hope dimension of WOC, and had a different pattern of attitudinal responses to the caring role, such as more frequently endorsing caring as a 'natural role', and least frequently having 'reconsidered their priorities' as a result, all of which may be consistent with cultural practices and values. Three-quarters of Māori carers had three or more sources of personal support. However, they were more likely to report their overall experience as being more burdensome than rewarding. This was not a strong association and may be a chance finding. Alternatively, there may be culture-specific complexities in responses to family caring which the present study cannot explain further.⁵⁶

Men as carers

The pattern of social support differed between men and women. Men reported less available attachment and a trend towards less adequate attachment. Men tended to have fewer sources of support and to be less frequently engaged with advocacy organisations. The finding of the present study may indicate that male carers are at higher risk of coping less well than female carers.

These observations are an interesting counterpoint to a prevailing popular view that women and men experience family caring differently, with women experiencing more loss, sacrifice and burden.⁹⁷ Although carers were predominantly women in the present sample, men were a substantial minority. They appeared to experience caring in ways barely distinguishable from those of women, and may be at risk of negative consequences, such as an elevated risk of recent-onset psychological symptoms, as discussed earlier.

5.1.8 Strengths and limitations of this study

This is the only in-depth study of family carers of people with schizophrenia in New Zealand, and its external validity is likely to be high within the New Zealand context. External validity beyond the New Zealand setting may be more limited, but all such studies are context-specific.

The restriction to index consumers with an illness duration of one to six years reduces the ability to generalise to all carers of people with schizophrenia. It could be argued that singling out one carer for each consumer is an unnatural constraint on consideration of what will clearly be a social network around the index consumer. This study used some instruments which had not been formally validated in the New Zealand population, particularly Māori, such as the VSSS, the Mastery Scale and the WOC questionnaire. The findings based on these measures may therefore be of lesser validity than the others. Finally, the analyses of data on Māori carers are limited – the small numbers of Māori meant that it was only possible to compare Māori with people of other ethnicities, and this type of analysis imposes theoretical constraints,⁹⁸ as well as failing to meet the commitments of Te Tiriti o Waitangi.

5.2 Implications of the study for theory, clinical practice, policy and research

Integration of the findings of this study with existing research has broad implications for theory, clinical practice, policy and research. These will be discussed in turn.

5.2.1 Implications for theory: a perspective from 'critical psychiatry'

Since the project began, the importance of family carers in clinical and social systems of care for people with mental illness has been recognised better and articulated more clearly in the policy documents of Royal Colleges, mental health service providers and public sector agencies such as Ministries of Health.^{84, 99, 100}

In New Zealand, however, this acknowledgement remains at the level of non-specific principles, suggested in the use of phrases such as 'engaging with family/whānau', and facilitating their 'participation' or 'working in partnership'. What this means in addition to sound clinical practice is not clear. What it means for the direction of research in this area of psychiatry is also not clear. Clearly articulated philosophies or theoretical frameworks, and mechanisms for the application of the principles in day-to-day service organisation and clinical practice, are still relatively undeveloped or unavailable.

In their book *Postpsychiatry*, which articulates the critical psychiatry perspective, Bracken and Thomas suggest that there has been a divergence between the direction and interests of mainstream academic psychiatry and the needs of contemporary clinical practitioners, so that at the points where the divide is widest, they may not be considering the same problems.¹⁰¹ The issue of family carers may be an example of a point where this divergence has occurred.

The extensive examination of the psychiatric literature undertaken in this study revealed that academic psychiatry articulates no explicit *theoretical frameworks* regarding the relationship between psychiatry and family carers. Put another way, the underlying assumptions about the relationship between the discipline of psychiatry and one of its key stakeholder communities are not readily available for scrutiny, to be contested or to be developed: rather, they are discernible only by inference from certain quite

particular perspectives found in the literature. Examples of these perspectives have been outlined in this report: people with schizophrenia are experienced primarily as a burden in caregiving relationships; family carers can influence the course of the illness; and they can be demanding of clinicians and services.¹⁰² One implication of the increasing sophistication of the cognitive models of caregiving, such as the stress-appraisal-coping model, is that it is possible for psychiatrists to intervene with carers to shape the course of these relationships. The intention of such intervention would be to reduce the suffering of consumers and reduce the burden on family carers. Why, then, would a theoretical framework enhance progress?

From a 'postpsychiatry' or critical psychiatry perspective, theory development is necessary for several reasons. Firstly, without a model or theory, while many research questions can be asked and answered, and hypotheses tested in studies such as this, there is no overarching framework to give the results meaning, to which they can contribute and from which more insightful questions can develop. Without such a framework, academics will continue to generate more of the same kinds of studies. Secondly, the discipline of developing and articulating a theory may expose underlying values that practitioners in the discipline (and others) may wish to challenge. Thirdly, the work of developing a theory or theories would be likely to prompt the development of a discourse on the relationship between family carers and the discipline of psychiatry, which could be informed by contributions from other disciplines such as sociology, anthropology or philosophy.

This thinking was prompted by the demonstration by the present study, and others, that family caring for people with schizophrenia cannot be adequately understood unless the wider context, and its interaction with the characteristics of carers, such as their age, sex and culture, is taken into account. This, in turn, arose from the observation of heterogeneity in the sample of carers, an observation also made by others in respect of other samples.^{83, 103} However, in the absence of theory, there is no systematic approach to accounting for contextual variation to ensure appropriate policy, service provision, clinical practice and research responses to the contemporary situation of family carers. The changing relationship between the discipline of psychiatry and mental health consumers

is a critical aspect of the context, which has not been investigated in this report.

Psychiatric research activity has focused on specific theories and hypothesis-testing within disciplinary boundaries, a number of which have been described in this study. In order to bring these elements together with perspectives from other disciplines, a higher-order theory or model is necessary: that is, what is called a 'mid-range theory', which is "informed by empirical generalisation but ... (provides) ... a broader and more abstract context that applies to a range of situations".¹⁰⁴

As an example, McGuire et al articulated the theoretical frameworks, implied and overt, that psychiatry has used to understand and investigate the therapeutic relationship between psychiatrists and consumers.¹⁰⁵ They concluded by advocating stronger links between psychiatry and psychological and sociological research.

It was not the aim of this study to develop a theory or model of family care for psychiatry. However, some tentative suggestions of matters that may be relevant can be made on the basis of the literature and the present study. For instance, a typology of carers for people with schizophrenia may be useful for policy development, following the example of Finch and Groves, who described a typology of carers for the elderly which included primary home carers, supporters and institutional carers.¹⁰⁶ This influenced the development of rational policies on community care of the elderly in the United Kingdom. In an alternative approach, Twigg characterised family carers of the elderly in three ways: carers as resources, carers as co-workers and carers as co-clients, which gave health professionals a structured way to think about carers they had contact with.¹⁰⁷ The diversity of carers in the present sample suggests that a typology of carers for people with schizophrenia could inform the development of a coherent approach to policy and service provision.

A useful theory might give some attention to the distinction between formal and family care in the case of schizophrenia, which may be less clear than the same distinction in models used in care of the elderly, where early work was done. An example of an area where this distinction might be important is that of attention to early warning signs of deterioration in mental state. Formal and family carers, and people with mental illnesses alike, agree that the recognition

and interpretation of early warning signs are critical to reducing the frequency and seriousness of relapse of severe mental illness. Mental health professionals have received lengthy and intensive training in order to do this, which 'legitimises' their knowledge and practice of these skills. Many family carers also have these skills, however, but they may not be able to generalise them, and they usually do not organise the information in the same way as mental health professionals do. Importantly, they often prioritise the information differently from professionals, and not only are they more sensitive to subtle changes in mental state, but they also give these subtle changes more weight in their decision-making about whether to act on the information.¹⁰⁸ Essentially, though, the task is the same – noticing changes in mental state – and clinicians frequently ask family carers to carry it out. Yet, for the most part, the knowledge generated by the family carer carries less weight than that of the professional and is valued less, possibly because of interpretation in the light of other presumed or actual information, such as how stressed the family carer is at the time.¹⁰⁸ The picture is further complicated by the suggestion from the present study that, although family carers use this role to legitimise their demands on the mental health system, it is not particularly prominent in their appraisal of their caring roles in relation to the consumer. These issues raise an important question about how professionals and family carers can function effectively alongside each other in relation to the mental health consumer. Management of the complexities might be easier if there were a theoretical framework within which researchers and clinicians could think about this aspect of their work.

In summary, a useful theory or model would accommodate the findings of this study and other recent literature from a range of disciplines in a parsimonious way. Key notions include the contribution of people with schizophrenia to their social systems, the heterogeneity of the family carers, the variation in the family carer experience (between carers and in that of individual carers over time) and the importance of context both narrow and broad,¹¹⁵ as the caring experience is both context-dependent and context-specific. By moving towards developing such a theory, psychiatry will demonstrate that in its relationship with family carers, it has adopted a more "mature approach that embraces complexity", as espoused recently by Kendler.¹¹⁶

5.2.2 Implications for clinical practice

In a sense, this study has limited direct implications for the clinical practice of psychiatry, precisely because psychiatry has not articulated any working model of itself in relation to family care to which work such as this can contribute. However, the contrast between the key findings of this and other recent studies on the one hand, and ‘received psychiatric wisdom’ on the other, does provide food for thought in the clinical situation regarding the need for individual practitioners to adopt a thoughtful stance towards the carers they meet. Discussions of carers’ issues are relatively undeveloped in major psychiatric textbooks – surprisingly, for example, in *Families and Mental Disorders: From burden to empowerment*¹¹⁷ and *Schizophrenia*.¹¹⁸ This contrasts with the findings of the present study and other work over the past 10 years, where the importance of a systemic context-sensitive approach to thinking about carers and their index consumers is highlighted, caregiving is viewed as including positive aspects and a key characteristic of carers is diversity. The development of a reflective capacity in relation to the dominant psychiatric discourse about family care would increase the pace at which attitudes to carers are changing.¹¹⁹

It is well-known that psycho-educational interventions for carers of people with schizophrenia have poor uptake in mental health services, despite evidence for their efficacy in improving the course of illness among index consumers, and their inclusion in clinical practice guidelines,¹²⁰ and there is accumulating evidence that it is difficult to retain carers in such programmes.¹²¹ Why are psychiatrists not strongly advocating these interventions? Although it may be due in part to practical difficulties with resourcing and implementation,¹²² it may also reflect the “deficiencies in our understanding” which Falloon suggested have “stalled progress in the refinement of these strategies”.¹²¹ The results of this study suggest that carers might benefit from interventions to increase their self-efficacy or from attending to their own needs rather than attending mainly to the index consumers’ illness; better mental health in carers may ameliorate some effects of expressed emotion on index consumers. The suggestion in this present study that social inequality may be reflected in carers’ satisfaction with services deserves consideration in every consultation. Finally, the carers’ heterogeneity, and the extent of disagreement between professionals

and index consumers about the identity of the key carer in the present sample, suggest that mental health professionals should consider including all carers in interventions and support initiatives for any particular consumer – not only parents or those living with the index consumer.

Despite their desire to be regarded as lay members of the health care team,^{123–126} family carers have not been treated as such by clinicians. Mental health services in New Zealand have made important advances in re-orientation toward the expressed needs of mental health consumers. Carers present a more challenging group, but some lessons could be learnt from the ways practice frameworks such as the ‘Recovery Model’ have shaped contemporary engagement of clinicians with consumers.¹⁰¹

A recent article on family carers of the elderly with mental health needs provides an example of refinement of the clinical approach to carers, in which partnership with carers perceived on a continuum within a “finely nuanced multilevel and dynamic context”.¹²⁷ At one end services and clinicians focus only on the consumer, and at the other there is a “true partnership in which the consumer, the carer and the services are truly working together towards shared goals”.¹²⁷ Positioning the consumer and carer together at the centre of clinical focus is considered to be the gold standard, and various systemic contingencies operate to move the interaction along the continuum at different times. The development of clinical frameworks such as this, which could be used to derive formulations of family carer systems in relation to individual consumers, could improve the day-to-day work of mental health clinicians.

Finally, in terms of implications for clinical practice, the findings of studies such as this need also to be married with policy and planning for New Zealand mental health services over the next decade, which requires a re-orientation of services towards primary-care provision and even community development. Future developments of approaches to working alongside family carers of those with mental illnesses, including schizophrenia, will need to account for this. Primary-care practitioners and psychiatrists view mental disorders from different perspectives, and there is potential for novel approaches to working with family carers of the mentally ill to emerge from a primary-care paradigm.

Despite the fact that family carers have been organised and lobbying for support since the 1970s, we are still searching for new models of co-operation and collaboration between them and formal service providers, including psychiatrists. The relationship must be redefined,^{30, 128} and for clinicians, a practical first step might be to begin working alongside local mental health service family advisors, who are employed by 11 of the 21 District Health Boards,²⁵ at about 50 percent of the recommended level.¹²⁴

5.3 What does this study mean for family carers of people with schizophrenia in New Zealand?

5.3.1 Implications for research

Given that family caregiving is a dynamic and developmental process, it is to be hoped that longitudinal studies will be invested in, in order to understand the complexities of the unfolding family carer experience, and that such studies will pay more attention to cultural and contextual issues. It is also to be hoped that future psychiatric research on family carers of people with schizophrenia makes better use of cross-disciplinary working, qualitative methods to inform understanding rather than explanation, and a broader focus extending beyond index consumers' prognoses. Particular attention could usefully be paid to factors that predict positive experiences of caregiving, to the relevance of the index consumer's psychiatric diagnosis to the understanding of caregiving, to why some potential caregivers do not take up the role, to the health behaviours of carers, to the contributions of index consumers to their social systems and to the functioning of social networks of carers formed around each index consumer.

Furthermore, this study strongly suggests a need for the independent investigation of several topics: family care among Māori, given the differences observed between Māori and non-Māori non-Pacific carers and associated index consumers; assertions about the validity of some constructs commonly used in family care research (such as burden); and the increased acceptance of the importance of context in relation to family care. Such a research programme would comprise studies that are sufficiently powered to test hypotheses rigorously, as well as thoughtfully designed qualitative studies.

5.3.2 Implications for policy and practice

The key to getting effective policy attention for family carers of people with schizophrenia will be securing the acceptance of a need for local innovation in response to local data; there is accumulating evidence, supported by this study, that the experience and capacity of family carers is largely determined by cultural and local contextual factors. In terms of local data, New Zealand lacks the evidence framework provided, for example, by the United Kingdom Census,¹¹⁹ but the next Time-Use Survey being commissioned by Statistics New Zealand provides an excellent opportunity to focus on family care from a perspective other than the economic one, which was the framework for the last survey.

While additional research is desirable, it is worth noting that even this more traditional cross-sectional study has revealed important information about family care in the context of severe mental illness in New Zealand. Although family carers are vulnerable to psychological distress, they are also, in general, resilient, and capable of noticing the positive features of their situations as well as the challenges. In our clinical work we are encouraged to notice the strengths of people suffering from mental disorders, and not to focus on deficits. There is an important lesson here for our thinking about our patients' families. In our work with them we can either undermine or enhance their resilience and capacity to find new ways of healthy family functioning in the face of change. Local guidance on working with families¹²⁹ includes strategies to support enhancement of family functioning by clinicians, but in busy clinical services they may not get a lot of traction, because service pressures work against the need to restore sensitivity to thinking about family systems, and introduce a non-judgemental awareness of the variety of family forms in contemporary New Zealand.

In 2008 the New Zealand *Carers' Strategy and Action Plan* set out a high-level government commitment to and vision for the development of support for informal carers in New Zealand.¹³⁰ It does not focus on carers of people with mental illness, but many of its principles are applicable to this group. Family carers of people with illnesses like schizophrenia will be able to use this document to support their specific claims on resources and services. Mental health professionals can also use it to argue for a greater and more nuanced focus on family carers in professional practice and service provision. This will be all the more important in the next few years of economic hardship for New Zealanders.

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APPENDIX: COMMONLY USED ABBREVIATIONS

AUDIT	Alcohol Use Disorders Identification Test
cGHQ	GHQ-28 score ascertained using 'chronic' scoring method
CI	Confidence Interval
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, version IV
ECI	Experience of Care-giving Inventory
GHQ-28	28 item General Health Questionnaire
NGO	Non-Governmental Organisation
nMnP	Non-Māori non-Pacific
NZDep96	New Zealand Deprivation Index 1996
NZDep96PC1	First principal component score of NZDep96 index
PC1	First principal component
SC	Sunny Collings
SES	Socio-Economic Status
SF	Supporting Families (formerly Schizophrenia Fellowship)
SFS	Social Functioning Scale
VSSS-32	32 item carer Verona Service Satisfaction Scale
WHO	World Health Organisation
WOC	Ways of Coping questionnaire

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