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**EXPLORING THE RELATIONSHIP BETWEEN MENTAL
HEALTH PROFESSIONALS AND FAMILY
CAREGIVERS, WHO CARE FOR 18-30 YEAR OLDS,
DIAGNOSED WITH A SERIOUS MENTAL ILLNESS, IN
TWO DISTRICT HEALTH BOARD AREAS OF NZ.**

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ABSTRACT

Despite compelling evidence of benefits for mentally ill family members when there is a working relationship between mental health professionals (MHPs) and family caregivers (FCGs), international and New Zealand literature has continued to reveal that the relationship is fraught with difficulties. Although there have been a number of international studies exploring the relationship from the family caregiver perspective there have been few international studies and no New Zealand studies conducted that have explored the MHPs perspective of this relationship. Therefore the purpose of this research was to explore this relationship from the FCG's perspective *and* the MHP's perspective.

In-depth interviews were conducted with six FCGs and seven MHPs, one of whom was also a FCG, from two North Island District Health Board areas. Four MHP themes and five FCG themes were identified which highlight a significant chasm that exists between the MHP's intention to build a relationship with the FCG, and the FCG's experience of the nature of this relationship. These findings are discussed and recommendations are made to bridge this chasm for the benefit of FCGs and MHPs, but ultimately the person with the mental illness.

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1 Cor 15: 57.

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GLOSSARY OF TERMS

Family/whanau

The term family can be used to refer to close family relatives (parents, siblings etc) but also wider family networks nominated by the mentally ill family member as being their family (Ministry of Health, (1998). The Maori term for family is **whanau** meaning extended family network.

Family member

This is a term given in this thesis to refer to the person within the family (son, daughter, wife, husband, partner, mother, father, sister, brother or within the extended family network) who has been diagnosed with a serious mental illness

Family caregiver (FCG)

In some documents the family caregiver has been referred to as 'the family member.' Therefore it is necessary to clarify that in this thesis the term family caregiver will refer to the person in the family who supports and provides care for the mentally ill family member either in the home or when the family member lives elsewhere.

Mental health professional (MHP)

In the context of this research a mental health professional is, a mental health nurse, a community mental health key worker or a social worker who is a member of a community mental health team in one of the two District Health Board areas visited.

Patient/consumer/ client/service user/tangata whaiora

These terms have all been used by mental health professionals when referring to the person diagnosed with a mental illness to whom they provide care.

Relationship

A relationship begins when contact and connection is made verbally or non-verbally between two or more people or groups. The relationship between mental health professionals and family caregivers is a helping relationship in the context of mental illness and is often initiated by the family caregiver. If that initial contact is positive and further supportive contact is regularly experienced, this will carry the relationship into effective communication, as information is shared built on mutual respect and trust. Where the communication is supportive and empathic and there is respect for each other's expertise a relationship can be built between family caregivers and mental health professionals.

Serious mental illness

A full description of these illnesses will not be provided in this glossary. Some information is necessary, however, to provide an insight into the experience of the person diagnosed with one of these illnesses and the experience of the family caregiver who may well be the first and only person to notice that something is definitely not right.

For the purposes of this research serious mental illness refers to the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) definition of Schizophrenia and other psychotic disorders and Mood Disorders (American Psychiatric Association, 2000). Psychosis refers to symptoms that can include "alteration of the senses, inability to sort and interpret incoming sensations and therefore inability to respond appropriately, delusions and hallucinations, altered sense of self, changes in emotions, changes in movements and changes in behaviour" (Torrey, 1995, p. 30). Experiencing even some of these symptoms is very frightening for the person who may be developing a serious mental illness. Often there is a lack of insight as to the abnormality of what is being experienced, which can cause the mentally ill person to refuse treatment or come off medication, believing that nothing is wrong with their thinking. For those observing the symptoms and behaviours, such as the family, workmates or friends it is obvious that there is definitely something wrong and these early warning signs can enable those who know the person best to obtain early intervention. Once treatment has been started there are often side effects of the medications which, when coupled with the distressing symptoms of these psychotic

disorders, can cause the person diagnosed with one of these illnesses to consider suicide. "Suicide is more common amongst people with schizophrenia than amongst the general population" (Schizophrenia Fellowship, 1996, p. 32). Also occasionally people diagnosed with a psychotic disorder such as Schizophrenia, may commit acts of serious violence against others when voices may be providing them with, what is perceived as, valid reasons for committing such acts.

Mood Disorders include Bipolar Disorder and Major Depression. A person is diagnosed with Major Depression when a depressed mood and loss of usual interest or pleasure are accompanied by five or more of nine symptoms that are present during a two week period. Symptoms may include constant tearfulness, significant weight loss, problems with sleep, loss of energy, problems with concentration, feelings of worthlessness or thoughts of suicide (American Psychiatric Association, 2000).

Bipolar Disorder involves two extremes of mood – major depression (deep sadness) and mania (elation). According to the DSM IV a manic episode refers to an episode of abnormal, persistent, elevated, expansive or irritable mood which lasts for at least one week. For a DSMIV diagnosis three other symptoms must be present which may include inflated self esteem and grandiose ideas, excessive talkativeness, decreased need for sleep, increased goal directed activities and involvement in pleasurable activities, believing themselves to be invincible, with the high potential for painful consequences (American Psychiatric Association, 2000, p. 357).

INTRODUCTORY PROLOGUE.

Since deinstitutionalisation, care in the community for people diagnosed with serious mental illness, has mainly been provided by families (Walker, 1982; Parker, 1993). Mental health professionals have continued to provide skilled inpatient hospital care and community outpatient clinical care in the community but it has been stated that services would be overwhelmed without the care that families provide in the community (Huxley, Hagan, Hennelly & Hunt, 1990). However, families are largely unprepared and untrained to cope with the complexities of caring for a mentally ill family member (Milliken & Rodney, 2003) and rely on mental health services to provide skilled intervention, treatment and support for their family member when needed.

When families are included and involved in treatment alongside professional care international results have revealed lower rates of relapse and reduced hospital admissions producing long-term benefits for the client (McFarlane, 1991; Falloon, 1999). Ministries of Health, both internationally and in New Zealand, have been guided by the compelling evidence of these benefits to recommend and direct mental health professionals to foster a working relationship and partnership with family caregivers.

However, international research exploring the family's perspective of the development of this relationship with mental health professionals, has revealed high levels of dissatisfaction. Families have reported being blamed for causing the illness in their family member (Hooyman & Gonyea, 1995), being excluded from treatment (Francell, Conn & Gray, 1988), having difficulty obtaining help and information when client confidentiality was given as an excuse (Hanson & Rapp, 1994; Pejler, 2001; Ferriter & Huband, 2003), not listened to (Muhlbauer, 2002) and finally feeling powerless (Mohr, 2000b).

During the same time span there have been few international in-depth studies exploring the nature of this relationship from the mental health professional's perspective. The research that has been conducted has revealed, that although there is an intention to involve families, this is often hindered by time constraints, lack of experience and lack of administrative support (Bernheim & Switalski, 1988). Mental health professionals in these studies have described awareness of the stress and grief families cope with (Reibschleger, 2001) but have also expressed outdated beliefs of family culpability (Reibschleger, 2002)

indicating that evidence of aetiology of mental illness is not filtering into clinical practice (Rubin, Cardenas, Warren, Pike & Wambach, 1998). The studies of Zipple, Langle, Spaniol and Fisher (1990) and Davis (2002) also highlighted the issue of client confidentiality for the mental health professional, causing conflict for them between the ethical and legal obligation to the client (see glossary of terms, p. vii) and the desire to be supportive to the family.

In New Zealand, few in-depth research studies have been conducted focusing on the nature of this relationship from the family caregivers perspective and no known studies exploring the relationship from the mental health professional's perspective. A working relationship and partnership between both informal (family caregivers) and formal (mental health professionals) caregivers in the community produce significant long-term benefits to the client (Falloon, 1999; McFarlane, 1991). Therefore it is appropriate that research is conducted that explores what the nature of this relationship is like in New Zealand and what the factors are that influence it.

This research will explore the relationship (see glossary of terms, p. viii) between family caregivers (FCGs) and mental health professionals (MHPs) (see glossary of terms, p. vii) who care for 18-30 year olds diagnosed with a serious mental illness (see glossary of terms, p. viii) in two New Zealand North Island District Health Board areas.

CHAPTER OVERVIEW

CHAPTER ONE.

This chapter will provide a history and background to community care for people diagnosed with a serious mental illness, followed by a review of the international and New Zealand research literature from 1982 - 2003, including studies exploring the family caregiver perspective and the mental health professional perspective of how that relationship has been experienced. Policies and literature specifically related to mental health in New Zealand and specific issues of Maori mental health will precede the final section, which discusses the Ministry of Health requirement of a partnership and working relationship between these two groups of caregivers.

CHAPTER TWO

Interpretative methodology and thematic analysis chosen to explore this relationship will be described and several studies that have used thematic analysis will illustrate the application of this form of analysis. Human Ethics applications were submitted to Massey University and the two area Health and Disability Ethics Committees where this study was conducted. Problems that were encountered with the request by the two Health and Disability Ethics committees to obtain client consent are highlighted. The method and procedure implemented to recruit mental health professional and family caregiver participants in both these areas is described and will complete chapter two.

CHAPTER THREE

Chapter three outlines four themes identified from the in-depth interviews describing the mental health professionals' perspective of this relationship and the factors that influence it, followed by five themes that emerged from interviewing family caregivers describing their perspective of this relationship. The final section of this chapter provides an illustration that seeks to interpret how, as a result of this study's findings, the relationship between mental health professionals and family caregivers is functioning in 2003.

CHAPTER FOUR

The final chapter discusses the issues that arose from the themes, in particular the common theme of client confidentiality that tended to influence most of the family caregiver themes but was also was an area of conflict for mental health professionals. Receiving and giving of essential information in relation to medication and treatment that assists the family caregiver to provide effective care for the mentally ill family member is of prime importance but the conflict arises for the mental health professional for whom client confidentiality is of prime importance. Recommendations follow, addressing this conflict of need and other expressed needs that arose from the themes. The limitations of this research and a concluding statement complete this chapter. Finally appendices mentioned in the methodology are included and the references listed.

CHAPTER ONE

HISTORY AND BACKGROUND OF CARE

From its inception, the shifting of people diagnosed with a serious mental illness, from an institution into the community, both internationally and in New Zealand, has been fraught with difficulties for the families of these people.

Prior to institutional care in the 17th and 18th centuries, families had been the sole carers of their mentally ill family members (Hatfield & Lefley, 1987). There were no medications or support services to assist the families to cope with the often bizarre, disruptive and even violent behaviours that were synonymous with mental illness. With the provision of hospital and institutional care for the mentally ill, in the latter part of the 18th century, families and professional carers had generally accepted that once the person was admitted, the remainder of his/her life would be spent in these closed mental institutions, which were often overcrowded and understaffed (Reisser & Schorske, 1994). Institutions or asylums were run more like a prison where calming agitated patients was limited to straitjackets and hot baths and the environment was not conducive to recovery (Hafner, 2002).

The discovery in the 1950's of new drug therapies that brought about a decrease in the acute symptoms of psychotic disorders, paved the way for a reduction in occupied beds in these psychiatric institutions (Tennant, 1996). These new medications helped to stabilise behaviours, which had contributed to the need for people with psychotic disorders to be institutionalised. The introduction of these drug therapies and the encouraging results challenged the belief about whether an asylum or institution was the appropriate place for treatment of people who were acutely mentally ill.

Some of the revelations of appalling treatment of patients placed in these institutions, led to the view that community based treatment settings for these people would be a more humane alternative to hospital locked doors and restraints (Tennant, 1996). In 1953 A World Health Organisation (WHO) Expert Commission recommended a shift of focus from mental health care in hospitals, to care in the community. The following year, in 1954, the Department of Health and Social Security in England and Wales initiated a policy that would return mental health care back to the general health care system by having psychiatric units in general hospitals

(Hafner, 2002). Psychiatrists, who initiated the movement of patients back into the community, thought that patients would benefit from coping with the demands of practical living and social interaction and that they would recover lost skills and develop new ones (Bebbington, Johnson & Thornicroft, 2002).

And so deinstitutionalization became an “in word” in many areas of social policy in the 1970’s, heralding the moving of people with many disabilities back out into the community in New Zealand (Tennant, 1996). There was an assumption however, that with stabilisation on the new medications, the person diagnosed with a mental illness, would be well enough to be discharged to live *in* the community. It could have been believed that these new medications would have the miraculous effect of enabling patients to take care of themselves with minimal support *by* the community.

People with mental illnesses who had spent, sometimes, a large portion of their lives in an institution, needed not only physical care and medication but with the move to the community they would need to be supported socially, financially, educationally, and vocationally. Moving from an institutional model of care to a community model of care required a huge adjustment for these people. Although some people would have disliked hospital, many could have been very anxious about moving into the community when contemplating the loss of familiarity of their institutional ‘home,’ the regularity of routine, and the security the institution had provided. Other people who had been living in institutions saw it as an escape from the isolation from society they had possibly endured for years (Bennie, 1993). The needs were varied and complex.

Policies of normalisation and community care however, did not take into account the need for the community to provide the care needed. It may have been clear for whom care was needed, but if care was to be provided *by* the community who or what was the community? It has been said that community care is the law, which was to bring about a shift from care provision by health services to care by social services but according to Ekdawi and Conning (1994) “community care” in this law was never clearly defined. It appears that this term has been and still is an ambiguous one. Walker (1982) defined community care as: “help and support given to individuals, including children, people with disabilities and elderly people, in non institutional settings.” (p. 5). So care that had been provided in an institution would now be provided outside the hospital *in* the community but by *whom* in the community?

Professional care in institutions had tended to be hierarchical until the shift to the community (Hill, 1982). The balance of power needed to change so that it would be

shared with other potential carers in the community. Bebbington et al. (2002) described the actual move into the community as the “simple relocation of old structures and hierarchies outside the hospital.” (p. 132). Many times in the past any proposals to share that power have not been met positively by the formal/ professional carers. Although the vision was for people with mental illness to be cared for in the community, the members of the community that felt compelled to care and who resulted in providing, co-ordinating and advocating that care, were the families (Walker, 1982). It is estimated that “65% of patients in mental health facilities are discharged to relatives” and “almost 40% of severely mentally ill adult population live with their families,” (Minkoff, 1978 cited in Lefley, 1988, p. 338).

The responsibility for the care of the patients shifting from institution to the community fell largely into the lap of the family, for which they were totally untrained to provide (Parker, 1993; Pejler, 2001; Doornbos, 2002). Bayley (1982) stated that unless a commitment could be made by formal/professional carers to work with informal/family carers, treatment of people needing care would not be effective. “The provision of care *by* the community depends to a large extent on care *for* the family and the community, on whether social conditions facilitate or hinder the provision of care,” (Walker, 1982, p. 32).

According to Jeon and Madjar (1998) informal care by families (*and significant others*) is needed because it is usually bound to long term, lifetime family relationships. However informal care alone will not provide for all the needs of a mentally ill family member. Both formal (professional) and informal care is needed to assist a person with any disability on their road to recovery (Hornby & Atkins, 1993).

Milliken and Rodney (2003) make the point that if caring for people with mental illness is challenging for trained formal/professional caregivers how much more challenging it must be for informal untrained carers such as the family. They identified multiple dilemmas faced by families during the initial stages of a mental illness developing in a family member. Some of the choices families reported having to make were; Is this teenage behaviour? Should we call the police? Do I confront bizarre behaviour or just keep the peace? Do I keep rescuing him or her? The answers to these questions and consequent decisions are difficult to make without knowledge of mental illness and it was suggested that families needed trained professional support and education to help them make those decisions as they endeavoured to care for their mentally ill family member.

The African proverb quoted by Munford and Sanders (1999) 'it takes a village to raise a child' (formal and informal carers) emphasises " the significance of the wider social group (village, whanau, hapu, iwi, community, town, suburb, nation) in raising children" (p.103). This statement is referring to families needing support with their dependent younger children in the community but it is a way of describing the support needs of families who have family members living with a disability and specifically a mental illness. The expertise of formal/professional care is essential to support the unprepared informal carers as they strive to meet the complex and changing health needs of their family members living in the community. Medications do not eliminate all the symptoms of mental illness and a large proportion of people moving out into the community still have persistent and severe impairments in psychological and social functioning. When families have had professional support it has caused them to have a greater sense of control and has been related to reductions in burden and improvements of well-being (Reinhard, 1994).

For community care to be successful therefore, there needed to be sensitive, thoughtful consultations with patients, parents and families. Lack of initial planning and clarity about who would take responsibility for meeting these needs has continued to be a complex area of concern for clients, professionals and families. It was not realised when planning the move from institution to community that the burden of caregiving in the community would fall on families as a consequence of these failures (Solomon & Marcenko, 1992). According to Goodwin (1997) "Disparity between policy assumptions and the lived reality of people involved in informal care is increasingly wide resulting in a range of pressures and problems for those concerned" (p. 126). There had been a failure to consult with families which probably contributed to the lack of information, education, training and support families needed. As Goodwin states, informal care had been seen by policy makers as providing only general support not the type of care that would require skill, time and energy. The community and the health care system have continued to rely heavily on families to provide care for their mentally ill family members. It has been said that services would be overwhelmed without the care that families provide for their mentally ill family members (Huxley, Hagan, Hennelly & Hunt, 1990). In the community, formal/professional care had limitations of time and resources (Lefley, 1988) but families would always be there for these people where circumstance and consent of the patient allowed.

The physical and mental burdens of providing care by families were also, more often than not, borne by the women in the family (Wilson, 1982). Feminist research identified women as predominantly the carers to those in their families with chronic illness such as a mental illness. As community care began to reveal huge gaps in its provision women automatically were filling those gaps. However, according to Hooyman and Gonyea (1995) "Women were more frequently blamed when their caregiving failed rather than acknowledged when it was successful" (p. 19). Theories such as the 'Schizophrenogenic mother,' the 'double bind' theory and 'marital schism and skew' were some of the popular theories circulating during the 1950's and 60's (Hatfield, 1987). Presumption about the possible causes for serious mental illness fuelled the belief that families and particularly mothers were to blame for the mental illness their child had developed.

Rutman (1996) interviewed 13 female caregivers of the elderly during two one-day research workshops. These caregivers dealt with similar psychiatric difficulties to those caregivers who care for people with mental illness. Participants described a feeling of powerlessness due to the lack of respect shown for their expertise but also because appropriate resources to assist them with their caring were not available within the care system. These female caregivers perceived the lack of resources and support as a reflection of the value society placed on the caregiving of aged, infirmed and mentally ill family members.

Despite the theories blaming women and families for the mental illness experienced by their family members, the women of these families continued to provide unpaid and undervalued care to those of their family who needed care. Behaviours synonymous with mental illness were difficult for caregivers to deal with. They were in need of support from professional expertise in handling these complex and ever changing behaviours, not blamed for the caring they were able to provide.

Many early family therapy interventions based on these early theories, failed, as families reacted negatively to being blamed by mental health professionals for contributing towards their family member's illness. With the shift away from the disease-based model of care to a health based care model accompanying the move to the community, which began in the 1970's, interventions began to be planned that focused on identifying strengths and empowering the family to provide care (Mohr, 2000a). However, according to Muesser and Glynn (1999), mental health professionals have

still been slow to recognise and include families as a valuable part of the client's treatment team.

LITERATURE REVIEW

There has been compelling evidence in recent research that has shown that providing single family and multi family psychoeducational interventions has beneficial effects for the family themselves and the family member with the mental illness. A strategy development meeting for an initiative by the World Fellowship of Schizophrenia and Allied Disorders (W.F.S.A.D.) called "Families as partners in care" was held in New Zealand in 1997. A statement was prepared for this meeting by Falloon, a well known proponent of family interventions, which briefly outlines the benefits of psychoeducational family interventions:

Since 1980, 22 controlled studies of long term psychoeducational family work, integrated with optimal drug and case management, have shown substantial additional benefits for people with schizophrenic disorders. Major exacerbation of psychotic symptoms and admissions to hospitals are more than halved, social disability is reduced; with increased employment rates, burdens of family carers are lowered and their health improved (W.F.S.A.D. 1998, p. 6).

When there have been psychoeducation family interventions provided to assist families to manage stress and gain skills of problem solving, there have been benefits for the whole family. Falloon and Fadden's (1993) Integrated Mental Health Care was developed in response to inadequate care being provided in the community for the mentally ill. The aim of the Buckingham project (England) from which this model of care arose was to create a model of community care, which would be based on empirical evidence and would provide guidance for, it was hoped, similar mental health services to be developed in other parts of the world. Falloon and Fadden stated that it was imperative that professionals who staffed these services were well-trained practitioners, that not only assessed and addressed the patient's needs but the needs of the whole family and that a two way process of consultation always took place. "Mental health professionals have as much to learn from the community caregivers (*often family caregivers*) as they had to offer in terms of knowledge and skills," (p. 20) Falloon and Fadden stated. This model of care was based on the vulnerability-stress model of intervention and provided stress management and training in problem solving

for the whole family within a treatment team which eventually included the family member. Families were not blamed but were supported and assisted while they, alongside professional carers encouraged their family member on the road to recovery. Professionals working in many areas of mental health in New Zealand have been given the opportunity to attend training courses in this model of care over the last ten years.

Collaboration between all carers on a treatment team appeared to be a practical and comprehensive response to making changes to the way mental health services were provided in the community. Falloon's (1999) Optimal treatment project, a multi-site study spread over 21 countries, was set up to evaluate, over five years, the effectiveness and benefits of this model of evidence based biomedical and psychosocial interventions for the patient and his/her family. The patient was required to comply with an optimal dose of medication to be part of this project. Initial results showed that hospital admissions were reduced by 55% for those receiving optimal treatment strategies, compared with 4% of those receiving only biomedical intervention and case management. However when interventions ceased the benefits also disappeared, indicating that patients and their families needed provision of interventions on a flexible as needed basis just as medication is provided (Falloon, 1999).

No-one would argue that drug therapy will remain a key intervention in controlling the severe symptoms of mental illness but as McFarlane (1991) states there is still a 40% chance of relapse. It is generally recognised now that severe mental illness is a biological brain disorder and families do need support and education to cope with the complex burden caused by constant exacerbation of the illness. MacFarlane reported that other benefits from providing family psychoeducational interventions to the whole family are to reduce guilt and blame, relieve fear, and widen social support networks all of which contribute towards easing the burden for the family.

When there is collaboration between professional and family carers, there are also benefits for the person experiencing psychosis. The "symptoms of mental illness such as confusion, cognitive deficits, isolation and withdrawal make it difficult for consumers to recognise signs of relapse and to seek help" (Bogart & Solomon, 1999, p.1321). When families are informed and able to share information with community mental health workers, they can distinguish medication side effects from early warning signs of relapse and possibly avert a crisis that may have required hospitalisation.

Kuipers and Bebbington (1990) state that families want to be involved alongside the professional team when making decisions about the treatment of their family

member and to have their own difficulties and contributions taken seriously “to be contributors rather than the passive recipients of such decisions” (p. 17). Caregivers often lack knowledge and need help to deal with the difficult behaviours they have to deal with. Mental health services often neglect the needs of the family that arise from the family member’s mental condition. These writers state that there appears to be two barriers that prevent mental health professionals working with the families of their patients. The first barrier is the negative attitudes some professionals have towards the families, possibly due to evidence from past research, which blamed families for the plight of their family member. The second barrier refers to the professional’s lack of knowledge about what families need and the lack of skill in being able to help meet those needs (p. viii). Therefore it is recommended that professionals need to become more aware of the problems that families face, then learn ways in which to assist and help them ease that burden.

Bishop, Clilverd, Cooklin and Hunt (2002) described the development and implementation of a six-week series of daylong workshops by a team of mental health workers and specialists in London. The Family project had been set up to train mental health professionals how to help and educate families and their family members as they adjusted to the effects of mental illness. Education during the workshops provided families with information about medication and side effects, as well as family relationships, how to access services and deal with some of the frustrations experienced when dealing with mental illness. Family caregivers stated that having attended the workshops they felt “ ‘less alone’, ‘listened to at last’ and ‘felt understood,’” (p. 34) and benefited from networking and sharing with other families. Mental health staff participant numbers were limited but those who took part reported also benefiting from being with clients and families in a less formal environment resulting in a more positive partnership relationship, where all were on a similar level learning about and respecting each other’s perspective.

Even though benefits were described by both mental health professionals and family caregivers who attended Bishop et al’s training courses, Rose (1998) stated that some of the families she interviewed had never been asked to take part in a programme that would provide education and skills to help them with their mentally ill family member. Families had previously expressed a need for education about how to deal with unpredictable behaviours. Marsh (1999) noted the absence of programmes and services specifically for families as did Doornbos (2002) who reported that services

directed towards supporting the caregivers were “virtually non-existent despite the fact that such interventions may have the potential to improve outcomes for them and their ill relative” (p. 39).

A training programme for mental health staff initiated by Schizophrenia Fellowship in Victoria, Australia, was developed to address some of the unhelpful blaming attitudes expressed by some staff. These attitudes and the limited contact with families had been identified as barriers to good partnerships between family caregivers and mental health professionals. The programme therefore, would be aimed to increase mental health staff members level of understanding of families with mentally ill family members, to challenge some of the negative attitudes held by some staff towards families and to help them to involve families more in the client’s treatment. Throughout the programme, collaboration between caregivers and professionals at all levels of planning, training and facilitation was encouraged. The brief training programme and extended programme offered to 99 staff members was evaluated using pre-test and post-test follow-up design. It was found that even though the level of respect and partnership between caregivers and mental health staff was improved during both brief and extended programmes, it was only the extended programme that promoted attitude change (Farhall, Webster, Hocking, Leggatt, Reiss & Young, 1998). However training programmes such as these, where family caregivers and professionals organise and conduct the programme together are not common and the lack of similar training may be one of the reasons why families who are dissatisfied with mental health services attention to their needs.

Research conducted from as early as 1982 till the present day has consistently revealed other reasons why family caregivers express high levels of dissatisfaction. Some of the research findings and relevant literature from 1982 till 2003 is described below, to clearly illustrate the dissatisfaction, frustrations and needs of family caregivers and the beliefs and attitudes held by mental health professionals during this period.

A survey conducted by Holden and Lewine (1982) found that families felt left out of treatment and felt ignored by professionals. They also stated that they had been given little advice as how to manage difficult behaviours. 140 out of 190 participants in this survey were dissatisfied with the help provided by mental health professionals. Families surveyed by Spaniol and Zipple (1988) also expressed a high level of dissatisfaction with mental health professionals. Families said that they needed more information especially in relation to medication, side effects and dosages and they

needed stress management to strengthen their ability to cope with the difficulties of living with a person with a mental illness. In contrast mental health professionals, who were also surveyed, believed that families were generally satisfied with the services they provided.

Francell, Conn and Gray (1988) interviewed family caregivers in small groups asking them about the factors that added to the burden they experienced when caring for mentally ill family members. Families spoke about the difficulties when trying to converse with foreign psychiatrists for whom English was a second language and who lacked understanding of the culture in which the families lived. Extreme dissatisfaction was also expressed with other staff who told them that nothing could be done for their relative who was experiencing severe symptoms of mental illness, unless they brought that person into the mental health centre. They had been frustrated with being excluded from the treatment process, long delays in having telephone enquiries returned and statements of blame and indifference to the concerns families expressed. Lefley (1988) also described families who had had calls to the psychiatrist unreturned.

Findings from research in the 1990's continued to reveal family dissatisfaction with mental health services to support them in their care of their mentally ill family members. Interviews conducted by Solomon and Marcenko, (1992) asked 57 families about their satisfaction with inpatient and outpatient treatment. Although satisfaction was expressed with the ability of services to meet their family members needs, over half (58%) of family participants were dissatisfied with the ability of mental health professionals to meet their own needs for emotional support, practical advice about medications and illness related information.

Hanson and Rapp (1994) in a study looking at the family's experience with mental health service programmes, found that during transition from hospital to the community, families complained about lack of involvement in the discharge process, a lack of needed information given by the hospital, lack of follow up, and lack of immediate service available in the community. These actions by mental health professionals created burden for the families as they sought to provide care to their mentally ill family member.

When health professionals do not listen to the families and do not believe their judgement of the need for their family member's hospitalisation, believing they are exaggerating the situation after long delays in obtaining help (Jeon & Madjar, 1998) this heightens distress for the family. However families experienced lower levels of distress

when professionals treated the family as allies and partners in the treatment process (Greenberg, Steven & Greenley, 1997). Telephone interviews had been conducted with 778 family caregivers to ascertain whether stress levels were lowered when the mentally ill family member and the family were provided with information and advice.

Reinhard (1994) also found that families experienced lower levels of burden when mental health professionals gave practical advice about managing behaviours thus enhancing the family caregivers' sense of control.

Family caregiver burden often differs with different stages of illness (acute episodes of psychosis or when their family member experienced chronic symptoms) and with different ages of parents. Cook, Lefley, Pickett and Cohler (1994) recommended that as a result of this finding, interventions needed to be tailored for these different ages and stages – younger parents needing more help with troublesome behaviours and older parents needing more help and respite to cope with the burden of ongoing responsibility of care.

After twenty years of families describing their needs when caring for their mentally ill family member findings of studies from 2000 – 2003 have continued to reveal that families are still expressing dissatisfaction with mental health services ability to meet their needs. During 180 interviews conducted in the United States by Johnson (2000), families reported feeling disregarded, dismissed or irrelevant by mental health professionals, particularly psychiatrists and staff at crisis centres. They felt excluded and any valuable information that could have been offered wasn't valued or requested. Mohr (2000b) when interviewing 40 parents about their experience and perspective of hospitalisation of their mentally ill children identified themes that caused families to feel excluded, to feel marginalised, abnormalised and displaced in the family member's life. They also felt bewildered by the jargon, and felt powerless. Mohr described the families' "frantic attempts at communication (*with staff members*), which resulted in staff members withdrawing from them, making families ever more frantic for information" (p. 604). It was crucial that families be involved in the treatment planning Mohr stated, as they played a key role in sustaining benefits to their family member.

Families, in a narrative study conducted by Pejler (2001) in Sweden, related how mental health service staff attitudes and actions were often a source of family anger. Staff members were seen as lacking interest in sharing information with parents and that they enforced client confidentiality in such a way that kept parents distanced from their family member's treatment. Much conflict in the nurse - parent relationship was

demonstrated by the nurses' attitude that they knew the client better than the parents. It was also noted that if the goals were, to involve parents as partners in care then professionals would have to find ways in which they could give information and support, as well as protect client confidentiality.

There has been an assumption that family burden and stress is more related to living with a family member who has a mental illness than when they live apart from each other. However Laidlaw, Coverdale, Falloon and Kydd (2002) found some evidence of caregivers who lived apart from their mentally ill family members experiencing similar stress levels to those whose family members lived with them. Families are often still very involved with supporting their family members and therefore have equal needs as those who have their family members living in their home. It is also noted that as a result of this ongoing stress, caregivers of people with psychiatric disabilities were three times as likely to experience severe psychological distress than those reported by the general population in Quebec, Canada (Provencher, Perreault, St-Onge & Rousseau, 2003).

Providing long-term support for their mentally ill family member raised another difficulty families have to deal with which contributes to their stress. Family caregivers have expressed difficulty with the level of age appropriateness of responsibility to expect of their family member with a mental illness. Most parents expect to socialise their children towards independence and the responsibilities for them to decrease, but when mental illness enters the scene, parents have to develop a new parental role, which provides appropriate care but also encourages a level of independence in their mentally ill family member. To develop this changed role families require support and practical advice by mental health professionals (Milliken & Northcott, 2003). "With the onset of serious illness old roles and patterns of relating to each other may undergo drastic alteration leaving family members (caregivers) uncertain as to who will do what to maintain family functioning" (Northouse & Northouse, 1993, p. 112). Therefore this is an area where families would benefit, not from judgement of their seeming over involvement, but education, skills and support that would encourage and maintain the mentally ill family members autonomy.

One could have assumed, with the elimination of family blaming theories and recommendations to include and involve families in their family member's treatment over the last twenty years, that the relationship between the mental health professionals and family caregivers would have improved. One would also expect that research

results would be showing that families were becoming more involved and supported, burdens and stress levels would be significantly lowered and mental health professionals would be sharing needed information and care of clients with families. In the most recent research this assumption has proved false.

Muhlbauer (2002) found that the majority of 26 caregiver participants she interviewed had problems with communication with mental health services – they were often not listened to or given needed information. Phases of the families navigating the storm of mental illness were identified. As the phases of “Development of Awareness” and “Crisis” (p. 1082) developed, followed by phases of “Instability” (p. 1083) and eventually “Moving toward stability” (p. 1085) attempts to communicate with mental health professionals and obtain needed information intensified. Difficulties with communication characterised all the six phases Muhlbauer identified along the families’ journey. 85% of the 76 caregivers’ narratives in Doornbos’ (2002) study also reported difficulties with communication, obtaining relevant information and being excluded from planning of care. Other difficulties observed by caregivers in this study were that mental health services were often understaffed and overworked. Stengard (2002) conducted a large research project in Finland using mailed questionnaires to explore how caregivers coped with the demands of their mentally ill family members. Even though all 398 caregivers involved in this study had expressed the need for support, all caregiving types had received only minimal support over the previous 12 months.

As recently as 2003, Ferriter and Huband reported that when they interviewed parents of sons and daughters suffering from Schizophrenia these families found self help groups and the police were the most helpful during crises involving their family member, rather than mental health services. Mental health professionals in Ferriter and Huband’s study, had been reported as, not forthcoming with information needed by parents and “when information was offered it was often inaccurate or insufficient” (p. 557). Psychiatrists and nurses received the brunt of families’ anger. Families described being ‘fobbed off’ with minimal and vague explanations when they voiced concerns about their family members. Not knowing how to respond in some difficult situations with their family member added to the “trapped” feeling they felt when dealing with these situations. Ferriter and Huband (2003) suggest that appropriate timely help and advice could help to alleviate this frustration.

Despite all the research commendations and health documents compiled by Ministries of Health in a number of countries over the last twenty years, families have

become increasingly disillusioned with the mental health system when they have observed, “changes in mental health programming appear to be based on either political pressure or economic restraints rather than clear scientific evidence of efficacy” (Milliken & Northcott, 2003, p. 108). Mohr (2000a) believes that profits are high on the list of priorities for service provision and the perceived expense of family involvement and training mental health professionals is seen as being too high. However Miller (2003) states that there needs to be ways to convince policy makers that in the long term involving families could be cost effective. Evidence of reduced hospital admissions (Falloon, 1999) adds weight to this premise.

Researchers and various writers have already made recommendations to policy makers and professional caregivers to take heed of these needs when planning services to enable families to become re-enfranchised so they can provide ongoing care for their mentally ill family members.

These research results reflect only a few of the numerous studies available expressing the family caregivers' perspectives of their relationship with mental health professionals when caring for their family member. The family has consistently expressed their need for respect, compassion, information and education. But what do mental health professionals think about involving families in the treatment of clients and particularly what do they think about the nature of their relationship with families? Very little research was found that explored what mental health professionals believed or experienced when dealing with families of clients.

Bernheim and Switalski (1988) surveyed inpatient and outpatient mental health staff about how they viewed families. A third of the 350 staff who returned the surveys, felt that interaction between family members often made the patients' illness worse and 11% often felt that information families gave them was unimportant or unreliable. 70% of Mental health staff surveyed though, felt that families should be involved in treatment and also offered some training that would assist them to intervene in such way that would reduce the risk of relapse in their mentally ill family member. The intention to involve families was high, but efforts to implement involvement were limited as a result of perceived time constraints. Inconsistent attitudes, lack of experience, perceptions of confidentiality requirements and lack of administrative support were identified in this study as impediments to involving families in the treatment of clients.

Concern was expressed by Rubin, Cardenas, Warren, Pike and Wambach (1998) when they surveyed the beliefs of senior and postgraduate students about family

culpability for their mentally ill family member. Amongst 167 social work students in the United States 57% of students expressed belief in parental and family dysfunction causing the patient's illness alongside an acknowledgement of the importance of biological causes. Three fifths of responses viewed unhealthy parenting as a major cause of illness and believed that to some degree people diagnosed with a serious mental illness, probably would have had an emotionally disturbed parent, which contributed towards their illness. The findings indicated that probably the more recent evidence about the aetiology and treatment of chronic mental illness is not being emphasised or integrated sufficiently into clinical practice. Although these students were social work students this research is relevant in light of the fact that mental health services in New Zealand do employ not only mental health nurse but also social workers as part of the community mental health treatment teams.

Riebschleger (2001) identified a number of themes when she interviewed focus groups and surveyed 37 mental health professionals in Michigan, United States. They viewed families as supportive caregivers, families in pain and uninformed families, but also identified them as unsupportive agitators and unequal partners. Reibschleger also noted that participants didn't appear to view caregivers as equal partners in a patient-family-professional team. There was acknowledgement by one participant that mental health professionals needed to teach, support and educate families but the majority of participants were unfamiliar with any of the psychoeducation or strength models for working with families. In another of Reibschleger's studies using a practice vignette (scenario) about a fictitious family coping with the consequences of mental illness in a family member, mental health professionals were surveyed and asked a number of questions about historical and present day emerging theoretical constructs about families coping with mental illness in their family member. Out of 73 mental health professionals, one out of four agreed that within this fictitious family there may be 'double bind' communication, 'schizophrenogenic' mother and 'high expressed emotion' even though there was no clear evidence of this described in the vignette (Reibschleger, 2002). Reibschleger was aware that findings could not be generalised due to the small sample of mental health professional participants. However attitudes such as these amongst mental health professionals, regardless of how small a sample, does not indicate progress in the changing of mental health professional attitudes towards families and building a positive relationship with them.

Thirty mental health professionals, who were recruited following a Professional Provider Family education Course developed by the National Alliance of the Mentally Ill (United States), were surveyed asking them what they believed the barriers were to collaboration between themselves and families of persons with serious mental illness (Kaas, Lee & Peitzman, 2003). Barriers identified were in order of chosen importance; lack of time, conflict about treating the client versus the family, the belief that family involvement might be harmful and not of any real benefit to the client, lack of expertise and service agency not supportive of professionals working with families.

Outdated beliefs about the cause of mental illness and the belief that involving the family may be harmful may still influence mental health professional's relationship with the family caregivers. Davis (2002) suggests though, that mental health professionals are caught between two perspectives – the first being the need not to jeopardise the first obligation to the relationship with the client and his/her autonomy, and secondly to listen to the family advocating for more involvement in treatment planning. Davis suggests that there is a need to reconcile the consumer movement advocating autonomy and the family support movement advocating for what he described as “state paternalism” when family caregivers require the mental health professional to monitor client activities on their behalf (p.244). However Zipple, Langle, Spaniol and Fisher (1990) saw this dilemma clearly as a mental health provider caught between the desire to be supportive to families and yet maintain their ethical and legal obligations to clients. They suggest that there needs to be ongoing dialogue with the consumer about the benefits of involving their family in the treatment process if s/he has not given permission for the family to be involved. A complete wall of privacy is often not in the interests of the consumer or the family who provide care in the community. Zipple et al. recommended that if the consumer is approached in a supportive way by a mental health professional who believes in the value of involving families, most consumers are willing to grant some degree of access to family caregivers. The belief of the mental health professional and the way s/he approaches the client may have quite a bearing on whether the consumer agrees to involve his/her family.

219 families and consumers attending a National Alliance for the Mentally Ill (NAMI) conference in the United States, were surveyed for a study conducted by Marshall and Solomon (2000) to examine the process of releasing information to families. Although 72% of family responses indicated that they received some information about their family member's illness, few indicated that they had been

involved in the treatment plan. Interestingly only 36% of consumers stated they had been encouraged to involve family in their treatment plan and only 25% of consumers stated that permission had been requested to disclose information to their family.

Prior to this study Bogart and Solomon (1999) stated that the responsibility for encouraging clients to involve their family and obtaining client consent should be the mental health professionals responsibility. Bogart and Solomon and Marsh (1999) recommend the use of a client consent form, which could be signed during admission to a specific mental health service agency, so families could be notified that the release form had been signed. A time limit on its validity would protect the client and ensure that changes in his/her social network would be considered. However updating the form would be essential to remind mental health providers and the patient of the importance of involving families in the treatment process (p. 1324). Bogart and Solomon suggested that, there needs to be a balance between the families' need for information and the consumers right to confidentiality and they described steps developed by mental health services in Pennsylvania and California (Unites States) to address this issue.

Releasing of information when there is a confidential therapeutic relationship with the client to maintain can present difficulties for mental health professionals if directions are not given to them outlining steps needed to release much needed information. Marshall and Solomon (2000) conducted a study to explore how mental health agencies discuss confidentiality when sharing of information with families (and consumers). High levels of dissatisfaction has been linked with families still not receiving necessary information to assist them with care of their family member and being told that the information they requested was confidential. Training was recommended that would "clarify the types of information that are confidential and non-confidential and the process for releasing confidential information" (Marshall & Solomon, p. 1010).

Mental health professionals do have an ethical responsibility to maintain confidentiality with clients but when that patient is refusing treatment and is clearly not able to care for themselves Milliken and Rodney (2003) believe that this situation should be considered to be 'dangerous to self.' Families have said that mental health professionals may miss behaviours that need to be addressed because they see the family member in a different context to that of the mental health professional. Therefore

mental health professionals needed to find ways to work with family caregivers to provide a balanced quality of care for clients (Solomon & Marcenko, 1992).

Leggatt (1993) agrees that when the client lacks insight and therefore may not give permission for communicating information to family caregivers, mental health professionals should still give relevant information to, and receive information from, family caregivers for the long-term benefit of the client. When clients are psychotic and cannot make mature rational decisions related to their own care, Leggatt suggests mental health professionals could make common-sense decisions in relationship to sharing of information and obtaining help for the client, if they were not so fearful of being sued for breach of confidentiality. Marsh (1999) agrees that consent requires competence and therefore commonsense should be used while the patient is experiencing psychotic symptoms (p. 367). Mental health professionals need to recognise that there are ways that they can work with the client as well as the family without breaking client confidentiality (Leggatt).

Peart (1996) says that information not being given to family 'because of the Privacy code' has caused much distress for families and should never have happened. It is not the Privacy code at fault Peart explains but "the lack of knowledge and understanding of the Code that is causing the problem"(p. 83). Possibly when this law is understood more clearly all those who have the client's best interests at heart, can provide the quality of care that will assist that person in his/her recovery.

Although there has been a number of research studies completed covering various aspects of mental health in New Zealand there is a paucity of research specifically exploring the relationship between family caregivers and mental health professionals. However 10 female and 4 male participants were interviewed for a doctoral study conducted by Richards-Ward (1996) examining the characteristics and complexities of the care provided within a family to a member diagnosed with Schizophrenia in New Zealand. When discussing their relationship with mental health services, participants stated that often their mentally ill family member's needs for resources and services in the community, where they had chosen to live, were increasingly not being provided. The consequence of the lack of adequate support had meant that these informal (*family*) caregivers were having to respond to those needs until there was a likelihood that family members were able to care for themselves or they were committed under the Mental Health (Compulsory Assessment and Treatment) Act, 1992. The caregivers found that mental health professionals were generally unhelpful and they did not provide them

with necessary information about their family member's diagnosis or treatment, (Richards-Ward, 1996). These findings confirm the international research reviewed.

A very small research study was conducted in New Zealand by three registered nurses who interviewed three family caregivers about their interactions with nurses in an acute mental inpatient unit (Nichols, Morgan, Pack & Betteridge, 2003). The need for information, being included and being cared for, were the three themes that the caregivers identified as being most important to them when their family member had to be admitted to the inpatient unit. One of the caregivers said that the nurses always kept her informed and this helped to build a relationship of trust with them. Another caregiver however, shared that a nurse had told her not be so over protective with her son. This caregiver knew something was wrong and that he needed help, as she said, "Parents know things – nurses need to recognise this" (p. 21).

In light of international research and the two limited New Zealand studies, how have policies and services in New Zealand been affected by these findings illuminating the benefits and need to involve the family caregivers? How have policies developed to reflect this vital recommendation for the long-term benefit of the family member/client.

Mental health in New Zealand

In 1994 the Honorable Jenny Shipley, Minister of Health launched the National Mental Health Strategy, "Looking forward." She stated that for too long mental health services had failed to meet the needs of consumers, carers and the community, and admitted that prior to 1994, there had been "many reports – that have pointed out deficiencies in mental health services," (Ministry of Health, 1994a, p. 3). This document acknowledged that with the change of focus from institutions to community care there had been a lack of resources available and a lack of responsiveness to consumers, caregivers and families. The minister promised that government would be committed to a community based model of mental health services.

Two key goals in "Looking forward" were identified, the first was "to decrease the prevalence of mental illness and mental health problems in the community" (p. 9). The second goal was "to increase the health status of and reduce the impact of mental disorders on consumers, their families, caregivers and the general community" (p. 9). Reasons were outlined for the choice of these goals but they did not address the changes that would need to take place to implement such goals. Efficient

services to provide comprehensive community care would require more than broad goals to affect any major changes in service provision

Among the list of principles arising from these goals, two principles referring to family involvement were stated which would guide the direction of mental health services for the future. Services were to be provided that supported and empowered consumers and their families/whanau and caregivers and contributed to the best outcomes for these groups of people (Ministry of Health, 1994a). Principles reflected the gaps identified and the desires expressed by the consumer and his/her family and caregivers but there was no specific direction as to how that might be achieved. How would family be empowered and supported by mental health services while they provided care for their mentally ill family member in the community?

The Mental Health Commission was established in 1996 to ensure implementation of these “Looking forward” strategies and to report on progress. The commission stated that family inclusive mental health services should assess the needs and strengths of the whole family. From that assessment it is suggested that a plan be formulated that provides information to the person with the mental illness and his/her key family members about mental illness and the skills needed to cope in the community.

A document published in the same month as “Looking forward” set out the “Standards for Needs Assessment for People with (*all*) Disabilities,” (Ministry of Health, 1994b). Standard Four stated clearly that this needs assessment would be “... a people oriented process and that the person, their family/whanau and caregivers will be respected for their knowledge and experience of disability” (p. 15). The family have often been referred to as the experts on how they experience the family member’s mental illness in their family and the professionals are acknowledged as the experts in medical and behavioural interventions to assist in the mentally ill family member’s recovery. Both family/informal and professional/formal experts are needed by the family member/client to enable him/her to adjust to the limitations of a mental illness.

The value of family to assist their mentally ill family member in the adjustment was recognised in the treatment of people diagnosed with a psychotic disorder at a “Beyond Care and Control?” N.Z. Workshop conducted also in 1994.

Families generally wish for the best for those they love. They need to be recognised as an important part of the continuum and kept informed. But their resources and needs also need to be recognised and treated with respect (Burns, Barrett, Daley Duignan & Saville – Smith, 1994, p. 4).

Two years later in 1996 a ministerial inquiry into Mental Health Services in New Zealand known as The Mason Report was conducted and produced some wide-ranging comments from families who had been living with the stress of a family member diagnosed with a mental illness. A common theme in the reports from families was that they were “rarely regarded as a valuable source of information during the assessment, planning and review and discharge stages of a family member” (p. 61). As one family member said “The family is the only group which knows patients when they are well and unwell --- often we have the information which can assist in that treatment” (p. 61). Their care and contribution is invaluable to the people providing professional and medical care and ultimately for the benefit of the client.

Mental health professionals also made statements in this Ministerial Inquiry (1996) of the stress experienced when team members were asked to take twice the normal caseloads. Also due to delays in replacement of staff moving from one part of the service to another uncertainties were causing staff resignations. Psychiatrists and nurses made strong statements about the critical lack of supported accommodation in the community. Mentally ill clients who are unable to return to family homes or previous accommodation, require supported accommodation while they recover and adjust to the limitations of the illness.

“Moving forward: The National Mental Health Plan for More and Better Services,” (Ministry of Health, 1997b) was produced as a guiding document to help implement the “Looking forward” (1994) goals. It also responded to the Mason report (1996) where families had expressed the need to be “listened to, have access to information that they needed and be included in treatment and support planning” (p. 23). Direction for ongoing improvement to mental health services was set to improve responsiveness of mental health services to families and caregivers and address their requirements.

Arising from these documents, strategies, reports and reviews, twenty National Mental Health Standards (1997a) were formulated with the purpose of becoming “part of the overall service improvement strategy.” The aim was to fully implement all the standards throughout the mental health sector by 2000. Audits and assessments were to be conducted as to their appropriateness and usefulness. Standard 10 specifically addressed what services would do for families – “Families and carers are involved in the planning, implementation and evaluation of the mental health service”(p. 21). This standard covered the use of appropriate involvement, participation, and contribution in

the service. It also necessitated provision of support, education and encouragement by the mental health service to maximise this involvement.

The standards came close to addressing what family/whanau needed to provide care for their mentally ill family member but individual providers had the responsibility of ensuring how the standards would guide their particular service. Only regular consultation with families would ensure that this standard was upheld and provision was suited to their local needs.

The Blueprint for Mental Health Services in New Zealand was released by the Mental Health Commission in 1998 and addressed only the second of the National Mental Health Strategy goals which was to increase the health status of, and reduce the impact of mental disorders on consumers, their families, caregivers and the general community." (p. 3). It is stated in this document that interventions that don't include the family will only have limited effectiveness because as it is stated, "People with serious mental illness are not ill in isolation," (Mental Health Commission, 1998a, p. 9). Therefore the whole family's needs should be assessed and plans made to co-ordinate treatment and support. When communication between key people (formal and informal caregivers) involved in the treatment of the consumer and meetings are held regularly there is a better outcome for all.

Attention was also drawn to negative attitudes from some mental health staff towards family, causing family to feel blamed and undervalued (Mental Health Commission, 1998a). For families to express their opinions in an accepting forum is helpful however these opinions need, not only to be heard and reported, but also to be listened to and acted upon when planning mental health strategies.

Clients have the right to choose not to have their family involved and the Blueprint also stated that mental health professionals have to respect this choice. However family opinion expressed in a Mental Health Commission Review (August, 1998b), prior to the Blueprint being released, illuminated "--- inappropriate reference to the Privacy Act as an excuse for not consulting with family and carers --- Interpretation of the Mental Health Act and the Privacy Act is excluding families"(p. 10).

The Privacy Act was enacted in 1993 to address individual privacy in relation to a broad range of relationships, one of those being confidentiality and trust between clinician and client in the mental health arena, (Mental Health Commission, 2002). However, the Act was not intended to be used as an excuse to withhold all information from families dealing with the mental illness of a family member. If the purpose of

collecting health information is to ensure effective treatment and the consumer is advised of the purpose, then that information “can be conveyed to a third party who is involved in providing care,” (Mental Health Commission, 2002, p. 18). Even when the client is acutely unwell it is advisable, according to some hospital policies, for the mental health professional to discuss with the client as to, which people they agree information can be shared with and what kinds of information may be shared. Families who provide care need certain information relating to the care of their family member upon discharge, to assist them in the family member’s recovery. “There needs to be a mutually respectful process of sharing information, resources and skills established in each situation,” (Community Liason Committee of the Royal Australian and New Zealand College of Psychiatrists, 2000, p. 4). However details outlining this process were lacking.

A 1999 Mental Health Commission Review of progress on the implementation of the strategies put forward in earlier publications, revealed that, despite improvements over recent years “the involvement of the families’ perspectives into policy and planning has been slower to develop than consumer involvement,” (Mental Health Commission, p. 29). Directions to mental health professionals to involve families were not enough to bring about progress in this area.

It was recognised that mental health professionals needed guidance to assist them when involving clients’ families. A Community Liaison Committee of the Royal Australian and New Zealand College of Psychiatrists for the Ministry of Health (2000) prepared guidance notes to assist in the “Involving families” process. They listed a number of key factors, which influence the effectiveness of this relationship:

- “consultation,
- co-operation,
- mutual respect,
- equality,
- sharing of complementary resources and skills, and
- clarity of expectations.” (p. 3).

These key factors focus on the need for mental health workers to work “with” and “beside” the families. A working relationship or partnership between family, the patient and the mental health professional is essential if there is to be sharing of information and benefits for the client. When there is a working relationship, gaps of knowledge

and skills can be identified and addressed for the benefit of all those involved in the treatment team. However, building a working relationship is a process. There needs to be clarification of who the patient defines as his/her family (biological or environmental) and equality needs to be developed and maintained. Mental health professionals need to be responsive to family's physical, emotional, social and spiritual experience and needs and there should be respect for the privacy and confidentiality needs of the patient *and* the family (Community Liaison Committee of the Royal Australian and New Zealand College of Psychiatrists, 2000).

This document's guidelines set out succinctly and in jargon free language for mental health professionals and the family how to deal with situations where the patient refuses consent to share personal information that the family may require to provide care. They recommend therefore, that where problems arise that require clarity, reference should be made to "Mental health professionals and patient information guidance notes" (Privacy Commissioner, 1997). It is stated clearly in these notes that the Privacy Act (*Code*) permits disclosure of health information to caregivers who should be given important information related to the care of their family member, such as medication requirements (p. 21). The agency providing care to the client would need to make it clear to the patient that the purpose of obtaining certain health information is to pass on necessary information to caregivers. However the Privacy Commissioner noted that a particular agency's code of ethics might differ from exceptions stated in the Code allowing disclosure. Wherever this situation arose the agency should take responsibility for the policy they develop, and reasons for non-disclosure should be given to the caregivers or whoever is asking for that information to be disclosed.

In April 2000 the role of families in the recovery of their family member with a mental illness was recognised with the amendment to the Mental Health Compulsory Assessment and Treatment Act (1992) requiring clinicians to consult with families during compulsory assessment and treatment, (Mental Health Commission, 2002). This initiative recognises the value of families and will ease the frustration and stress that families experience when their family member has an acute psychotic episode. But families have expressed a desire to be involved not only in the assessment of their family member but in the long-term treatment and care of their family member. When the family is the main caregiver there is a need for communication with mental health key workers to assist them with information and support.

A Review of the Implementation of the Privacy Act 1993 and the Health Information Privacy Code 1994 by District Health Boards' Mental Health Services (Mental Health Commission, 2002), once again revealed high levels of frustration by families with their level of involvement with mental health services. This view was consistent in all three sites visited. Families expressed a need for "information about the diagnosis, the prognosis, the treatment plan, medication (*and its side effects*), and how they can best support their family member on their recovery journey" (p. 38). Although most families felt that the information packs that some services provided were helpful, they felt that these should form the basis for a long-term relationship with mental health services. Many families felt that they were still being considered as a nuisance, and that many clinicians still hid behind the Privacy Act as a reason for not releasing information about their family member (Mental Health Commission, 2002).

However, in the same review, clinicians expressed confusion about rights of the client and the needs of the family when dealing with the receiving or releasing of information. To weigh up the respective interests of the different parties and make a decision is not always an easy path and clinicians admitted to often err on the side of caution. Maintaining trust with the service user (*client*) is the clinician's primary focus even though s/he is aware of the family's need for information. Clinicians expressed a need for clarity of the law governing sharing of information and the need for more in-service training (Mental Health Commission, 2002).

The most recent Mental Health Commission (2003) document has reported on progress of the implementation of the Blueprint for Mental Health Services in New Zealand. The obligation that providers had towards family participation under the National Mental Health Standards was "to develop policies and procedures that actively support family/whanau participation in decision making and monitoring of services" (p. 40). Muesser and Fox (2000) had stated that the possible reason why family participation didn't often occur could be because there was no specific person responsible for the implementation of strategies to ensure it happened. Many New Zealand District Health Boards (DHBs) may believe they have fulfilled the obligation for family participation by employing family advisors who provide peer support and education services for family caregivers, and advisory services to mental health professionals (Mental Health Commission, 2003). However it was reported in this document that during Compulsory Assessment and treatment orders mental health professionals had not consulted with families, which had led to some well-publicised

tragedies. There have also been many instances of violence in New Zealand against the family, following the discharge and lack of appropriate professional care of family members with mental illness. Consultations are required with family during this process, however heed has not been taken, resulting in the murder of a number of people who are closely related (*family and significant others*) to the mentally ill person. Mental health professionals may on occasions consult with families as the Mental Health Act requires but this is not the same as "...heed the opinions of ..."

(Coddington, 2001, p. 39).

There is clearly hesitation and reluctance by mental health professionals to involve families in the care of their family member. In 2003 the Mental Health Commission stated that mental health professionals often comply with the requirement of family input but are "not proactive in seeking involvement of or information from the family." (p. 41). Consultation with them is part of this involvement and needs initiation from mental health professionals themselves.

"Good outcomes occur when needs are met," (p. 6) states the Blueprint for Mental Health Services in New Zealand (1998). Among the seven important strategic directions for the development of mental health services was the need for more and better services and ultimately good outcomes for Maori and Pacific people in New Zealand.

Maori and Pacific Mental Health in New Zealand

Mental health services have often been described as monocultural because they have not taken into consideration the needs and beliefs of other cultures living in New Zealand, particularly Maori and Samoan (Durie, 2001, Tamasese, Peteru & Waldegrave, 1997). According to Burns, Barrett, Daley, Duignan & Saville-Smith (1994) "the cultural integrity of families needs to be recognised" (p. 4) as it should for people from all different cultures.

A Maori Mental Health National Strategic Framework, *Te Puawaitanga* released in 2002, provided a framework and plan to assist District Health Boards to develop culturally appropriate services for Maori. The number one goal in this strategy was "to strengthen and develop the Maori mental health workforce," (Mental Health Commission, 2003, p. 30). *Te Rau Puawai* (supporting Maori students to gain qualifications in mental health) and *Te Rau Matatini* (supporting and developing the Maori mental health workforce) have contributed towards this goal. It was

acknowledged that since 1998 there has been an increase in provision of services specifically for Maori by Maori and that there had been initiatives to encourage Maori into the mental health workforce.

Maori had previously voiced much concern about the disruption caused when their people were separated from their land, which was owned on a collective basis. Maori believe this disruption has led to a breakdown in the traditional family/whanau values and ultimately their identity and support (Durie 1986). The separation of Maori from their land *and* their whanau/family is often a prescription for illness (Durie, 1989). Therefore Durie suggests that a partnership and sharing of power between tribal elders and mental health professionals acknowledging each other's expertise, is needed to remedy this situation. Maori have expressed a need for services *for* Maori to be provided *by* Maori to ensure that the service is based on Maori processes and beliefs that bring restoration of cultural values and identity to clients (Keelan cited in Durie, 2001).

The characteristics of such a service would include the use of Maori language, "incorporation of tikanga Maori (Maori custom), involvement of whanau, hapu and iwi, the use of traditional healing practices (*karakia* (prayer), *rongoa* (traditional herbal medicines) and *tohunga* (traditional healer) and the provisions for cultural assessment, cultural practices and whakawhanaungatanga (family relationship building)" (Durie, 2001, p. 227). Almost two thirds of Maori mental health service users interviewed in a University of Waikato mental health narratives project in New Zealand said that they had appreciated having access to a mental health service that allowed them to be part of this traditional Maori healing process, (Mental Health Commission, 2002).

The Samoan people in New Zealand also believe that the mentally ill person cannot be separated from their family, village, districts, and country of birth (Tamasese et al, 1997). These factors are essential to the sense of identity and belonging necessary for the Samoan person and therefore services, which provide for the inclusion of these cultural components, is required. Samoan people have stated that western diagnoses and treatment focused on the physical side of the mentally ill person whereas they viewed the person holistically - physical (body and mental) and spiritual dimensions could not be separated during the healing of the mentally ill person. Medical scholarships needed to be made available to enable Samoan students to study and become qualified in medicine. In a progress report by the Mental Health Commission (2003) it is noted that twenty awards of up to \$10,000 were now available each year for

Pacific/Samoan students to complete studies and training in mental health. Provision of these awards will ensure that culturally appropriate services would be provided by and for the Samoan people.

When a family member becomes unwell, families of all cultures, who are able and willing, want to become involved in contributing towards the recovery of that family member. Families want mental health services to include them in the recovery treatment process, by sharing information with them that is imperative to their family member's adjustment and progress. They also want mental health services to involve them in planning and decision-making, and provide support, education and training to help them cope with the needs of their family member (Community Liason Committee of the Royal Australian and New Zealand College of Psychiatrists, 2000).

The Treaty of Waitangi, New Zealand's founding and living document, was signed in 1840 as a covenant and constitutional agreement between the Crown and Maori in New Zealand (Project Waitangi, 1986). Burns et al (1994) stated that the principles of the Treaty of Waitangi should guide the development of all mental health services in New Zealand.

The three articles of the Treaty of Waitangi were finally adopted by the Board of Health's standing committee on Maori Health in 1985, as the foundation for good health for all New Zealanders (Durie, 1989). To fulfil this adoption there would have to be recognition of the self-determination of Maori, participation by Maori and equal partnership with them to develop culturally appropriate services. Whanau/family participation and partnership with mental health professionals was also crucial to honouring the principles of the Treaty for all New Zealanders. New Zealand's mental health planning and development now endeavours to honour these strong guiding principles

It is appropriate in relation to this research that family/whanau participation and partnership are key principles in this Treaty. It is on the basis of partnership that respect and equality is developed between groups of people who are working together for the benefit of each other, whether those groups are Maori and Pakeha, tribal elders and mental health professionals, or whanau/family caregivers and mental health professionals.

It is necessary therefore, to define a partnership and the relationship, which will support it.

Partnership and relationship

“Ti Tiriti O Waitangi (The Treaty of Waitangi) underpins the provision of health care for all New Zealanders,” quotes the Standards of Practice for Mental Health Nursing (Australian and New Zealand College of Mental Health Nurses, 1995, p. 1). These standards also state that professional practice is about involving family and communities in the care and support of clients and embracing, developing and maintaining partnership with family. Therefore Ministry of Health and Mental Health Commission documents and reports have recommended and directed that there be participation by families and a partnership formed between mental health professionals and caregivers as they provide care and treatment for mentally ill clients.

A partnership requires “a relationship in which two or more people *work together*” (Collins, 1999), and in the context of mental health, the relationship formed between these two groups of caregivers is ultimately for the long-term benefit of the person diagnosed with a mental illness. The family is not asking for a friendship but for a supportive working relationship with the professionals who are helping their mentally ill family member, for whom they provide care. According to Brammer and MacDonald (1996) the helping process involves building a relationship, which includes support and understanding, from which positive action can be facilitated. It is impossible to build a relationship without communication and likewise there can be “no effective communication, no influence, or understanding, without the presence of some kind of a relationship between the parties” (Andrewartha, 2002, p.184).

Brammer and MacDonald (1996) go on to say that length of contact affects this helping process. Families have said that often contact with professional staff which is necessary to build a relationship did not help to alleviate the burden of caring for their mentally ill family member” (Ferriter & Huband, 2003). Contact was brief and infrequent, contributing to the family’s sense of isolation. Families feel less alienated when contacts with mental health professionals have been recent (Tessler, Gamache & Fisher, 1991). Tessler et al’s findings highlight the need for mental health professionals to maintain regular contact with family caregivers.

As a foundation for a relationship between family and professionals, professionals would also need to perceive families positively, “believing that they are competent in meeting their needs and solving their problems” (p. 94) and so build on the family strengths (Jones, Garlow, Rutherford Turnbull III & Barber, 1996). Building on this foundation of positive belief in family caregivers’ abilities Jones et al. suggest that

professionals can then actively listen to families and provide help that will enable the family caregivers to become more skilled in solving specific problems they identify that need to be dealt with. Supporting and accepting the decisions, that family caregivers make, ensures that an effective working relationship can be formed.

Gartner, Lipsky and Turnbull (1991), when describing relationships between support services and families who have a child with a disability, describe these different caring relationships.

The family's relationship is usually 'individual, intimate, lifelong and subjective.' The professionals involvement with the child is 'time-delimited, in the context of many other children, and partakes of objectivity.' Neither is better than the other - they are different. The expertise of parents and of professionals is equivalent. --- As with most partnerships it is in bringing together persons with differing skills and aptitudes – differing expertise – that a successful relationship can be developed. (p. 82).

In the context of mental health and this research, clients are no longer children but families do have knowledge that is not always accessible by the professional during assessment and treatment planning, therefore there should be a recognition of the equal expertise that families and professionals possess when providing care to mentally ill family members/clients. Professional credibility with families could be improved when families are respected for their expertise as they work together towards the common goal of meeting the mentally ill family member's needs (Peternelj-Taylor and Hartley, 1993).

However family caregivers do have a responsibility to respect the equally important contribution that mental health professionals have to assist mentally ill family members towards recovery. Heflinger and Bickman (1996) discussed the attitude of families from advocacy movements, that aggressively demand their rights, who always presume conflict exists and that, professionals are deliberately withholding information and/or services from them. Attitudes such as these, provokes tension between professionals and families, which the writers say, can often hinder the development of a partnership.

Therefore, as June Read a well respected Educator in the mental health sector in New Zealand, stated, "Formal (mental health professionals) and informal carers (families) and the people for whom they care, need to become aware of each other's viewpoints, consider the advantages and disadvantages of working together in partnership and discover what each has to contribute to such a partnership" (Ministry of

Health, 1996, p. 68). Without this mutual respect it may be difficult to form a partnership and maintain it. Assumptions are listed in The Code of Ethics (New Zealand Nurses Association, 1995) that state “that relationships and interactions take place in a climate of respect for the other” (p. 10). The code describes respect in relation to individual/group/community with the view to creating a partnership that allows active participation in the nursing process. Although there is an emphasis on the client expertise in this document and no specific mention of the caregiver role this assumption could be extended to the expertise of the family as being part of the community that provides informal care to the client.

For partnerships to work there needs to be an understanding by families of the professional perspective of care and a real understanding by professionals of what the full impact of mental illness is on the whole family (Bishop et al. 2002; Kaas et al. 2003). Kaas et al. suggests that there is a need for “mental health providers to affirm the shared sense of partnership for the treatment of a person with a mental illness and reject the traditional ‘us versus them’ that tends to favour the provider’s judgement over the family’s experience” (p. 751). Mohr (2000a) states also that there has been much talk about participation and partnership but “professional language and subsequent behaviour continues to reflect a hierarchical position in respect to families --- places the professional in the role of “expert.” --- and a ‘them’ and ‘us’ attitude” (p. 18). An attitude of ‘them and us’ would appear to be a roadblock to a successful partnership.

Miles cited in the N.Z. Report of the Ministerial Inquiry to the Minister of Health (1996), stated that involving families requires a special skill that requires training that is balanced between being “academic and experiential” (Ministry of Health. p. 66). Hanson and Rapp (1992) stated that even though university courses do include training as to how to involve families, this is usually only in the form of one single module and may not be long enough to affect change. Therefore universities need to take the lead in providing more specialised training as to how to involve families more in practice. Farhall, Webster, Hocking, Leggatt, Reiss and Young (1998) found in Australia that where there was a need for mental health professionals to have a change of attitude towards families, this was more likely to occur following an extended training programme for professionals, rather than following a brief training programme. The evaluation report followed twelve weekly three-hour sessions including family caregivers and staff from inpatient and community mental centres.

In 1988 Spaniol and Zipple had also identified “the dramatic differences in the perceptions of families and professionals regarding satisfaction with mental health services and activities,” (p. 43) suggesting a gap between intention to involve families in the client’s treatment and the actual experiences of both groups of caregivers. However many professionals are aware of a gap that exists between themselves and the families (Hanson & Rapp, 1992). This gap is identified by Heflinger and Bickman (1996) as being between the *intent* to involve family members and the *actual* experiences of parents and professionals in mental health service delivery” (p. 103). Mohr (2000a) agreed that there was a significant gap between what professional caregivers say they *should* do to include families as members of the treatment teams and what they actually *do* in reality.

Therefore, if and where a gap exists there is an urgent need to address the causes of such a gap. A working relationship must be built between mental health professionals and family caregivers that will, and in the long term, benefit the people diagnosed with a mental illness and all those who care for them.

Conclusion.

Research revealing the benefits of involving families in the assessment and treatment of their family member and the provision of education, training and skills to cope with the complexities of mental illness in a family member has been found to reduce relapse thus lowering hospitalisation rates (Falloon, 1999). However, the literature has also highlighted numerous studies over the last 20 years, which have shown that families are still not being involved or included in the treatment of their family member as often as they would like to be and discussed some of the possible reasons for that. A limited number of studies have interviewed or surveyed the mental health professional’s perspective and these have described the negative beliefs and attitudes they have towards involving families in the treatment of clients. These studies also described the mental health professional’s perception that generally family caregivers were satisfied with the provision of mental health services they and their mentally ill family member received.

As a result of research conducted from 1982 to 2003 many recommendations have been made to policy makers and mental health professionals both nationally and internationally, encouraging and directing mental health services to involve family

caregivers in the treatment of their mentally ill family member. The review of New Zealand documents and reviews (1994 – 2003) certainly reflects a growing awareness of the need for a working relationship with family caregivers. Nonetheless it would appear from recent literature that families are still having difficulty being recognised as important team members in the treatment of their family member and therefore included on the team.

Family caregivers' experiences and views about their relationship with mental health professionals have been covered in numerous studies internationally and two studies here in New Zealand. It would appear though, that there is a lack of research, which has explored in depth the nature of the relationship from the mental health professional's perspective (Kaas et al, 2003).

Therefore in-depth interviews will be conducted with both mental health professionals and family caregivers, to explore the nature of the relationship between them to endeavour to understand the nature of this relationship and the factors that influence it.

Chapter two will describe the methodology used for this research and the method and procedure followed to explore this relationship.

CHAPTER TWO

METHODOLOGY

Introduction.

During the latter half of the 19th century and the 20th century human science researchers had been interested in working with the language and words of experience rather than traditional numbers. Positivist (quantitative) research had been concerned with “discovering facts from the social phenomena” and interpretative (qualitative) methodologies were interested in “understanding human behaviour from the informants perspective” (Minichiello, Aroni, Timewell & Alexander, 1995, p. 10). Researchers following the positivist tradition believed that exploration of social phenomenon should use the same scientific techniques as had been used to explore the natural sciences, however using these techniques in social research did not provide the depth of enquiry researchers were looking for. The interpretative paradigm inspired by the German Romantic Movement, on the other hand, provided “a non scientific account of enquiry” (Clark, 1997, p. 33) and recognised that exploring personal life experience and how that is experienced from the participant’s perspective could reveal an abundance of rich material with which to describe and interpret situations (Tesch, 1990).

Data gathering during interpretative qualitative research uses in-depth interviewing. Interviews are conducted when participants cannot be observed as they are involved directly in the situations needing to be studied (Seidman, 1998). To understand the situation to be explored the researcher needs to find out what the person thinks, feels, fears, desires or believes. As Minichiello et al. (1995) states this can only be known by inference and “one of the best forms of evidence for such inferences is the in-depth interview”(p. 22). During in-depth interviews, participants have an opportunity to tell their story as it is and this gives the researcher a chance to listen, and give value to those individual stories. The context of each story helps the researcher to grasp a fuller understanding of what is going on in certain situations (Seidman, 1998).

This research

As outlined in the introduction, the purpose of my research was to explore the nature of the relationship that family caregivers have with mental health professionals as they both provide care for 18-30 year olds diagnosed with a serious mental illness in two District Health Board areas of New Zealand. To discover and understand the factors that influence this relationship, it was important to me to gain an in-depth view of how this relationship is experienced and so it was decided to conduct in-depth interviews with family caregivers and mental health professionals. It was important to gain the perspectives of this relationship from both groups of caregivers.

Mohr (2000) stated that having a mother diagnosed with a serious mental illness meant that her research, covering professional attitudes in mental health settings, could not, by any means, be termed valuefree. Due to her personal experience of mental illness she found it difficult to “maintain a neutral stance in regard to her findings” (p. 597). I also have a family member diagnosed with a serious mental illness so my relationship with mental health professionals is ongoing, making it sometimes difficult for me to maintain neutrality also. Therefore it was essential that supervision of this Masters degree was vigilant to ensure mental health professionals’ views and comments they shared, concerning their relationship with family caregivers, were respected and considered equally and that I was always consciously aware of a possible bias.

My intimate knowledge of the family caregiving experience may be seen as a limitation. However this experience could also be seen as contributing a deeper understanding to the complex issues that surround the family caregiver’s and mental health professional’s relationship as they provide care for the family member/client diagnosed with a serious mental illness.

During the last seven years, New Zealand Ministry of Health has asked for submissions from families, consumers and clinicians to describe their experiences with mental health services (Ministry of Health, 1996). These submissions and recommendations produced many different perspectives which policy makers have used to guide future mental health services in New Zealand. However Mental Health Commission teams have also conducted surveys and spoken to focus groups about how family caregivers and consumers experience mental

health services when providing care to their mentally ill family members. Focus groups are a way of gaining public opinion about issues that are under scrutiny, (Bouma, 1996). However they are probably more suited to gaining the views of a community of people on policy development rather than the personal thoughts and feelings of an individual experiencing various situations. During an in-depth interview individuals may share more deeply their unique experience when they are more likely not to be influenced by the opinions of others or when they have difficulty making themselves heard.

To date it would appear that individual family caregivers and individual community mental health professionals in New Zealand have not been able to confidentially give their own personal perspective about the specific factors that influence the nature of their relationship. Although individual perspectives of the relationship have been revealed via the use of submissions, surveys and focus groups in New Zealand, the factors that influence the nature of the relationship have not been explored in any depth.

Therefore it was decided to interview 3-6 community mental health key workers and 3-6 family caregivers from two District Health Boards in New Zealand. Both District Health Boards were from separate geographic areas.

Semi – structured interview questions (*appendix four and five*) were designed to enable participants to share the nature of the relationship they have experienced with each other. The words participants use and the interpretations they make about this relationship are of focal interest in this research, (Minichiello et al, 1995)

Why use Thematic analysis?

During data collection there may be intuitive interpretation of an experience but it is during data analysis that there is a time to reflect on the meaning of that individual experience. Tesch (1990) states that searching for meaning can be found by identifying themes in the data. During the interviews, participants express some of these themes, but others emerge from more intensive scrutiny of the transcriptions.

Thematic analysis is a way of seeing something in the data or sensing a theme that is not obvious to others at first glance. Having identified these themes

or patterns the process progresses further by attempting to make sense of them (Boyatzis, 1998).

Thematic analysis has been used by many researchers in the area of caregiving experiences. Many readings of the data and reflecting on it helped to identify and describe the phenomenon of caregiving in context during Rose's (1998) study of the caregiving experience. She singled out tentative themes following identification of keywords and phrases in the first interviews she had conducted, which led to second interviews resulting in emerging themes being retained or rejected.

Kellett and Mannion (1999) also used words, phrases and passages to identify themes generated from in-depth interviews conducted to explore family caregiving of an older relative and the nurse - family caregiver relationship. In-depth interviews were also conducted by Ayres (2000) to explore the meaning of family adaptability to caregiving. Interview data was classified into themes, subthemes, categories and classes as she searched across all accounts, across each individual account and compared two individual accounts to identify overall patterns of meaning.

Therefore this method of analysis was chosen as the most appropriate to gain a clear picture of the issues and factors that affect the relationship between family caregivers and mental health professionals.

Method and Procedure

Both areas (Area A and Area B) where the planned research was to be conducted were visited, prior to submission of Human Ethics Committee applications, to explain the purpose of the research to key people in general and Maori mental health services in those areas.

In August of 2002 application was made to the Massey University Human Ethics Committee (MUHEC) for approval to conduct this research in two District Health Board (DHB) areas in New Zealand. Application also had to be made to the Regional Health and Disability (H&D) Ethics Committees from these two areas. A lead committee was nominated to oversee the application made to both H & D Ethics committees. The proposed plan was to advertise for participants in October and complete the interviews by the end of November 2002.

Approval was granted from MUHEC (PN Protocol – 02/117) on September 17th, following amendments made concerning inclusion of MUHEC approval on the letter of introduction and information sheet (*appendix one and two*) and consent form (*appendix three*) sent to possible participants.

Problems encountered with Health & Disability (H&D) Ethics committee applications (Ethics reference: 02/08/15 (area confidential))

The researcher was invited to attend the Lead H&D Ethics Committee meeting (Area A) to answer any queries about the research to be conducted. No concerns were raised at this meeting but later that month concern was expressed by Area B committee members that families would be talking to the researcher without the consent from their family member (diagnosed with a mental illness).

Fears were expressed by committee members (Area B) that the family member with the mental illness might read the thesis or an article about the research at a future date and recognise themselves, thus jeopardising their right to privacy. Therefore only provisional approval was granted on October 10th, asking that patient consent be obtained before family caregivers could be interviewed by the researcher.

The inability of family caregivers to talk about their *own* experience of their relationship with mental health professionals, without their family member's permission was contested. After consultation with the researcher's supervisor and the chairperson of the Massey Human Ethics Committee, it was agreed that the fears expressed with regard to patient privacy were groundless, as confidentiality was clearly upheld by:

- the use of pseudonyms
- avoidance of identification of the DHB area where interviews were conducted, in the thesis or any articles published by the researcher and
- close supervision by thesis supervisors to monitor the analysis and to ensure that anonymity of all participants and family members was maintained.

Re-application was submitted and final approval to proceed with this research was granted on 9th December, 2002.

Recruiting participants.

Permission from the respective General Directors of Mental Health from the respective District Health Board (DHB) areas had already been sought to meet with Community mental health and Maori mental health team leaders to assist with inviting mental health professionals to participate in this research. Visits were made to the two DHB areas to introduce myself to community mental health team leaders to inform them of the purpose for this research and to ask their permission and cooperation with recruiting participants from their respective community mental health teams to participate. All directors and team leaders granted permission with the exception of Maori mental health services (Area B), from whom no response was received and therefore no meeting could be arranged.

Team leaders placed advertisements in the staff rooms inviting mental health professionals to participate in the research and individual letters of invitations were distributed amongst the team members.

When visiting the two DHB areas Schizophrenia Fellowship and Richmond Fellowship fieldworkers were visited to discuss the research with them. Although no difficulties were anticipated they were asked if they could be available to support any family caregiver participant who may need someone to talk to following the interviews. These fieldworkers also agreed to be my contact support while interviewing in their area.

Advertisements were placed in the local free newspapers in both areas, inviting family caregivers to participate. It was hoped that, by advertising more widely, the researcher would recruit a wide variety of participants from the general population. However this did not eventuate as only one person responded to the advertisement in Area A and no newspaper responses were received from family caregivers in Area B.

With the assistance of the chairperson of the family support group in area A, I was able to recruit the two remaining family caregivers needed from this area. However it was only by using snowballing via two personal friends that I was able to gain two family caregiver participants and two more mental health professional participants from area B.

Letter of introduction and the Information sheet (*Appendix one, MHP and Appendix two, FCG*) and Consent forms (*Appendix three*) were mailed to the four

mental health professionals and three family caregiver participants who had agreed by phone or email to consider being interviewed. Completed consent forms were returned with no withdrawals. While in area B I was able to recruit three mental health professional participants, one of whom was also an family caregiver and three family caregiver participants. Finally seven mental health professionals and six family caregivers completed consent forms and agreed to be interviewed. Interview questions were written as a guide to explore the relationship from the mental health professional's perspective (*Appendix four*) and the family caregiver's perspective (*Appendix five*) asking background questions as to how the participant became involved in the mental health area leading into questions about the negative and positive factors influencing the relationship. The reasons and perceptions of the contact they had with each other, the policies they were aware of that encouraged the involvement of families were discussed, leaving time for any additional information each participant may have wanted to share with me at the conclusion. Mental health professional and family caregiver interviews were completed in Area A in March 2003 and Area B in April 2003 well behind the planned timetable.

Transcriptions were read once through in entirety to familiarise myself again with the perspective the family caregivers and mental health professionals were expressing, then they were read numerous times with the intent to search the transcriptions for significant words and phrases that described the nature of their relationship.

Five main themes were identified from family caregiver interviews and four main themes were identified from mental health professional interviews. These themes and the sub-themes will be discussed in the next chapter.

CHAPTER THREE

THEMES AFFECTING RELATIONSHIP

Introduction.

The seven mental health professional (MHPs) (including one who had been a family caregiver) and six family caregiver (FCGs) participants who provide care for 18-30 year olds diagnosed with a serious mental illness, were interviewed. Each group of participants had a particular perspective on what kind of relationship should or did exist between themselves and the other group of participants and the factors they believed influenced that relationship. Therefore in this chapter the themes that were identified within each group are presented separately.

Pseudonyms were used for all participants as well as any other names mentioned during the interviews. No reference was made to the geographic location where interviews were conducted to ensure anonymity for all participants.

Mental health professionals (MHPs) themes.

Four main themes describing MHPs knowledge and awareness of the need to involve families and the factors that influence the relationship between MHPs and FCGs, were identified from the interview material.

OUTLINE OF THEMES.

Theme One.

Awareness.

(A) Involving family caregivers.

- (a) Positive effects on the client
- (b) Negative effects on the client.
- (c) Some room for improvement.
- (d) Maori perspective on involvement of family/whanau.

(B) Mental illness affects family caregivers.

- (a) Sources of stress
- (b) Support needs

Theme Two.**Problems within mental health services.**

- (a) Difficulties with psychiatrists
- (b) Difficulties with the inpatient unit and crisis services.
- (c) Difficulties with other community mental health service colleagues.
- (d) Difficulties with time constraints
- (e) Difficulties with lack of training
- (f) Difficulties with policies and procedures
- (g) Difficulties specific to the two supported accommodation services
- (h) Difficulties with lack of appropriate supported accommodation.

Theme Three.**Problems with families.**

- (a) Who am I working for?
- (b) MHP's "fix everything"?
- (c) Family caregiver complaints.

Theme Four.**Problems with confidentiality.**

- (a) Win/win situations.
- (b) Win/lose situations.
- (c) Rights of the family?
- (d) Consent forms not used routinely.

THEME ONE: Awareness**(A) Involving family caregivers.****(a) Positive effects on the client.**

There was general acknowledgement amongst MHPs of the clearly stated Ministry of Health and Mental Health Commission directives to involve families in the client's treatment and the valuable support families provide clients on their road to recovery.

Several MHP's stated that involving families in the client's treatment helped the client during his/her recovery. "The problems will go along a lot better when you're simply involving the family ---the prognosis is much better – inviting them to

participate and being quite direct about that,”(John). Rachael said that when she is letting the family be part of the process it makes her work a lot easier because she knows the client is being supported, following discharge back into the community. Families provide Rachael with essential historical and relevant information that assists her to help the client while s/he is adjusting to living with a mental illness. George was often more hopeful of a client’s recovery when that client has family or other consistent support. Not having this long-term regular support was identified by Polly as one of the problems clients faced in their recovery. Clients without family support can become isolated from community sources of support, other than the professional mental health service support provided and this can affect their adjustment in the community. When making adjustments to any major life changes, including the onset of a long term mental illness, support and encouragement from not only professional health carers but significant others in their community is necessary.

A number of MHPs interpreted the National Mental Health Standard's directives to involve families in the client’s treatment as just reinforcing “good (professional) practise.” The key elements of good practise were described by several MHPs as being, genuine nurse warmth, mental empathy, respect for the family and building a relationship with the family as they would with a colleague or client.

MHPs spoke of the need to work together with the family and build a rapport with them when treating the family member with the illness. However, even though they indicated that efforts were often made to build good relationships with the client’s family, there were very few examples given, as to what they did specifically to encourage this relationship.

MHPs have a good knowledge of the requirement to involve families and form a relationship with them but there seemed to be much uncertainty as to how this could be put into practice. MHPs also reiterated that the client needed good supportive family relationships and this was a good reason for involving families in treatment of the client. However, MHPs also spoke about some of the negative effects some family relationships can have on the client.

(b) Negative effects on the client.

MHPs described families who act in a custodial or paternalistic manner towards the client. Treating the mentally ill family member like a child or lowering of age appropriate expectations of the family member by family caregivers was seen by MHPs as disempowering and therefore a hindrance in the recovery of their clients. John

believed that that person “may not get into any great difficulties but I don’t think they’ll grow or change.” Rachael agreed that “parents treat them (*clients*), age inappropriately and this doesn’t go down well (*with the clients*) --- the family member (*client*) can feel really disempowered or the family doesn’t have respect for them anymore --- deep down they (*clients*) understand that their independence is slipping away.” Polly illustrated a male client’s loss of independence. “He drives and does the shopping (*for his mother*) – (*but*) he is treated like this other person who can’t manage his money.” Inappropriate age expectations in this scenario, may be due to the mother not adjusting her expectations according to the wellness of her son or because she was fearful, from past experiences when he was unwell, of his inability to manage his own finances. Also the male client may not have expressed his displeasure at this treatment and may need to be trained by MHPs to skilfully deal with this situation himself.

“A family who has dysfunctional dynamics, whatever they may be, can make things more difficult -been abusive or mistreated in the past – the relationship won’t be good (*between client and family*),” (George). The negative affect of family dysfunction on the client may mean helping the family to deal with the dysfunction that may have contributed to the mental illness in their family member. It is possible that some dysfunction could be caused by the family caregiver dealing with long term stress, grief and burden of caring for their mentally ill family member. However the client’s need for treatment is perceived as paramount by mental health professionals, therefore these issues may not be able to be investigated further by them.

There was some acknowledgement by MHPs that they could improve on how they dealt with families of clients.

(c) Some room for improvement.

John, Rachael and George acknowledged that there certainly was room for improvement in some areas of their practise, particularly where they had not considered involving the family in the treatment of a client, where information has not been passed on, where family history had not been taken and families had not been listened to. George shared some valuable insight that he had learnt from past mistakes - “I’ve often learned some hard lessons from that - not listening, then going away and forgetting about it. Further down the track you look back and they (*family*) were right and you should have had a different view.” No illustrations were given of times when families had been listened to from the beginning and a crisis had been averted. Although there was acknowledgement of where mistakes have been made, acknowledgement is only a

first step to improving the way MHPs deal with families. Discussion to ascertain the reasons for the mistakes being made and strategies addressing those issues would take this acknowledgement a step further.

MHPs stated that families had not been directed to community family support groups when there had been a need for more support than what mental health services were able to provide for them– “I notice I don’t do that a lot - I need to critique myself on that,”(John). A number of family support agencies exist in N.Z but families may be unaware of their existence during a first episode or even subsequent episodes of mental illness. Where MHPs don’t provide education and support to families during this time of adjustment, informing them of this valuable resource in the community is essential.

John’s service manager used to remind him that, “Family participation, consumer participation, integration – these are the pillars which the service should be delivered on.” These are indeed pillars that mental health services need to be built upon but if one pillar is missing, such as family participation, the building is in danger of collapsing. The service needs all these pillars to provide a comprehensive service to their clients. However, recognising the need for these pillars is far from incorporating them into everyday practice. The absence of actual examples of where family involvement had been valued and respected seemed to indicate that the need to involve families is acknowledged but not part of MHPs everyday practice.

Two Maori participants were interviewed and their cultural perspective of involvement of families is important when considering any directives and requirements to involve families.

(d) Maori perspective on involvement of family/whanau.

The treaty is built on the four principles of partnership, protection, participation and self-determination. Maori mental health services endeavour to integrate these principles into their provision of care for Maori mental health clients.

The three Maori MHPs interviewed contributed much information about the value of family (whanau) for Maori and the expectation that family be involved when providing a mental health service for Maori. Contact with families is a very important component of the Maori service to the client as this helps to bring a sense of belonging and a place to stand. “Their identity’s important, their marae, their whanau – there’s more to family,”(PS). So restoring links with Whanau, Hapu and Iwi contributes towards that person’s progress and recovery. The whanau/family is seen as an integral part of the person and therefore the principle of partnership between MHPs, client and

family is encouraged, if the tangata whaiora (client) consents to their involvement. Family participation is highly desirable and contributes towards fulfilling the requirements of the Treaty.

Also it was stated that the difference between Maori and Pakeha health is in the way Maori deal with things and how they perceive them. "The healing process is quite different." (Pare). The emphasis during recovery is placed on the whole person – Tahahinengaro (unseen mind), Wairua (spirit), Tipuna (ancestors), Whakapapa (geneology), whanau (family) and Tinana (physical issues), (PS). The Kaihauora of this Maori mental health supported accommodation home described the importance that is also placed on using Tikanga (traditional Maori protocols). When these protocols are not observed it can cause Maori clients and family to feel quite uncomfortable. Other cultural components such as Rongoa (traditional medicinal use of plants) may also be used to maintain wellness alongside anti-psychotic and other medications.

When a client is developing a mental illness or dealing with the effects of it on his/her life, s/he often "looks back at their family with memories – they'll want to go back to their place that they were safe in, maybe as a child, in their heart," (PS). He implied that when a client was adjusting to a mental illness the Maori client may remember the care and nurture they received as part of the wider whanau and area where they were raised. This may cause the client to want to make contact with that whanau and have their support as they work towards recovery. Therefore PS said that it is important for those who express the desire to be linked with whanau, to try and place and maintain clients back in their own communities with their own whanau. Whanau/family is a valued component of the Maori identity, which helps to give the Maori client the sense of belonging they may have lacked prior to their illness. A breakdown in a sense of belonging is considered a prime source of stress for Maori clients, triggering the development of a mental illness.

These MHPs believed that the best thing is to be open with the whole family, in terms of what everyone is doing due to the belief that the Maori sense of identity is closely linked with whanau. However confidentiality of the client still has to be maintained. The client may not want his/her family involved in his/her care and this right has to be respected. Unfortunately the client's refusal to have family involved in his/her treatment is a difficulty that families of all cultures have to deal with. Maori and mainstream MHPs have to deal with the family needs for information and involvement while respecting the client's wishes. The client's right to confidentiality

and the MHP having to deal with the family's need for information is covered more fully in the fourth theme.

Although the Maori MHP participants shared a lot of information about what was important when providing Maori with a mental health service specific to their cultural needs, there were few examples given of how they had actually involved families in the care of the Maori clients they support. Some criticism was also directed towards families whose expectations of their family members were too high and families who demanded information that the MHPs believed was confidential.

There were few examples of where MHPs had built good working relationships with the client's family or how they fulfilled the family's needs for education and support. Generally there was more of an emphasis on the clients' needs rather than the family's needs, despite questions during the interviews asking about the positive and negative factors that affected the MHPs' relationship with the families.

It was interesting to note that the MHP, who also had a mentally ill family member, had a different perspective about the family's needs depending upon from which position she was speaking. When dealing with her family member this MHP found it was much more distressing because of the emotional ties she had with her son, whereas when she worked with clients she found that she was able to be more objective. Experiencing the need for reassurance, affirmation and information while she was distressed family caregiver and then being asked for these elements of care when in the position of MHP provides valuable insight as to how to communicate with families of clients during these times.

All seven MHPs expressed awareness, not only of the need to involve families in the treatment of the client, but of the stress the family experiences when providing care to their mentally ill family member and the resulting need for support.

(B) Mental illness affects family caregivers.

(a) Sources of stress

MHPs described some of the sources of stress families endure when there is a family member developing or has been diagnosed with a mental illness. Fear was identified as a common source of stress for families. "They're frightened or they're exhausted," (John), "They think this person's going to behave strangely – they're fearful that something's going to happen," (PS). "They (family caregivers) give in and do things for them (younger clients) because they're frightened." (Polly).

MHPs shared examples of family caregivers “copping it” when their client was unwell (George) and that they were often fearful because “no-one was there to support them,” (PS). It was also acknowledged that sometimes the consequences of a family member with a mental illness who is dangerous and “calling all the shots” is very stressful for those family caregivers. Polly said that they “just have to manage the best they can.” To manage as best they can seems a huge responsibility for the already stressed family and especially when there is little support to deal with these behaviours. PS doesn’t believe that families should be caring for adults “who have got very, very challenging behaviours.” In these instances there would appear to be a real need to assess the family’s ability and willingness to care for family members who continue to exhibit such volatile behaviour.

Fear is often a strong motivator for families’ actions when a family member becomes acutely unwell needing medical intervention. Following an acute episode that may have involved delusions, hallucinations and instances, where there has been real danger to self or others requiring a call for ambulance or police assistance; trying to negotiate a compulsory treatment order where a family member has no insight to the need for being admitted to a hospital ward; observing severe side effects from medications; all these can produce fear for the caregivers as they consider their family member’s safety, health and future.

Other emotions that MHPs said families experienced were, worry (Rachael), feeling desperate and feeling like, “they hate this person at the moment.”(Pare). Families often hate how the illness has changed the behaviour of a person who has been a valued and loved member of a family.

Lewis identified blaming themselves as another source of stress, “A mother says, “What have we done wrong? Was it because we were working?”” He said, “I can understand the natural process that most families go through and it’s quite normal for her to be searching for reasons.” Lewis told this mother that blaming herself was not going to help herself or her family member. Ongoing education about mental illness, reassurance and support may be needed to provide evidence to this mother that she was in no way to blame for her family member’s mental illness.

The stress of dealing with the complex problems associated with caring for a family member diagnosed with a serious mental illness, can cause families to give up or become “burnt out.” Two MHPs said that some families have really done their dash in terms of supporting their family members and they’ve had enough of it all. As George

says, “They (family caregivers) don’t want to know anymore --- they don’t want the client to contact them – they’ve disowned them.” He spoke of the high rate of burnout amongst the families of clients who possibly have kept going and not been able to give up for a variety of reasons. “We can expect too much from families. I might see someone for half an hour a week – they (family caregivers) are seeing them every day - --- they are all day every day – they can’t switch off --- they never get a break.”(George). “I don’t blame them sometimes for wanting a break,” Polly added. When families have become stressed and in need of a break she has had to show families how to give each other private space so that client and the caregivers can begin to have a life of their own.

MHPs interviewed, were generally aware of the constant stress of dealing with a family member who was experiencing psychotic symptoms 24 hours a day. Apart from enabling them to create some space for themselves few suggestions were given to how MHPs could share the burden of care and therefore help families to avoid becoming burnout.

Some families have finally had enough or can’t maintain the level of care they have been providing. MHPs stated that they now have to assist the client who has been supported by his/her family in the community to find another source of friendship and support. This can be difficult and time consuming for MHPs to arrange.

George described family caregivers feeling isolated and unsupported because one person in the family is providing most of the caregiving. However there were no suggestions as to how families experiencing this isolation could find more support so the burden did not fall on only one person. Although family meetings, to discuss the sharing of the burden with other members of the family or other community care providers could have been a solution, it was expressed by some MHPs that it was rare for them to organise and conduct meetings to address family concerns and issues.

Pare has observed that a lot of mothers “just take such a lot of responsibility.” As has been discussed women are traditionally the nurturers and caregivers in the family but who cares for the women while they are providing most of the care for a mentally ill family member? Lewis has had to help one family solve this problem and part of his work with one client involved “mobilising Dad to support Mum in a positive way.” It was encouraging to hear how this MHP had not only recognised the mother’s need for support but had actively worked with the whole family to find a solution to the problem.

MHPs were very aware that a number of families had had bad experiences with mental health services in the past, which affected the formation of a relationship with a new MHP. “One fellow actually turned his back on me when I walked into the house and refused to talk to me – he was expecting shoddy service – he perceived shoddy service.”(George). A negative response from family caregivers provided a challenge to George, to try and prove that he was going to do his best for the family. Polly also made the statement that “You pick up a lot of baggage as they (*family caregivers*) go along,” (Polly). Past experience of relationships with mental health professionals presents a challenge when attempting to form a new relationship with the client’s family. Although one MHP indicated his determination to build that trust he was aware that building trust again requires much time, patience and effort.

Often this trust has been broken when as John highlighted, there has been a need for families’ to have a confidential “talk about how hard it’s been or how frightening or how frustrating this has been.” He acknowledged that they should provide opportunities for meeting with the families more often so that this family caregiver need is addressed. Rachael also spoke of this need because “family caregivers talk a lot more candidly away from their family member (*with the mental illness*) at times.” To make the opportunity for this to happen will take some planning and organising using the MHPs knowledge and skill in dealing with the family and the client needs. A balance will have to be provided between the family member’s rights to privacy and the family caregiver’s right to share and receive information confidentially. These issues will be discussed further in theme four.

Making decisions about getting their family member admitted, can be a very difficult time for the family “Sometimes they can be very concerned about their family member and ultimately we need to get them admitted and it’s a very hard decision for them to make,”(Rachael). Other hospital admissions do not require compulsory admissions against the patient’s wishes. Families can be in quite a quandary when having to consider whether they sign the papers for a compulsory treatment order as they don’t want to upset their family member and be blamed for ‘forcing them into hospital.’ MHPs said that often they take the responsibility to sign the papers for a compulsory treatment order thus easing some of the family guilt and stress.

George was particularly aware of the family’s need to offload, let off steam and receive some reassurance. He mentioned that one particular caregiver “got quite a reputation amongst the service of phoning up and being abusive when her partner was

unwell.” When he just listened, this caregiver said “after half an hour or so” that she now felt a lot better. Families have “been under a hell of a lot of stress and it’s easy for me to put the phone down and say, that was over nothing, but for them it’s real and sometimes you only need to do a little bit of reassuring,”(George). Listening takes time but this MHP did take the time to listen and ease the burden experienced by this family caregiver.

When family caregivers see that their family members, who have been diagnosed with a mental illness, are not able to reach their goals or attain the goals the family were hopeful of them reaching, this can also be a great source of stress. “They (*family members*) don’t reach those milestones and careers – it all goes out the window – very difficult and painful. They (*family caregivers*) are managing their grief and pain.” (George). Watching their family member come to terms with the illness is hard enough but they also have to deal with the loss of dreams that they may have had for their family member or see the dreams that the family member had made for him/herself disappear also. Awareness of the ongoing grief families experience is a first step but many MHPs did not discuss how they deal with the family’s grief.

Pare, having had a family member with a mental illness herself, stated that she had to get counselling to help her deal with it all. She said that often, families have to deal with a lot of issues, and that they need to get counselling if they are able to. Polly was also aware of families having to deal with “that grief of what they have lost ---they might need to go off and have counselling themselves for that grief and going through that process,”(Polly). However many families would not be able to afford to go to counselling individually or as a family. The responsibility for providing similar professional counselling support while families’ work their way through the grief process, might lie with mental health professionals who would have a greater understanding of mental illness and the problems associated with caring for a mentally ill family member.

(b) Support needs

MHPs provide some support for the families coping with stress However building rapport and eventually a relationship requires contact with the family by phone, home visits or meetings which takes time and effort. It requires equal contribution by phone or visiting or meetings. Families often made contact with MHPs and some examples of when families contacted the MHPs were discussed.

The reasons for initiation of contact between the MHP and the family caregiver varied considerably. John said that caregivers contact him “wanting to find out what’s actually happening. They’re worried – or the doctor’s put them (*family member*) on some medication and they have no idea (about it), wanting to be involved or wanting you to take some of the problem away.” George had a number of family caregivers contact him “when family members are showing signs of unwellness or to cancel an appointment on behalf of the client,” and sometimes they also ring with complaints about how something has been handled. Often family caregivers “have concerns or ring with things which they can’t answer. I, kind of, act as the communication process with the psychiatrist and the other members of the team,” (Rachael). Lewis mentioned that he knows that families need to be able to contact him at times so he would rather have them contact him and avert a crisis than leave it till the next day or the next appointment. MHPs are sources of information about the care of their family member and therefore it would be necessary for regular contact to take place with them.

Pare and PS, being managers of supported accommodation homes have families who live some distance away, contacting them to ask if family members need money or clothes or to ask if they can come to visit their family member. Having families contact them for these reasons is encouraged as it is supportive for the clients to have family take an interest in their welfare and maintains the links they often value with family.

Although families contacted MHPs frequently, there were few examples of when MHPs contacted the families. George and Polly said that they would contact families if they are “a bit worried or there needed to be a change in treatment” or the client was “not doing very well and may need to go into respite or hospital.” Some MHPs contacted family caregivers to advise them of family meetings but most of the MHPs said that family meetings were not a regular occurrence.

MHPs acknowledged that the family’s need for education and training was an area that required more attention by mental health services. MHPs do not offer any specific education and training to families at present and there was only one suggestion by one MHP to provide any in the future.

Pare had previously been involved in the setting up of the Schizophrenia Fellowship in one of the geographic areas visited and saw this family support group as a means of providing the education and support needed. “For a long, long time one of the struggles that we had, was to get some sort of training in place for the families to get an understanding of the illness. They don’t know how to support properly,” (Pare). Lewis

believed that families need to be equipped to pick up any sign of the person getting unwell and that education would help these families to identify early warning signs specific to their family member. Once again there seemed to be uncertainty amongst MHPs about how they could provide this education apart from providing pamphlet information available from Schizophrenia Fellowship.

Families who have either just face the first episode of mental illness in a family member or may not have a diagnosis yet have different needs to those families who have been living with chronic mental illness in their family member, according to Rachael. These families often “still feel positive and optimistic a lot of the time about what the future may be.” She said that spending time with families, who have cared for their family members for a long time, is quite negative for these families in the early stages of diagnosis. She expressed a desire to do more group sessions with families dealing with the early stages of mental illness, so families could come together and receive education together --- “It gives them an opportunity to network together.” The desire to create this opportunity for families would provide for some of the family needs for support but at this stage there were no definite plans to start such a group in this area.

The vulnerability of the family caregivers was described by George: “It’s about treating the family like a clock and if one cog breaks down and stops working properly that affects all the other cogs in the family as well.”(George). However even though MHPs are aware of the family’s sources of stress and the needs related to this stress, MHPs described various difficulties that they believed hindered their ability to provide for the family caregivers needs. The following difficulties were perceived by MHPs as hindrances in their ability to have a working relationship with the families and to involve them in the treatment of clients.

THEME TWO: Problems within mental health services.

MHPs in both geographic areas expressed frustration when dealing with other professionals involved in the care of the client.

(a) Difficulties with psychiatrists.

A number of MHPs expressed the frustration with such a high turnover of psychiatrists in their respective DHBs. When there is such a high turnover there can be a lack of continuity of treatment, particularly when communication in the reports and files is not passed on or not fully recorded for future reference. According to John, he

has heard families say, “Oh no, not another one!” when a new psychiatrist comes on the scene, because they have often had so many changes of professionals providing treatment for their family member and each one may have had a different way of treating their family member. There needs to be continuity and integration of treatment so the individual’s recovery journey can continue to move forward as s/he is ready and this may be a valid hindrance in the recovery of the client and a source of frustration for the family caregivers.

It was felt by MHPs, that although nurses and social workers would think much more readily about involving the family in the treatment process there needed to be a lot more work done to get psychiatrists to involve families and to share important information with them. According to MHPs there has been considerable difficulty in getting this group of professionals to share information with people involved in their clients’ treatment. Psychiatrists were often perceived by MHPs as a “conservative profession ----who were slow to embrace change” and as “behind the times.” Psychiatrists were also perceived as being in a position of great power as the expert and this attitude was not in keeping with the premise that “you’re not the expert –you’re actually just one part of it (*the team*)” (John). There was an attitude, Pare had observed, that was still prevalent amongst many psychiatrists which conveyed, “Look I’m the professional here!” A pompous attitude by one member of the treatment team will not help to build a relationship among all people involved in the treatment and support of the client.

Psychiatrists were often heard and seen to “minimise the client,” (PS), which did nothing to restore the client’s confidence in his/her ability to work towards recovery. A client is not an illness. They need to be seen as a whole person with many components – strengths, talents, personality, family and friends, to name a few. However this belief is a key component of the recovery focus and would need to be embraced by all on the treatment team.

Several MHPs commented that Psychiatrists never listened and that even they themselves were not heard when supporting a client at an appointment. The impression was conveyed to them that psychiatrists were there only to identify symptoms and dispense medication accordingly. However, in these situations, surely it is the responsibility of the MHP to advocate for the client and ensure that the psychiatrist receives this relevant information? The MHP would have background knowledge of

the client similar to that of the family caregiver, which would be essential to further progress in treatment.

One psychiatrist was reported as divulging to an MHP that it was not necessary to enlist the help of a special interpreter to assist an Asian family to understand what had happened to their son and grandson who had become acutely unwell. Members of the client's family were very distressed and very concerned about his health. According to this MHP, respect and consideration for the cultural differences and needs of this family were judged to be a waste of the psychiatrist's time. It was encouraging that this MHP was not only aware of the family's need but was prepared to take the responsibility for trying to provide for their need of an interpreter.

Another MHP commented that in his experience with Psychiatrists, they often "don't have the foggiest what is going on with the families." Families were under tremendous stress but this often eluded the psychiatrists' attention. Psychiatrists were perceived as not having a clue as to what was happening with the client's family and this attitude caused considerable frustration for this MHP.

Therefore, the relationship psychiatrists had with MHPs and families during the treatment of clients was not looked upon in a positive light by any of the MHPs interviewed.

(b) Difficulties with the inpatient unit and crisis services.

The attitudes of staff at the inpatient units caused some difficulties for the community mental health team professionals also. Frustration was expressed over the different focus that inpatient units have, compared with the focus of community mental health – "They look after sick people - we look after well people," (Polly). As a result of this different focus, ongoing care to the client is not always co-ordinated well. Lewis says that the "Inpatient unit is often just concerned with meds (*medicine*) and discharging the patient – out in a few days and still very psychotic – nothing has been done for them (*clients*)." Discharging clients without due communication or integrated planning between inpatient care and community care may cause far-reaching consequences affecting not only the clients, but also the family and the community at large.

As staff from inpatient units were not interviewed it was not possible to ascertain their perspective in relation to the issues raised. However, communication between inpatient services and community mental health services should be imperative for the

treatment and the recovery of the client. Communication between Crisis services and these services is also essential.

“Crisis teams have a difficult role,” according to Rachael as “– they are there to assess and admit people to put it bluntly. Clients get very unhappy with the way the process happened.” Procedures for admission are very stressful times for clients and their families, when possibly the client is in denial of their need of treatment but the family could have been observing an ongoing deterioration in the mental state of their family member. The MHPs expertise and skill in risk assessment and admission protocol would be needed to facilitate this process with as little stress as possible for the client and family.

(c) Difficulties with other community mental health service colleagues.

MHPs criticised some of the methods used by their colleagues. Pare felt another part of the mental health service should have been responsible in a certain situation for giving families some key information and had neglected to do so, causing a lot of stress for the families. She felt that there was no excuse for information involving care not to be passed on to those providing care of the client.

Other colleagues were observed who “go in and take over and sort things out and create dependency ---- and those who focus on the psychiatric symptoms and don’t look beyond the psychiatric system,”(Lewis). Going in and rescuing was not seen to be helpful long term, as when that MHP was no longer available, then the family needed to be able to continue to cope independently of the MHP. Families needed to be supported and empowered to solve the difficulties in a way that would be consistent and achievable for the whole family.

Sometimes MHPs thought it was necessary for them to look at other areas of the client’s life such as troublesome relationships or financial difficulties, which may be triggering certain symptoms. A relationship with the client and the family can identify these individual triggers and some solutions that will help the client and the family to manage the stress that may be triggering symptoms, more effectively.

Difficulties with other professionals within the service were not the only reasons given for lack of a positive working relationship with families. Other reasons related to MHPs conditions of employment were discussed.

(d) Difficulties with time constraints

Involving families was often seen by MHPs as very time consuming and “there’s never enough hours in the week to do all the work – it’s time constraint – it’s a biggy,

that's the main one," (George). Carrying a caseload of 40 or more and travelling big distances with files having to be kept in four different locations does not allow time to provide the fuller service that Lewis would like to be providing. Frustration was also expressed by MHPs about the time needed to do statistics, such as recording the number of visits completed and details about those visits, attending team meetings and in-service courses. All these commitments they felt, limited their time to meet and communicate with families.

However, Pare saw 'not having enough time' as an excuse. "That's a cop out," she said, "the reality for me is that if it's going to happen, then we set the time aside – it's a matter of organisation." Coping with the many components of any job, effective time management is essential. Communication with the family is a part of the job description and therefore contact with families may need an equal time slot alongside other commitments to the client.

(e) Difficulties with lack of training.

MHPs mentioned that there often was a lack of training in the area of involving families. One of George's goals last year was "to get better at working with families. When he sought to find out what training was available, there was "very little, very little. Off the top of my head I can't recall ever doing any training. I remember last year looking around and there wasn't a lot to be found." MHPs acknowledged that they do not have the specific skills required to involve families and that they need to develop that skill but if the education providers do not plan courses that are specific to MHPs needing to gain these skills, this frustration will remain.

Some MHPs had attended Falloon and Fadden's (1993) "Integrated mental health care training" which is a programme to encourage and train MHPs how to involve families in a way that would be beneficial for the client, the family and the professional. Although the principles were seen as sound by MHPs, the methods were often seen as "artificial" (George), "being pitched at such a basic level--- and very painting by numbers (*follows too simple steps*). --- Doctors particularly felt patronised by him," (John). There appeared to be a belief that these simple methods would not work when assisting families in the care of family members.

Uncertainty about how to involve families and lack of training to gain skill in this area was expressed by two MHPs. Integrated mental health care training has been made available to MHPs in NZ but three MHPs found that the methods used were not acceptable to them, even when international research investigating the use of these

methods has shown such promising results. This Integrated single-family model of intervention, which involves education of the whole family, identifying early warning signs and problem solving skills may be just what families need to empower them in the caregiving. As this model includes the whole family and the professionals on the treatment team, it could be an appropriate and helpful way to build a relationship between MHPs and family caregivers.

(f) Difficulties with policies and procedures.

Two participants were very critical of their own service policies and the governmental policies. These were seen as protocols that were written down but often were not followed and were about “saving our own butts.”(Pare). Often policies were seen as evidence for the auditors when they came in so they could see that they had this policy on, for example, ‘what to do when incidents occurred.’ But as PS stated, “What are we doing about it?” “Protocols are wonderful but if you’re not going to follow them then the thing is not going to work there,”(Pare). Policies had to be filed and observed for the safety of the clients but were more often seen as providing safety for the service when something went wrong.

When asked about any policies that specifically directed MHPs to involve families MHPs did not mention any of their own DHB policies and were not familiar with many of the Mental Health Commission and Ministry of Health reports. These documents list reasons for involving families and encourage mental health services to plan policies giving directions about how families should be involved. Although “The National Mental health standards” were recognised as they direct MHPs to involve families in the treatment of clients “The Blueprint for Mental Health Services” which is a leading document in the provision of mental health services in New Zealand was not discussed.

(g) Difficulties specific to the two Supported accommodation services

Pare’s main difficulty was in the area of providing resources for the residents (clients) especially in regard to maintaining staff levels, which were at a minimum at the present time.

PS is the Kaihauora of a supported accommodation home, noted that there is often a lack of resources and that supported accommodation services are bursting at the seams - “that puts pressure on a service that is going well and you haven’t got a revolving door syndrome.” People can’t be discharged then come back some time later as their place may have already been filled. He would really like for people to sit down

and discuss the growing need for supported accommodation in the community and to look at ways to resolve the problem of overcrowding.

A great deal of frustration was experienced by this Kaihauora when there was lack of support from community mental health services for supported accommodation clients and the staff, when dealing with some of the complex and sometimes dangerous situations that arise in these homes.

“Telling psychiatric services about the challenging behaviours and the experiences they (*staff*) are observing and they say, “That’s your job – you deal with it.” --- We have had some really fiery encounters with some of the services locally here. We’ve had some of the key workers who’ve just walked out on me,” (PS).

Mental health services responding in this manner to his frustrations when trying to provide a good service to his clients caused him to become quite irate. He has often had to speak to Mainstream mental health services about their lack of support to his staff when dealing with very challenging situations that arise in this accommodation service.

There was a need for the provision of more supported accommodation services to be available PS stated because when one person leaves often they need to return but the bed space has already been filled. MHPs did not speak about how these problems affected families of the clients but it could be assumed that if staff have difficulty coping with the changing accommodation needs of clients as the illness fluctuates, the families would have difficulties also. If their mentally ill family member had made significant progress in their recovery to move from the supported accommodation into unsupported accommodation there would be times when the family would have to provide care at home again if symptoms exacerbated and supported accommodation was needed again. Although this would indeed be stressful for the family member no mention was made of how stressful this may be for the family caregivers as they endeavoured to fill the gap left by the lack of available supported accommodation in the community.

(h) Difficulty with lack of appropriate supported accommodation.

In addition to the need for more supported accommodation in the community is the need for age appropriate supported accommodation which caused great concern for MHPs. “There isn’t a home for young people, so constantly I’m in a position of finding accommodation with 50 year olds for a 25 year old client.”(Rachael). Offering a young

client accommodation in with much older possibly chronically ill residents is not appropriate and MHPs stated that families weren't happy about this arrangement either

Although this theme highlights the communication difficulties faced by MHPs within their own service and with their peers the focus of this research was to explore the relationship MHPs had with the family caregivers. The difficulties outlined in this theme could be seen as excuses for the lack of effective communication and of building a working relationship with family caregivers or ongoing problems that require solving by MHPs and the services with whom they are employed.

The MHPs did discuss problems that they faced when they did attempt to work with families, which tested their skill, training and patience and these will be discussed in the next theme.

THEME THREE: Problems with some families.

(a) Who am I working for?

This question is one many MHPs ask themselves -- "It's actually clearly the client primarily but if I work for both of them---?" (George). MHPs often found that the interests of the family and client are in conflict with each other and dealing with that conflict can be very difficult to manage. According to MHPs the therapeutic relationship with the client is paramount and must be maintained at all costs. MHPs were aware that the family had valid needs to enable them to provide care or to just understand the illness but he believed the client's needs were above those of the family.

However where there are two valid sets of needs within the one family MHP skill, and a thorough knowledge of the rights of both groups of people will be required to manage a delicate and often tense, balancing act. Uncertainty about how this can be managed may contribute to the MHPs dilemma.

(b) MHPs fix everything?

According to MHPs, family caregivers had the expectation that MHPs were the ones to 'fix everything.' MHPs were often blamed when something went wrong. Family caregivers were perceived as having unrealistic expectations of the prognosis of their family member, especially when deterioration occurred. "People have tried really, really hard to provide a good service in a lot of cases and that client has a poor prognosis and doesn't have a great future. I think that the response of families is to look to blame somebody," (Rachael). However it may be necessary for MHPs to ask themselves if they have contributed to the family's frustration and their need to blame

someone. MHPs did not express any awareness, that the family's need to blame someone may be triggered by frustration and lack of response to their concerns and needs.

Other inappropriate expectations of the MHP to fix or change things in the family member's life that were long standing were discussed also. John described one mother he had had difficulty with, "She seemed to think I could control her son – stopping him going into a relationship with this woman that she didn't like." This mother accused the MHP as "not being of much use" if he couldn't stop the son being involved in a relationship of which she disapproved. Another mother was concerned about her 40-year-old son's teeth and used to phone George up regularly asking him to get the son to go to the dentist. In discussion with the client he had decided that he was quite happy with his "rotten teeth" and therefore this concern was not an area this MHP was able to influence, as he said it was outside his role to interfere in the client's personal decisions.

However Lewis did interfere on a client's behalf where the family had had access to their mentally ill family member's benefit. This MHP believed it was his role to intervene on the client's behalf to ensure that the client's benefit was not accessed without his/her consent.

There appeared to be a conflict over whether an MHP can interfere on behalf of the client on the one hand and not interfere on behalf of the family on the other. Even though these are separate incidences the family's concerns in the former example could have been equally as valid as the client's in the latter example.

One family caregiver's complaint to PS about their family member's food and diet was difficult to deal with, especially as that client had come to a point where s/he could only just cope with the changes they had chosen to work on in their life at that time. The family was concerned about the client's weight gain and general health and had the expectation that it was the MHP's job to do something about that. This may be another instance of where some notice may need to be taken of the concerns but also, some education provided to the family about mental illness, including how anti psychotic medications can be associated with weight problems, could have allayed family fears in the interim. Whose responsibility is it to note the family concerns and "fix them" where necessary and whose responsibility is it to educate the family about these issues?

The family sometimes "dumps the responsibility" for areas of the mentally ill family members care on the MHP. John has had caregivers saying, "Well it's your problem – you sort your responsibilities." Are families told what the MHP's role and

responsibility is and is not? The role that an MHP will play in the family member's treatment should be clarified to the client and the family when treatment begins. Unrealistic expectations from family caregivers may continue, where the specific role of the MHP in the care of the client is not clarified.

When Pare first worked mental health there was an expectation that MHPs were there to keep the clients well. This MHP described features of the recovery model that directs mental health service delivery. "It's changing –we have to now support them, to teach them, to keep themselves well." In theory, this model empowers the client to make decisions about their redefined future and assists them to continue to make adjustments as they learn to live with mental illness with support from professional and non-professional people in the community.

However for MHPs the actual practice of a recovery model of delivery would seem to be still in the developing stages causing MHPs to be tentative and uncertain about its incorporation into their professional practice with the client and family. Possibly as result of MHP uncertainties surrounding how to involve families in the recovery model MHPs do have to deal with a number of complaints from family caregivers.

(c) Family caregiver complaints.

According to MHPs some complaints are delivered in quite aggressive, persistent and confrontational ways. This is a source of stress for MHPs as they seek to solve or change the situation that has occurred.

"Some key workers talk about some families that are really demanding or bullying – some family caregivers who've been near on impossible – subject to complaints towards the key worker and extremely demanding about what they want. They've not been happy and they'll be complaining at the drop of a hat – you kind of bend over backwards. One family – spitting tacks about the sort of service they had but it's a matter of biting the lip about that." (John).

There was no explanation of what "bending over backwards" action was taken or whether this action addressed the *real* concerns the family were expressing. This was a stressful situation for MHPs to deal with but it may be necessary for the MHP to ask themselves why families had to be demanding or bullying and what they could do to rectify the situation?

One MHP said that often families "expectations are far too high for what we can provide even when we have told them what we can provide." Families whose

expectations are so high are perceived as a real nuisance by MHPs and are thought to sabotage the care they provide for clients.

Polly enjoys working with caregivers that are positive and are willing to have a relationship. People that she sees as negative are a challenge to her to make them more positive. "You don't get anywhere if you're working with negative people," she said. MHPs in Theme one had discussed their awareness of the stress families' experience. Therefore, expecting families, who are under stress, to be positive during all communication with MHPs may be too high an expectation on the part of MHPs.

Sometimes when MHPs had a difficult or negative family to work with they changed roles to give each other a break. Polly said that staff often talked about the fact that "they carry most the burden for everything so who cares for the carers." Although this method may have helped manage the MHPs' stress it was not mentioned how the change of roles may have affected the client or the family.

PS stated that mental health was a very difficult area to work in. Trying to be like ten people sometimes was the reality of the situation so he believed in looking after himself so he could do his work more effectively. Every job has times of high stress so MHPs do need to manage their stress well and take care of themselves during these times.

Another area, which caused a number of challenges amongst MHPs, was the area of sharing of information and the right to confidentiality, which is discussed in the next theme.

THEME FOUR: Problems with confidentiality.

A dilemma often faced by MHPs was when a family requested information and wanted to be involved in treatment but the client would not consent for their family to receive information or to be involved. Even when clients have given consent it can be difficult to decide what kinds of information should be shared with the family, without disclosing personal information that should remain confidential within the client/MHP relationship. Knowledge, skill and experience are needed to deal with these conflicts of interest when they arise. MHP's shared the various ways that they deal with this problem.

(a) Win/win situations

Because client confidentiality had to be respected at all times, the MHPs generally asked the client if they minded if certain information could be handed on to family. "I

just pop the question, “How do you feel if I talk to your wife or ask her to be involved – very few would decline that – I won’t necessarily talk to them and involve them in everything – some things that I hear in this job are very personal,”(John). Asking the client ensured that the relationship of trust with the client was not jeopardised but allowed families to receive the information that they needed. The MHPs stance of not being too beaucroatic, acting in good faith and being respectful to the client and using common sense resolved many situations. George said that he would usually say, “Look I want to speak to your Dad or I want to give your Mum a ring and see what she thinks.” When the client agrees to release some information it is a win/ win situation where both sets of needs, the need for client confidentiality and the family need for information are met.

Another method used by one MHP was to ask the client to discuss the issues that the family wanted addressing, during a family meeting. He would ask his client if he/she could tell the family what they needed to know. This MHP believed that by approaching it this way he is not disclosing anything that he shouldn’t. The client is then disclosing as much information as s/he chooses to with the family. It is a process of enabling them to open up and be honest with each other.

(b) Win/lose situations.

Some MHPs admitted that gaining the client’s consent before divulging any information was quite a process and it did not always produce a positive result for the family. A number of MHPs find it very limiting when the client said that they did not want their family involved. Sometimes George has had to ask the client to contact his/her family to tell them why he/she doesn’t want them involved. George has gone so far as to tell the client that if he/she didn’t tell the family then he would ring them himself, especially when the family may continue to keep ringing the MHP asking for the information. This MHP found that when the client refuses consent and therefore information has to be withheld from the family it becomes a very awkward situation for him to deal with.

Rachael was very aware of the fact that even though it was difficult for her when consent was not granted, it was also very difficult for the family, whom she said, can feel quite excluded. When the family has been and will be providing care to varying degrees, not being able to obtain key information can be a source of extreme frustration and fear for the family. The family can become very upset and angry about this exclusion and so MHPs find themselves having to deal with justifiably irate family

caregivers needing information that the MHP believes they cannot give. When families ring for certain information that PS cannot give to them, he realises “Families do not cope very well but I can’t do anything about that – legally because of our contract we can’t divulge information.”

Although these MHPs were aware of the feelings of exclusion families felt when consent was not granted, they did not have any solutions to dealing with this. They believed that they were bound by their employer’s legal requirements in their contracts not to release information to the family when the client refused consent.

MHPs were innovative in the ways they handled the family’s need for information in some instances, but even these methods were not always successful in helping the family to gain information they needed. This is an area where there may be lack of understanding of the finer details of the privacy and confidentiality laws covering what kinds of information can be shared, and the special times when information can be shared with families, even when consent has not been granted.

(c) Rights of the family?

According to MHPs, client confidentiality and consent of release of any information has to be respected at all times. However, when the family caregivers themselves asked for confidentiality when contacting the MHPs, it was seen as not being inclusive of the client. John was aware that when he did tell the client the information the family had shared with him, this could put the family in a difficult situation. The conflict for him was that he believes when family caregivers ask for information to be kept confidential “it interferes with the therapeutic relationship.” He provided the example that “if a client finds out that he (*John*) has been speaking to the family without his/her knowledge or consent, the client may think, “How can I trust John again.” George also expressed similar difficulties with families asking that he not tell their family member about the communication they have had with him, but he tells them “he’s (*the family member’s*) going to want to know why I am asking him (certain questions) and I can’t lie to him! I really have to (*tell him*).” Dealing with situations like these can cause much conflict and stress for MHPs.

When a family asks Pare not to tell the client about their conversation with her she asks that the family caregiver “write to her (*the mentally ill family member*) or ring her up,” and discuss what the family caregiver had just shared with Pare. She believed she could not keep the family caregiver’s information confidential and that the client had a right to know that the family had rung and discussed certain issues. She said that

she would not put herself in the position of being “this person who is going between.” Pare makes it very clear to family caregivers from the start that nothing will be held back from the client if the family communicates with her. In another example an MHP said that families were allowed to tell the MHP “anything they liked but that what she does with the content of that communication was her call, basically!” It appears incomprehensible that an MHP is able to keep client confidentiality but unable to keep family confidentiality.

One MHP spoke about a situation where she had kept the family information confidential but the family themselves had divulged to the client that they had communicated with her. Occasionally, however “the client has been doing a bit of detective work” and has managed to find out for him/herself about the communication between the MHP and the family. The interests of the family and the client are in conflict, which makes situations like these very complicated for the MHP to handle.

Another method of dealing with this problem is using client consent forms. MHPs were asked how these were used in their practice.

(d) Consent forms not used routinely.

Though most hospitals and health services have client consent forms to be used at admission to the service, to indicate with whom information may be shared, most MHPs said that these were not used. One MHP said that there used to be a form but he didn't know what happened to it and another said that they get so many forms that many just go “by the by – you can rip them up- you're not using that!”

Sometimes the consent to have family involved may be noted in the client's file but it was evident that many MHPs did not consider that this was an important form to be filled out or reviewed at regular intervals.

If clients were asked to whom information could be given this was not documented in written form unless there was a change of decision, “which can happen quite frequently with clients” according to Rachael. Clients could change their minds about family being involved during a psychotic episode or following an acute episode so it would seem to be imperative that when these changes occur that they be noted on file for any MHPs who are involved with the client to be made aware.

It is certainly a predicament for MHPs when they have direction from their client that they don't want their family involved. Apart from one MHP who stated that clients often change their minds, depending on which phase of the illness they were experiencing, there seemed to be an assumption by most MHPs, that once a client had

clearly directed that they did not want their family involved that this probably wouldn't change and therefore these directions were not regularly reviewed.

Summary of MHP themes

Confidentiality of the client and the family's need for certain information is a complex issue for MHPs to deal with, and probably indirectly affects most of the other areas of difficulties that MHPs face when dealing with families and other areas of mental health service delivery.

Theme one (A &B) revealed that MHPs are aware of the supportive role families can play in the recovery of the client and the positive effects this has on the client. However the specific effects of family involvement such as reducing relapse and hospitalisation were not mentioned or discussed.

Families, however, were not always considered by MHPs as having a positive effect on the recovery of the client. Too high expectations of clients during recovery, a lack of knowledge providing a recovery focus and age inappropriate paternalistic caring were factors highlighted by MHPs as having a negative effect on clients' recovery.

MHPs all expressed awareness of the enormous stress families often cope with when caring for mentally ill family members. Family caregivers needs as a result of this stress were identified but MHPs were often unsure how they could meet some of these needs. Three out of seven MHPs admitted that often families were not involved in their client's treatment as much as they should be according to Ministry of Health directives and that families had often not been listened to or given the information they needed to provide care for their family member.

Although MHPs were genuinely aware of family caregivers needs and attempted to involve families in their practices, many difficulties that were perceived to hinder that process were discussed. These difficulties were given as, what may be, valid reasons or excuses, for the lack of positive family involvement and good working relationships with family caregivers. These reasons or excuses covered difficulties with colleagues and other services within mental health delivery, lack of training, and problems with some families who expected and demanded more than they could provide. Some of these difficulties faced by MHPs certainly need addressing if these are indeed valid reasons for the lack of family involvement in the treatment of the client. However, no individual or collective solutions were offered that could help to eliminate most of the

difficulties and pave the way for a more effective working relationship with family caregivers.

To obtain a clearer picture of this relationship, it was necessary to gain the family caregivers' perspective of the relationship and the factors affecting their relationship with MHPs.

Interviewing family caregivers (FCGs) highlighted themes that covered some similar issues raised by MHPs, but FCGs issues were specific to their experience of the relationship they had had with MHPs. These themes are revealed and discussed next.

Family caregivers (FCG's) themes.

Five themes were identified from the caregiver interviews that focused on the factors that influenced the relationship FCGs have with MHPs and centred on obtaining help and admission when their family members became acutely unwell.

OUTLINE OF THEMES.

Theme One

Growing distrust.

- (a) Not believed.
- (b) Broken commitments.

Theme two

Kept in the dark.

- (a) Not informed.
- (b) Not consulted

Theme three

Frustration, anger, fear and despair.

Theme four

Blamed and ignored.

- (a) Psychiatrists responses
- (b) MHP defensiveness and lack of respect for the FCG
- (c) MHPs don't listen to FCGs
- (d) Some positive comments.

Theme five

Abandoned and powerless.

- (a) Confidentiality for client *and* family?
- (b) What's the point of consent forms?

THEME ONE: Growing distrust.

Forming a relationship built on trust is essential if FCGs and MHPs are to work together for the benefit of their mentally ill family member. However FCGs described situations where they began to lose trust in MHPs to support their family member or themselves.

(a) Not believed.

During the onset of an acute episode of mental illness FCGs described their experiences in trying to get appropriate and timely help. Not having their descriptions and fears believed, as the symptoms of the illness became more and more obvious to them, was very distressing for FCGs. Beth was told that her son's behaviour was typically that of a normal teenager; she knew that something was definitely wrong and that his behaviour was clearly psychotic. Jude was also informed when her daughter started to become unwell that "it was just teenage stuff. They didn't believe that there was anything wrong with her (*daughter*)."

When a family member is becoming unwell family caregivers may want to believe that it is just teenage behaviour, but when their family member continues to act strangely and speak strangely they know that something is definitely wrong. Not being believed when at last they have contacted MHPs for help can be very distressing for the family who knows this person so well.

When Lee's son was becoming manic, "They (*MHPs*) wouldn't believe me that talking all the time and setting off fire alarms was totally out of character for my son." The consequences of not believing this mother resulted in the son being arrested after breaking in to someone's home, being convicted and sentenced to prison. Two MHPs including a forensic psychiatrist who had assessed him prior to this conviction concluded that he knew what he was doing, however, when Lee visited him in prison he was still saying all sorts of bizarre things.

Jude was very relieved when the private psychiatrist, to whom she took her 16-year-old daughter, believed what she and her daughter were telling him. When her daughter came out of her first appointment, "She was sobbing because at last somebody

believed that this was happening to her and that it wasn't her choice." The MHP had told Jude and her daughter that "she could basically choose whether or not she wanted to be this miserable." The possibility of this private psychiatrist being more motivated to provide a more client and family friendly service to prospective clients, who would ensure his livelihood, could have been a factor influencing this scenario. Psychiatrists employed by public hospitals may not be as motivated towards providing the same client/family friendly service as they are contracted to provide the service.

Marie and her family were very angry when they were also not believed. The family had reported that her brother's health was deteriorating - "He had locked himself in his flat. He was paranoid and therefore had made weapons to keep himself safe." These unusual and threatening behaviours are synonymous with acute mental illness. Therefore it is strange that MHPs did not respond to Marie and her family's concerns for her brother. The MHP had only visited her brother two or three times over the past two years and therefore had not had experience of him becoming acutely unwell prior to this time. The family knew that this behaviour indicated a need for immediate intervention. If they had been believed earlier, Marie said, there would not have been the need to lie to him and cajole him into being sectioned (*committed under The Mental Health Act*) with the result of him becoming very frightened.

Sally said it was the worst time for her trying to get MHPs to believe her and recognise that something was wrong. It was only when her neighbour who had been a psychiatric nurse, rang the Crisis service and confirmed what Sally had been telling them that MHPs responded to Sally's call for help with her son's crisis.

Five of six FCGS had not been believed when they had called mental health services for help with their family members. After assessment and treatment had finally been commenced, promises to check on family members living on their own while family were having well needed breaks or when family caregivers had concerns for their family member's mental health status, were often not kept by MHPs. Therefore trust in MHPs to provide good reliable care to their family members continued to diminish.

(b) Broken commitments.

Lee's distrust in mental health services has continued to grow during the times her son has been mentally unwell. On three separate occasions Lee contacted the Crisis team to ask them to go and see him because she had real concerns for her son's safety but they never visited or contacted him. "I was told that a nurse would visit him between Christmas and New Year, but nobody did." Even when a Client Relapse

Prevention plan had been put into place, listing the symptoms that would be responded to, as being early warning signs of deterioration, the Crisis team refused to respond to the planned action.

Deborah also expressed a growing lack of trust in mental health services following many desperate attempts to obtain help from MHPs for her daughter. The depot injection her daughter needed to control the symptoms of her mental illness had to be administered on time otherwise the symptoms tended to exacerbate very quickly. Deborah describes, “ringing round silly trying to get them to come, or us to take her in.” She said that contacting MHPs at Mental health services was “virtually impossible at times.” If she went to the mental health services in person she would often find no-one on the desk, or if she rang and left a message for them to ring her back she often did not get her messages returned.”

It can be very frustrating and stressful when FCGs know that the behaviour and symptoms being exhibited are not normal for that person. Not being believed and therefore no appropriate action taken addressing those concerns, add to that stress. Also when plans and promises are made by MHPs concerning care of family members and then not followed through, this causes FCGs to lose trust in the MHPs and the service they believed were there to help them to care for their mentally ill family member.

Lack of appropriate response to their family member’s deterioration was one area of stress however the lack of information given to them, and the lack of consultation with them concerning their mentally ill family member was another area families had to deal with. Communication consists of sharing information. Lack of response, and lack of consultation did not encourage communication between these two groups of caregivers. Communication is a key factor in the development of a positive relationship.

THEME TWO: Kept in the dark.

FCGs related a number of incidents where essential information related to the care of their family member was not given. During the time of assessment FCGs also described times when MHPs had not consulted with them about the concerns FCGs had voiced. MHPs had not consulted with them about the development of the illness in their family member, or about any possible treatment needed for their family member to bring symptoms under control.

(a) Not informed.

For some time Sally was given no idea as to what could be wrong with her son. It was only when their neighbour gave them a booklet on Schizophrenia that “we had any idea what could be possibly wrong with him – it was like we had no idea at all!” Although a diagnosis is rarely given during a first episode, families need to be informed of what could be wrong and given some information about psychosis to help them understand the symptoms, behaviours and side effects of any medications.

Later, Sally was also not informed as to why her son, who was living at home at the time, had been discharged from the keyworkers list of clients. After ringing the keyworker who had previously been appointed to her son’s care, to express her concern about her son not taking his medication, she was informed that because her son had been discharged from this key workers list of clients, she would have to ring Crisis Intervention services. This solution was “way over the top,” she said as she felt that just a chat with her son’s key worker would have probably been all that was needed to encourage him to continue with his medication.

When a mentally ill family member decides that they don’t want to or don’t need to take medication any more, it can be a very stressful time for family caregivers. They have seen the signs of psychosis prior to an acute episode, or seen deterioration due to non-compliance on other occasions and therefore they know exactly when intervention is required.

Deborah described a number of situations where the family should have been informed about medication and incidents that occurred while their teenage daughter was under the clinical care of mental health services. MHPs from Crisis services came to their home at one time when their daughter was unwell and gave her a medication, but did not explain it’s sedating effects to the family – the daughter “took off” (*a common response when she was unwell*). Deborah rang Crisis, who reprimanded the family for not keeping her safe at home! But as Deborah said, “If she gets killed, whose fault is it? It’s not ours – you should have told me what the drug could do.”

However, the worst situation of an FCG not being informed was following the rape of Deborah’s young daughter while on the unit - “She got raped (*that night*) – they never phoned us till 8 the next morning when they phoned the police and that is bad.” MHPs never gave an explanation as to why their daughter’s room had not been locked and therefore her safety ensured. While in the inpatient ward their daughter had an inalienable right to absolute safety during this vulnerable time. The family had a right

to expect this safety for their daughter and to be informed immediately of anything that required their support and advocacy.

Beth's son became unwell at a very young age and even though he was a minor it was extremely difficult to get information about their son's care. "The psychiatrist would never let us know what was happening – when, why, how. ---- "It was on a "we didn't need to know" basis." As a minor, and as caregivers of a person who needed support with the taking of his medication, the family needed specific information about treatment so they could care for their son. Even as their son got older there was never any agreement made about who with or what information could be shared.

Lee was able to get information about her son following one discharge because the key worker had her son's permission to ring his mother by signing a client consent form. Consent forms when used can provide guidance to MHPs concerning with whom the client gives permission to be involved and receive information during his/her treatment. However on another occasion Lee asked for some information about the results of a CAT scan her son had had during assessment. It was sent to her "in technical medical language which a non-medical person could not understand." FCGs need information given in simple non- medical jargon.

(b) Not consulted.

Marie remarked on the fact that her brother had moved around New Zealand quite a bit and had had several admissions in other places however following one of the more recent admissions in his home- town it was discovered that "none of his history from previous files had been obtained." Files from previous admissions would have contained information that was necessary for his present treatment.

Jude was really angry when her daughter aged 14 or 15 at the time, came home one weekend from school (*five-day-a-week boarder at the time*) and told her mother that the doctor there, had put her on Prozac. "I was stunned that there had been no discussion about this. ---- The doctor had been sufficiently concerned that he was looking at committing her and he hadn't even rung me, he hadn't intended to ring me until he had made a decision about whether to commit her!" During a more recent episode, Jude was extremely dismayed when she wasn't involved in the interview at all - "no collaborative history taken - no discussion whatsoever."

Lack of consultation with this client's family about possible treatment, especially when the client is so young and still under the care of the family, denies the right FCGs have to take responsibility for their family member's care. MHPs who are

in a position of professional power, seem to make decisions that they believe are in the total interests of the client, but without any consultation with the people who know them best. Also if Jude had been able to provide her daughter's family history this may have revealed some of the causes for the problems her daughter was having and enabled MHPs to make a more correct assessment and give more appropriate treatment.

However families can become so exhausted with the constant battle of trying to be included in a family member's treatment, that they can become very frustrated and despair of their ability to obtain help to care and support their family member during recovery. Recalling these stressful situations often evoked some strong emotions from family caregivers.

THEME THREE: Frustration, anger, fear and despair.

Family caregivers painted some extremely vivid pictures of how hard it was for them trying to deal with mental health services when added to the stress of dealing with and caring for a mentally ill family member.

Sally describes how she experienced the exacerbation of her son's illness and consequent diagnosis of schizophrenia. "You're actually there at the coal face trying to keep this kid's head above water. They were horrible times the whole time." Another mother described the time her daughter was becoming unwell and not being able to get the appropriate help for her as "so tough – so difficult - the worst times." When Pare's son became mentally ill it devastated her family, she said, and she always felt that no one understood what they had to cope with. Despair and devastation can be as a result of feeling isolated from support and understanding in the community. Where are FCGs to obtain this support and understanding?

Intense frustration and anger was expressed by all of the family caregivers when trying to get help for their family member, or information about the illness, or details about medication and side effects. One mother shared how she had spent a lot of time crying and being angry due to frustrations experienced over a long period of time, when trying to get help for her son and her family so they could start to deal with whatever was wrong with him. Marie, Lee and Jude also expressed deep anger and frustration towards MHPs for not including them or consulting with them during diagnosis, treatment, and making decisions that affected them as families.

Deborah talked about how frustrated and desperate she became when there were always excuses given (*by MHPs*) when she was unable to contact them or to access

appropriate help during a crisis. Even though her daughter now lives in another town, she recalled a recent conversation she had had with her daughter's MHP in the other area, who also expressed his frustration when he'd been trying for "three days to contact mental health services" to arrange appropriate medications for Deborah's daughter who was coming home for a holiday. Deborah had replied to the MHP, "Now you know how we feel, and you're a professional in your work and you could pull some strings – we have no strings to pull." Why should a family or another MHP need 'strings to pull' to make contact, obtain help, or pass on information?

Beth and Marie had despaired over a number of years while dealing with inadequacies of mental health services as MHPs continued to not inform them or consult with them. Marie could not understand why the same problems continued to happen even after the family had addressed their concerns very strongly with MHPs on several occasions. She said that they were determined not to accept their exclusion from involvement concerning decisions related to her brother's care, especially when he had given permission and wanted them involved.

Often the FCGs' anger was borne out of fear for their family member's future. Sally described her visit to see her son on a ward following an acute psychotic episode when he was given an overdose of medication, as being "like something out of Colditz." This description conjures up a picture of a prison, cold and dark, with little in the way of home comforts – not a place where she believed her son should have been sent to recover. "It was the most distressing thing I've ever seen in my life," she said.

Sally and Jude held tremendous fear for their family members being placed in a ward in their own hometowns. "I was paranoid about him coming back here," Sally said, due to her fears related to the foreign psychiatrist she had had to deal with in her hometown. Jude was so afraid of her daughter ever being admitted to the inpatient ward that she sought out a private psychiatrist to provide psychiatric care for her daughter. She was adamant that she never wanted her daughter to be admitted to the inpatient ward, because she maintained that she had seen, in her professional capacity, how disrespectfully and badly patients and family were treated there. Jude had observed the process of admission from a professional perspective also. As a result of those observations she feared for her daughter's safety and recovery if she ever had to be admitted to the inpatient ward.

Two FCGs also expressed fear for their own sanity. "It's too, too stressful. It's hard mentally and emotionally --- I thought I was going round the twist," said Beth.

Fear, arising from the way her son was treated during his hospital admission, and not being informed about why her son was so ill, caused Sally to be afraid that she would end up in the psychiatric ward herself.

These FCGs were talking about situations that happened a year or more prior to these interviews. Although all family caregivers expressed a determination to complete the interviews, the experiences they shared were still very real and painful for them to discuss. Some of the situations that caused the most distress were when FCGs were either blamed for causing the illness or ignored therefore not treated with respect. Theme Four deals with these attitudes by MHPs towards FCGs.

THEME FOUR: Blamed and ignored.

(a) Psychiatrists responses.

During Crisis times with their family member, FCGs were often treated impatiently, without respect, and without empathy, even though these qualities were expressed as good professional practice by MHPs during provision of service to clients diagnosed with a serious mental illness.

Sally was most upset about a foreign psychiatrist who “was very abrasive – just banged on the table and said, “This is a life long illness you know!” As Pare said the impact of the long-term nature of mental illness can be devastating not only for the client but for his/her family. Although FCGs will probably need to come to terms with a long-term diagnosis, this information needs to be presented patiently and in a caring and empathic way that demonstrates care for FCGs and also gives room for hope.

Sally also described this same psychiatrist’s attitude towards her as a female as very disconcerting. She was most upset that he would hardly look at her or speak directly to her when she and her son were at an appointment with him. She perceived this as a dismissive attitude towards women. More often than not it is the women who are the main caregivers for their mentally ill family members and are the ones that need to be informed and supported in that role by MHPs. Therefore if MHPs hold an attitude towards women such as this it becomes a barrier to this relationship.

During the 1950’s women were often blamed for their contribution towards the illness of their family member. Research has clearly shown that a number of these theories have little validity as a cause of mental illness. However, Beth said that her son’s psychiatrist told her that the illness was her fault. When she broke down in tears

and told him how frustrated she was feeling, he placed information in front of her about how she could lower expressed emotion in her home. This woman had been confused and distressed about the bizarre beliefs her son was having. An accusation such as this seems reprehensible, in light of research that absolves mothers from the cause of their family member's illness, and it shows little recognition of the stress she has been under while she had been seeking help and caring for her son. She described the way she was treated by this psychiatrist and other mental health professionals during that time as being "treated like an alien."

Pare also spoke of getting a lot of resistance and a lot of flak as a mother – she stated that mothers had a very hard time because they are the ones who take a lot of the responsibility on for their family member when a crisis arises.

The psychiatrist who assessed Jude's daughter was not "remotely interested" in anything she had to say related to the development of her daughter's illness. Jude saw psychiatrists as "putting themselves on their God pedestal," conveying the attitude that they knew her daughter better than she did and that their expertise was superior to hers.

(b) MHP defensiveness and lack of respect for the family

Defensiveness demonstrated by MHP's in some situations was not appreciated by FCGs when complaints were made about how their family or their family member had been treated. The way Marie's brother was cajoled and tricked into admission and a compulsory treatment order at the hospital caused her brother to become very frightened and when this method was challenged, the MHP became very defensive of her actions. Defensiveness by MHP's does nothing to reassure the family. According to Marie MHPs acknowledged that admitting Marie's brother on to the inpatient ward could have been handled differently. Recognition of where mistakes have been made, and a commitment to families to improve in those areas, or an explanation of the reasons this MHP using this method to admit Marie's brother, could have diffused this family's complaint and their stress.

It would also appear that when FCGs gave an indication of having some knowledge about how certain medications and treatment affected their family member, and suggested possible changes, this was not appreciated by MHPs. One mother when she tried to explain what she felt was needed for her daughter was spoken to in a very derogatory manner. "So you're the mental health worker are you?" retorted the MHP! This FCG's knowledge was evidently perceived as a threat to the MHP's expertise when the MHP reacted to the caregiver in this manner. FCGs often do have insight as

to how their mentally ill family member reacts in different situations or with different medications. They know from experience and observation during the course of the illness what has worked and what hasn't.

One FCG was told that "you get what you are given" when she and her mentally ill family member asked for a change in key worker. Resources may be stretched but this response demonstrates inflexibility or unwillingness to address the issues surrounding the perceived need for a change. This family persevered and eventually was able to have their son and brother's key worker changed. Many FCGs are not as persistent and become quite despairing about their ability to implement any change on behalf of their family member.

Even more disturbing was the comment that a mother made about the repercussions that came back on her daughter if she "opened her big mouth." She was afraid to complain about the treatment they, as FCGs, had received, because she knew from previous experience that her daughter would be treated differently as a result of her complaint. As one MHP had warned Deborah, "Your attitude comes back on you." Such unprofessional behaviour cuts across the FCGs inalienable right to be treated with respect and the right to make a complaint.

The effect of having to wait from 11pm till 5am at a police station for help to arrive, when a father had to go to work at 6am, is also lack of consideration for the family's situation. This family had requested help from the Crisis team as their daughter was unwell, and when assistance was not forthcoming, at their wits end, they went to the police station. Despite repeated phone calls asking for assistance, Crisis did not respond until 5am. On a number of occasions the family had to wait for similar lengths of time before MHPs respond to their request for help with their daughter, causing much distress for the whole family.

How much less stressful it could have been for all concerned, if there had been a family meeting to plan a strategy of dealing with the problems that instigated the situation. The problem could have been eliminated with the formation of a plan to handle the situation more appropriately when it occurred in the future.

Dependence by this family on the police for intervention when MHP's had said there was "nothing we can do," was a regular occurrence. Police treated them with respect and consideration and often were the ones to ring Crisis Intervention services explaining the need for urgent intervention. This service often responded to the police

phone calls asking for assistance after having ignored the family's pleas for help. Who was to be believed when help was requested?

(c) MHPs don't listen to FCGs.

FCGs also need to be included in the decision making process during possible diagnosis and treatment where their contribution is valued, and where their historical perspective, alongside long term knowledge of the family member, is respected. Jude had real fears for her daughter's safety as a result of not being listened to. "I don't know if Amy would be alive now, which is tragic – because you weren't listened to." Her daughter had been irritable – had had "three self harm attempts and huge problems with thinking and processing information." Her sleep patterns had been "all up the shoot and she was either not eating at all or bingeing and drinking excessively." The young psychiatrist who assessed her daughter wasn't interested in this information. If the MHP had listened to Jude he would have gained a clearer picture of the history leading up to the present symptoms, treatment could have possibly been started much earlier and a lot less stress and burden would have been placed on the family.

Although an MHP may have his/her own perception of urgency regarding the need for certain interventions, there is always a need to listen to the family's perception of urgency and act accordingly. One mother reported to the MHP that there was an urgent need to have other accommodation found for her mentally ill son before her daughter arrived home to live. The family member with the mental illness, who was also living at home at this stage, had abused this daughter and it was inappropriate to have him living there while the daughter was at home. Although an urgent request was made to the MHP "she didn't worry, didn't hurry, didn't do anything much" and eventually the FCG had to find a caravan at the camping ground for him. Once again, listening to FCGs and acting upon their requests could have avoided more stress for this family.

These uncaring and at times abrupt responses from MHPs have added to the stress of coping with a family member who has a serious mental illness.

(d) Some positive comments?

Marie stated that when the family became so frustrated with MHPs for not listening to them and not consulting them regarding her brother's progress and discharge, they insisted on having meetings where they could lay their complaints and establish a better ground for communication. It was only after the family demanded their right to be heard and listened to, that regular family meetings were instigated.

During these meetings minutes were taken and circulated, so that all matters could be addressed and each person would know what tasks they had to action before the next meeting. MHPs apologised about the mistakes made concerning the way the family had been treated and the family's concerns were addressed and acted upon. The family were very pleased with this response and have found the relationship with MHPs much more open and respecting of their contribution since that time but have said that "they will continue to make a fuss when there is a breakdown in communication."

Lee also felt supported by one MHP who rang her a few times to see how she was coping. Her son had previously decided that he didn't like this particular MHP and refused to have her as his keyworker. Lee appreciated the MHP's recognition of her needs for support as she continued to provide care for her son in her own home.

Beth was also impressed by an MHP who came in and helped the family one weekend to move their son into a flat, even though the son had been discharged from this MHP's list. It appeared that where MHPs not only were aware of the stress these three FCGs were experiencing but also responded to that need and contacted them offering unexpected assistance and support, that this was most appreciated.

However recall of positive interactions with MHPs was rare. Generally the experience of the relationship with MHPs was negative. The negative interactions that FCGs had with MHPs were often directly related to confidentiality issues. These issues are discussed in the final theme.

THEME FIVE: Abandoned and powerless.

(a) Confidentiality for whom?

Although FCGs are told that the patient has a right to confidentiality in their relationship with MHPs, often this right is taken to the extreme. Five of the six FCGs felt client confidentiality was used as an excuse by MHPs when FCGs requested essential information related to the care of their mentally ill family member. FCGs felt client confidentiality was also used as an excuse for them not to be able to *give* information confidentially to MHPs. They said that when they had fears for their family member's mental health status, they needed to give information about that without it being repeated to the family member.

FCGs have information that relates to the level of wellness of their family member, which they need to communicate to the MHP. If it is reported to the family member that the family has informed the MHP of certain concerns, this can jeopardise

the tenuous relationship the family may have with their mentally ill family member. Beth was often verbally abused following an appointment where she shared her concerns about her son with the psychiatrist. Although her son never physically abused her, the situation became quite volatile on occasions. She assumed that she was speaking in confidence to the psychiatrist but the information was passed straight on to her son often causing much conflict and escalation of her son's anger towards her at home. Did the psychiatrist consider the consequences when he didn't keep confidentiality for this mother?

FCGs have been very frustrated with the use of the Privacy Act as an excuse for them not to receive information. "The Privacy Act and everything was a load of rubbish," Sally said when she was frustrated in her efforts to find out why her son was unconscious in intensive care, following one admission. She believes that he had been overdosed and that MHPs had almost killed him, but she says, "to this day I have never got to the bottom of it." This mother knew something had gone very wrong but no-one would tell her. The use of the Privacy Act was given by MHPs as an excuse for not telling her the reasons that her son had been admitted into Intensive Care.

Beth's son was still a minor when she asked MHPs what they thought was happening with her son and what medication he was on. "It wasn't deemed necessary for us to know what was happening or what medication he was taking or anything because it breached the Privacy Act." This family were legally responsible for his care and without this information it was very difficult and stressful providing care for their son

(b) What's the point of consent forms?

Consent forms are one method of ascertaining to whom the client wants information shared during his/her treatment. It would seem one way of gaining permission or gaining an advanced directive for the present or future time when the family member is acutely unwell. However, according to FCGs, these are not in regular use in the two geographical areas visited. The forms have been used in the past, but in recent years the only indication of with whom the client wants information shared, has only been noted in client file notes.

On many occasions this consent has not been reviewed unless there has been a change indicated by the client. FCGs said, that even when the mentally ill family member has granted consent for his/her family to be informed, this did not always happen. One family wondered why their family member had ever signed a consent

form because MHPs said that they had not seen the signed consent form in the file and therefore had not read or acted upon it. This lack of attention to the availability of the signed consent form caused considerable frustration and stress for the family.

Lee had similar problems even though her son had signed a consent form giving permission for her to have information relating to his treatment. Lee had been visiting her son every week and was concerned when he continued to tell her some of his very bizarre delusions. While expressing her concerns she asked the prison nurse if he was taking his medication, to which the nurse responded, "We do not discuss adults with other adults." There appears, once again, no recognition of the stress this mother was experiencing when she knew that her son was still very delusional. Lee needed to know if her son was receiving treatment while in prison. Her son had signed a consent form giving permission for his mother to be informed which, if it had been acted upon, would have avoided much of the stress and frustration this mother experienced.

Marie's brother had also given permission for his family to be consulted and informed but they were not consulted about his discharge from an acute inpatient ward to subacute accommodation.

Three FCGs were unaware of the use of client consent forms during admission to mental health services. These FCGs were sure that their mentally ill family members had not been asked to complete a consent form indicating to whom they wanted information given. Not being able to obtain information that pertains to the care of their family member can cause FCGs to feel misunderstood and abandoned by the very service instituted to support them to care for their family members in the community.

Summary of FCG themes.

FCGs themes have drawn attention to the continuous stress a family bears either when they are trying to get help for their family member who is becoming unwell during a first acute episode or a consequent episode of psychosis, or when they are trying to deal with behaviours and symptoms that they often have little knowledge of how to handle. Not being believed, listened to, respected or consulted, in addition to carrying the burden of caring for a loved family member who has been diagnosed with a mental illness is often an overwhelming task and for some can become an impossible task. Most of the memories recalled by FCGs about their interactions with MHPs during this traumatic period were negative apart from three very brief positive

comments about two MHPs who listened and provided some assistance and admitted where mistakes had been made.

A trusting relationship between MHPs and FCGs was not reflected in the FCG themes as FCGs became frustrated, angry, fearful and despairing during efforts to obtain appropriate intervention for their mentally ill family member. Rather than a trusting relationship being established, the first theme reflects MHPs growing distrust as FCGs' concerns were not believed, and commitments by MHPs to provide care were not fulfilled. Many examples of being 'Kept in the dark' were portrayed when there was a lack of information given, and a lack of consultation during the treatment and diagnosis of their family member. FCGs expressed frustration and despair as their trust continued to diminish in the MHPs' ability to assist them in their caregiving role. Distress experienced when negotiating the mental health system and attempting to communicate with MHPs during exacerbation of their family member's mental illness caused two FCGs to fear that they might also end up in a psychiatric inpatient ward. All FCGs expressed that the time when they had been seeking help for their family member and dealing with MHPs was an extremely stressful time ("the worst time" according to three FCGs). FCGs' confidence in MHPs' ability to provide care for their family member was severely shaken.

To be blamed for their family member's illness was very painful for the FCGs to deal with and when their expertise was not respected or was ignored by some MHPs, the pain continued. Participants expressed powerlessness to implement changes, as they felt abandoned by the very system that they initially thought would support the whole family as they learnt to live with the mental illness. Powerlessness and ever deepening distrust continued to multiply with the Privacy Act being used as an excuse for FCGs not receiving information regarding care of their mentally ill family members.

A gap continued to appear throughout these themes, affecting communication between FCGs and the MHPs, and therefore affecting their ability to build a relationship.

THE RELATIONSHIP CHASM.

Despite MHPs' knowledge and awareness of the need to have a relationship with FCGs and involve families in the treatment of clients, FCGs spoke more often about times when they were not involved, not listened to, not believed, not informed, not

consulted, not respected, and therefore could not have a working relationship with MHPs who provided professional care for their family member.

MHPs gave the impression that even though, in some instances, they had made mistakes and acknowledged a need to improve their response to involving families more, that they were relating as much as possible to FCGs in ways that supported them. However, FCGs described requests for regular involvement and contact with MHPs being fraught with difficulties, throughout the phases of mental illness their family member has experienced.

A positive working relationship between FCGs and MHPs appeared to be lacking. Apart from two encouraging instances of brief encounters with MHPs, FCGs more often than not had felt abandoned by MHPs. Their continued attempts to obtain help from MHPs during the deterioration of their family member, or when requesting essential information about treatment and medication, had added to the stress they already experienced while trying to deal with the complex problems associated with caring for a mentally ill family member.

In Figure 1 (see p. 86) the following statements illustrate the gap that appears to exist between what MHPs know, and have an awareness of, and what the FCGs experience of that relationship. When an MHP says that it is important that as MHPs they work together (with the FCG) and an FCG is saying that her experience is that she is treated like an alien by MHPs, there is a gap between MHP understanding/knowledge/intent and their actions towards families. A further illustration of this gap is when the MHPs are saying that to support families and help them understand the illness is part of their responsibility and FCGs are saying nobody understood and little information about the illness their family member was suspected of developing, was given to them. The assessment of the reality is quite different between these two groups. Another example of this apparent chasm is when FCGs are saying that they are not believed or consulted but MHPs are saying that the family is the expert about their family member. A third aspect of this chasm of MHP intent and FCG experience that appears to exist, is when MHPs know that FCGs need information about medications and treatments but MHPs believe that because of client confidentiality they legally can't share that information. This chasm is illustrated by some final MHP/FCG quotes in relation to the use of client consent forms. In the past there have been DHB directions for clients to sign a consent form during admission, indicating who they want to be involved in their treatment and to whom they wish information to be given or not

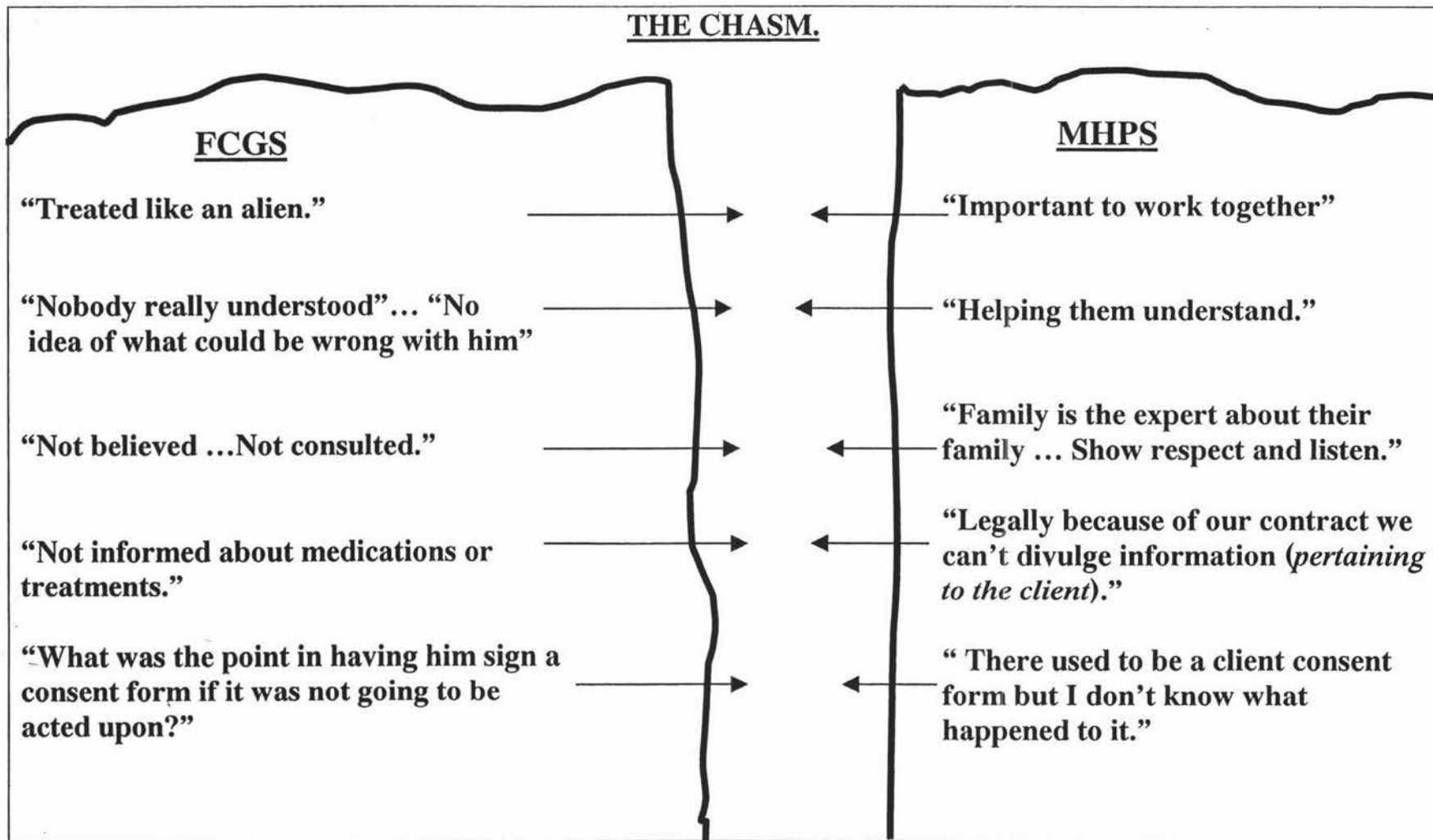
to be given. When these consent forms are either, not used, or the client's decision is not referred to by MHPs, or the client's decision is not reviewed regularly, it becomes beyond the FCG's ability to breach this chasm.

FCGs become frustrated, feel ignored, despairing and abandoned in their efforts to obtain much needed information or be consulted about discharge and treatment of their family member. FCGs stand in a position of powerlessness on one side of the chasm, continuing to ask for support and information to help them provide care for their mentally ill family member. MHPs stand on the other side of the chasm in a place of what appears to be powerfulness, often using the Privacy Act as an excuse for withholding much needed information and assistance.

While the MHP themes reveal that MHPs face many difficulties within their own mental health service provision these issues are not issues that are the FCGs' responsibility to resolve, they are issues that need addressing within their own DHB and their own service. However these issues indirectly affect and contribute towards the chasm that seems to exist in the relationship between MHPs and FCGs.

This chasm, or gap as it has been referred to in recent literature, has been identified in past research and will be discussed in the next chapter. Recommendations will be made as to how bridges could be built across this chasm, to ensure a trusting working relationship is formed between MHPs and FCGs that will ultimately benefit the client.

FIGURE I. Representation of the relationship between Mental Health Professionals (MHPs) and Family Caregivers (FCGs)



CHAPTER FOUR

DISCUSSION, RECOMMENDATIONS AND LIMITATIONS.

Introduction.

The aim of this research was to explore the relationship between family caregivers and mental health professionals who care for 18-30 year olds who are diagnosed with a serious mental illness. Exploring the relationship involved interviewing both mental health professionals and family caregivers and discussing the factors that might influence that relationship.

Four mental health professional themes and five family caregiver themes were identified that illustrated the nature of the relationship that exists between mental health professionals and family caregivers in two areas of New Zealand. Mental health professionals described an awareness of the need to have a working relationship with families and the benefit to themselves when they involved families in client treatment, but they also discussed a number of problems that affected their ability to develop this relationship. Mental health professionals discussed problems that they faced in their own service; problems with, what they referred to, as 'difficult' families, and problems surrounding confidentiality issues. Family caregivers on the other hand spoke of their growing distrust with mental health professionals, as they were not believed, were blamed, were not informed, were ignored and were not consulted, resulting in frustration, fear, anger, powerlessness and despair.

New Zealand Ministry of Health and Mental Health Commission documents (1994-2002) have provided directives to mental health professionals to build a relationship with family caregivers that would enable them to be more involved in the treatment of clients. Specific steps as to how this relationship was to be established were left to the District Health Boards to plan and implement. Mental health professionals and family caregivers in this study have revealed what appears to be a gap or chasm (Figure 1, see p. 86) between the mental health professional's intention to build a relationship with families, and the family caregivers' descriptions and perceptions of this relationship. This lack of

congruence between these two groups of caregivers will be discussed in relation to the findings of this research and the literature.

As the literature has shown, most of the informal care needed by mentally ill people in the community has been provided by family caregivers (Lefley, 1988; McFarlane, 1991; Solomon & Marcenko, 1992; Parker, 1993; Pejler, 2001; Doornbos, 2002). Mental health services would be overwhelmed without the care that families provide for their mentally ill family member (Huxley, Hagan, Hennelly & Hunt, 1990). However the apparent lack of resources and support to assist family caregivers to provide that care has been seen by family caregivers as a reflection of the value society places on caregiving for all people with support needs in the community – the aged, the infirmed and the mentally ill (Rutman, 1996).

“People with a serious mental illness are not ill in isolation” (Mental Health Commission, 1998, p. 9) therefore, it makes commonsense for a working relationship to be built between both mental health professionals and family caregivers. The founding principles of the Treaty of Waitangi speak of the importance of an equal partnership, where two groups of people work together (Durie, 1989). However a partnership is negotiated in a relationship where there is effective communication. For family caregivers and mental health professionals, building a working relationship is a priority for the long-term benefit of the client. Without a relationship there is no effective communication (Brammer & Macdonald, 1996) and it could be said that without contact and respect between these two groups of caregivers there can be no relationship.

Family caregiver perspective on the relationship.

Family caregivers in this present study stated that contact with mental health professionals when providing care for their family member was difficult. Contact was generally initiated by family caregivers when requesting information or offering information in relation to providing care for their mentally ill family member. Responses by mental health professionals, to these requests often questioned the expertise and integrity of the family caregivers. Arrogant and dismissive comments were made by mental health professionals to two family caregivers when they made suggestions based on their knowledge of their family member about the kind of intervention that may have been

necessary. These comments may indicate the mental health professional's belief that professional expertise is superior to that of the family caregivers and the possibility of a 'them and us' attitude described by Kaas et al. (2003). Not being listened to and not believed were described by family caregivers in this current study and that of Jeon and Madjar (1998) revealing this attitude may be influencing the lack of a positive relationship that "takes place in a climate of respect for the other" as described in the New Zealand Nurses Association Code of Ethics" (1995, p. 10).

As family caregivers spent more time with their family members than the limited time mental health professionals had with clients, they recognized early warning signs of deterioration that professionals may have missed, and were more aware of the need for early intervention. Attempts to contact mental health professionals and communication with them, including psychiatrists, nevertheless, had been frustrating and stressful revealing cracks in the formation of this relationship. These findings confirm results from Francell et al. (1988), Muhlbauer (2002), Doornbos (2002) and Ferriter and Huband (2003), who also found that the majority of caregivers in these studies found contact and communication with mental health professionals to be unhelpful causing much distress for the caregivers.

Lack of appropriate and timely response when trying to obtain help for their family member and being excluded from the treatment process increases family caregivers' dissatisfaction with mental health professionals. Lack of response during times of crisis injects distrust and hinders the development of a relationship between these two groups of caregivers. Holden and Lewine (1988), Francell et al. (1988) and Johnson (2000) also described families feeling left out of treatment and ignored by professionals and caregivers. In the studies by Hanson and Rapp (1994), Johnson (2000) and Mohr (2000) family caregivers expressed similar frustrations and dissatisfactions about repeated attempts to be involved in their family members' treatment. Jeon and Madjar's (1998) Australian study and Pejler's (2001) study in Sweden, Doornbos (2002), Muhlbauer (2002) and Ferriter and Huband's (2003) studies from the United States all highlighted families who described having difficulty communicating with mental health professionals.

A well functioning relationship is one in which family caregivers can contact mental health professionals and vice versa in an atmosphere of mutual respect and trust. Difficulties with contact and communication will continue to widen cracks in this

relationship, and if changes are not implemented, studies will continue to report high levels of family caregiver dissatisfaction.

One reason that was suggested in the literature and described by two of the caregivers in this current study for the demonstration of lack of respect by mental health professionals, including psychiatrists, was that they still believe that families, more specifically women, are in some way to blame for causing the clients' illness (Spaniol & Zipple, 1988; Doornbos, 2002). Hooyman and Gonyea (1995) also highlighted women caregivers being blamed for being instrumental in causing their family members illness and rarely being encouraged for the nurturing caregiving that they provided. The blaming of women and the criticism of families, who treat their family member inappropriately for their chronological age, also indicated that outdated beliefs of family culpability (Rubin et al, 1998) could still be prevalent among some mental health professionals. Recently attributed biological causes of mental illness may not have been widely accepted among some mental health professionals. Studies in the United States exploring mental health professionals' attitudes and beliefs about the families of clients have confirmed these results (Rubin et al.1998; Farhall et al.1998; Reibschleger, 2001, 2002) however more research needs to be conducted to ascertain the generalization and validity of this perception. The cracks widen still further in the relationship between these two groups of caregivers to form a chasm, when these beliefs and attitudes are still being held by mental health professionals.

There were only three incidents in this study where family caregivers commented positively about the relationship that they have had with mental health professionals. Therefore, the caregivers themes revealed a very negative picture of how this relationship was perceived and tended to confirm the presence of an impassible chasm between these two groups of caregivers.

Family caregivers have often seen their family members becoming unwell and when they are providing support and care in the community on a regular basis they are more likely to notice when things go wrong. Family caregivers participating in this study recognize that when they don't have the skills or the knowledge to understand what is happening, the mental health professional who does have the training and the skill are the people to contact. However family caregivers continue to distrust and sometimes despair of the professionals and the services that could provide skilled help to assist them to provide

care for their mentally ill family member, due to all the difficulties discussed. The chasm that appears to exist between these two groups of caregivers is certainly a deep one from the caregivers' perspective, which may not easily be bridged.

Mental health professionals in this present study however were largely unaware of this chasm and indicated that they are doing their best to involve families. They stated that it was important that they build a relationship with family caregivers like they would with a client and described their perspective of the relationship and the factors that have influenced contact and communication with family caregivers.

Mental health professionals' perspective

Similar to Reibschleger's study in 2001, this present study revealed awareness by mental health professionals of the immense stress families cope with and their need for information, when they are providing care for a mentally ill family member. Awareness can produce intention to involve families but action by mental health professionals is necessary to address the requests and needs of the family caregivers.

Entrenched beliefs of blame for causing the family member's illness, was not evident, as the mental health professionals talked about their relationship with family caregivers. This was in contrast to statements made by professionals in Farhall et al's (1998) Australian study where blaming attitudes by staff and lack of contact with family caregivers was instrumental in the planning of a training programme for professionals to seek to dispel some of these myths of blame. Rubin et al. (1998) and Reibschleger's (2002) results also found evidence of the belief that parental or family dysfunction caused the illness of their family member. Mental health professionals in this study did describe dysfunctional families as being difficult to deal with when treating the client. This may be an area where the mental health professional experiences conflict about who they are working for – the client or the family. Some dysfunction could be a response to stress, grief and lack of help in dealing with the difficult symptoms and behaviours of mental illness. Family psychoeducation involving professional support and skill has been shown to help ease family burden (Falloon, 1999; McFarlane, 1991; Bishop et al. 2002) and it may

be possible that some dysfunction may be dealt with during this type of intervention if it was available.

Although the intention by mental health professionals to involve family caregivers wherever possible and to support them in the care of their family member was expressed by participants in this current study, there appeared to be uncertainty of how this could be achieved in light of the difficulties they faced. They also seemed to be unfamiliar with many of the Ministry of Health and Mental Health Commission documents or District Health Board policies giving directions to involve families. Difficulties within their own services such as time constraints confirmed Bernheim and Switalski's (1988) results from a New York study fifteen years previously. Time constraints and heavy workloads were perceived as a barrier to building a relationship with the families and involving families in treatment although one mental health professional saw time constraints as just another excuse for not involving the family in treatment. Team meetings, administrative duties such as writing up reports and time taken in traveling to outlying areas to visit clients were mentioned as limiting mental health professionals' ability to have an ongoing working relationship with families. This is a problem that may need to be addressed by all mental health services and District Health Boards if involving families is to become a priority in the care of clients.

None of the mental health professionals interviewed were psychiatrists, nevertheless there was strong criticism of psychiatrists' professional practice when dealing with families, by mental health professionals in this study. They were described as being a conservative profession, being slow to embrace change. This criticism of psychiatrists is quite a unique finding of the present study. The mental health professional's attitude towards them does not seem to have been explored and therefore has not been reported in the research literature.

A lack of appropriate and available training in specific skills in how to involve families of clients was expressed by mental health professionals in this study, in spite of the literature recommending that all mental health professionals need training that will assist them to develop these skills (Kuipers & Bebbington, 1990; Hornby & Atkins, 2000). In the literature, mental health professionals who had attended training programmes conducted in Australia (Jeon & Madjar, 1998) and London (Bishop et al. 2002) stated that they had

benefited from these programmes. Professionals and family caregivers both had responsibility for facilitating parts of the programme and were also participants together, which mental health professionals in these studies, had resulted in a more positive partnership relationship. Working together is a sign of a developing partnership.

It can only be reiterated in light of McFarlane (1991) and Falloon's (1999) findings, that when formal (*mental health professionals*) and informal (*family caregivers*) caregivers are working together, the outcomes are more promising for the client, the family caregivers *and* the mental health professionals. The length of training has been found to have a bearing on the establishment of a strong working relationship between professionals and non-professionals (Jeon & Madjar, 1998). It seems that extended training courses are not available in New Zealand and Hanson and Rapp (1992) stated that most University courses only provided a single module of training related to involving families.

Falloon and Faddens' Integrated Mental Health Care model, which was popular in the 1990's, has not been accepted by mental health professionals in these two areas as a model that is appropriate for use in New Zealand, despite the promising results of similar models of care which provide psychoeducation and support for the whole family. The models' methods were dismissed by some mental health professionals in this study as too simple and therefore not useful, however the model of care does support the whole family including the mentally ill family member, and encourages building relationships among all those who are involved in the client's care and treatment. Research may be needed to ascertain whether or not this model has been taught in other parts of New Zealand and what benefits have resulted from the training, but also how mental health professionals in those other areas perceive the use of this model. Support and education were areas that mental health professionals in this study stated as needing attention by mental health services which confirms the recommendation made by Milliken and Rodney (2003) for trained professional support and education.

The Report of the Ministerial Inquiry to the Minister of Health (1996) had noted that there was a desperate need for supported accommodation in the community and the two professionals who managed supported accommodation homes in the community spoke of the high demand for client spaces in these homes. It would appear from the findings of this study, that there is still a desperate need for more supported accommodation, especially age

appropriate supported accommodation in the community. The lack of it often placed stress on mental health professionals and families and on their relationship when trying to find suitable accommodation for the family member/client in the community

Due to the few in-depth studies available that have explored the relationship with family caregivers from the mental health professionals' perspective and the small sample of participants from only two District Health Board areas in New Zealand, conclusions drawn from the mental health professional perspective are limited.

However it would seem that what these two groups of caregivers have in common is the fact they are both providing different kinds of care to the person diagnosed with a serious mental illness therefore both are needed to support the family member/client on their road to recovery.

In providing care for the client one theme emerged that was common to both mental health professionals and family caregivers. This theme further illustrates the chasm separating these two groups of caregivers from building a positive relationship.

A common theme affecting this relationship.

Theme Four (MHP) and Theme Five (FCG) highlighted the area that seemed to cause the most conflict for mental health professionals and family caregivers alike; mental health professionals dealing with problems concerning confidentiality (Theme four) and the family caregivers feelings of abandonment and powerlessness (Theme Five) as a result of being given the excuse of client confidentiality, as a reason for not being given information. This area of conflict widened the gap of the chasm in this relationship. The family caregivers' inability to obtain information and the mental health professionals' seeming inability to give the needed information affected the contact, communication and relationship between these two groups.

It is acknowledged that mental health professionals have a legal obligation to keep client confidentiality, but not all information is confidential and release of some information related to medication, side effects and treatment should not jeopardise the therapeutic relationship with the client. Information can be disclosed to a third party who is involved in providing care if the purpose of collecting that information was to ensure

effective treatment and if that purpose was conveyed to the client at the time of its collection (Mental Health Commission, 2002). Family caregivers who are directly involved in the care of their family members either in the home or in the community need information to ensure effective treatment and care.

Family caregivers need to be able to contact mental health professionals and communicate confidentially any deterioration in well-being of their family member. When mental health professionals share the family's confidential information (such as fears for the family member's deteriorating mental health status) with the client, this disregards the family's right to confidentiality. One family caregiver in this study gave an example where family confidentiality had not been respected resulting in the family member's agitation towards the caregiver. Five of the seven mental health professionals were aware that this was a problem for families but also felt that keeping family confidentiality was excluding the client. Contact and confidential communication of relevant information with the mentally ill family member's treatment team is crucial to obtain early intervention. It should not be necessary to breach family confidentiality that may jeopardise intervention as well as the relationship the family may have with the client.

The dilemma for mental health professionals according to Zipple et al. (1990) was that of keeping client confidentiality *and* being supportive to the families. Conflict about who they were working for – the client or the family, was described as a barrier to a functioning relationship by the mental health professionals in this present study and in Kaas et al's (2003) study in the United States. This conundrum may require more clear guidelines of the mental health professional's roles and responsibilities towards the client *and* more specific guidelines of their role and responsibilities towards the family. It would be essential to clarify these roles to the client and the family during the first admission interview.

When clients refused to involve their families and release information to the family this puts mental health professionals in this study in a very awkward situation. As a solution three of the professionals described the process of specifically asking clients to discuss the information requested by their family caregiver with their family to try and address these situations. Leggatt (1993) stated that often professionals have been fearful of being sued for breach of confidentiality and therefore tend to act on the side of caution

rather than using commonsense when it came to sharing essential information with family caregivers. Frequent incidents of being 'kept in the dark' when not given information about diagnosis, medication and treatment related to the care of their mentally ill family member was identified as one of the main family caregiver themes in this present study. Peart (1996) agreed that families have been caused much distress as a result of being given the excuse of the Privacy Act. Recommendations have previously been made that specific training is needed to clarify the difference between confidential and non-confidential information and the steps that can be used to release confidential information (Peart, 1996; Marshall & Solomon, 2000). Specific training in the use of client confidentiality for mental health professionals in New Zealand may not be regularly provided and this could be where the anomaly occurs. Clarifying confidentiality surrounding the release of information to family caregivers may lessen mental health professionals' fears, and could enable them to make more commonsense decisions in the future.

It was clear in this present study that the majority of mental health professionals did not use client consent forms and rarely reviewed decisions previously made, confirming Marshall and Solomon's (2000) findings that permission had not been requested from 25% of consumers and only 36% had been encouraged to involve their families in their treatment. Consistent use of client consent forms is one method of ensuring that a decision is made in writing for all treatment team members to refer to when dealing with the client. Clients have a right to refuse permission for the whole family or certain members of the family not to be involved but if there is ongoing communication about the benefits of involving the client's family this may change. When the mental health professional encourages the client to involve the family and regularly reviews the consent or lack of consent to release information, this action conveys a message of value to the family caregiver. Valuing and respecting the family caregiver's role contributes towards a positive relationship that works together for the benefit of the client.

Eight family caregivers in a narrative study (Heather, 2004) just released in New Zealand, confirmed the family caregivers findings of this study. Heather stated that the need to be informed, to be listened to, taken seriously and believed, and to be treated as a valuable member of the family member's treatment were essential components of a relationship that would enable these family caregivers to become 'partners in care.'

The intention of mental health professionals to build a relationship with family caregivers and involve them more in the treatment of clients, contrasts starkly with the family caregivers' experience of this relationship. This incongruence has created the chasm between these two groups and recommendations follow which could begin to narrow the chasm so mental health professionals and family caregivers can work together during the recovery of the client.

Recommendations

The following recommendations have arisen from this research.

- The process of building a relationship with families, arising from Ministry of Health and the Mental Health Commission directives and strategies needs to be more *specifically described* with provision of *detailed* guidelines. Directives from the Ministry of Health have been too general and therefore appear to have produced uncertainty about how these directives can be put into action within the present mental health system. It should also be clearly stated that initiating this relationship is the mental health professional's responsibility during first contact but maintaining it is the responsibility of both mental health professional and the family caregiver.
- Mental health professionals expressed a lack of specific training to increase their knowledge and skill of involving families in the treatment process. This request needs to be addressed as a priority by mental health providers and tertiary education providers, as training of extended duration has previously been recommended in preference to the single modules of many tertiary courses. Family caregivers' participation and facilitation during these courses should be encouraged at every level. The benefits of this collaborative form of training would assist both groups of caregivers to begin to understand and respect each other's perspective and expertise, as they work together for the ultimate benefit to the client.
- Specific training and detailed guidelines on the use of client confidentiality and how to release much needed information to families should be provided regularly to all mental health professionals but also to family caregivers and clients/family members. Client *and* family confidentiality should be respected and specific guidelines should be

provided to clarify what is non-confidential and confidential information to all involved on the client/family member's treatment team.

- The consistent use of client consent forms for disclosure of information and the regular review of these forms would signal to other treatment team members and the family, who can be informed and what kinds of information can be shared. Also regular reviews of decisions made by the client should be conducted with encouragement from the professional of the benefit of involving family and the benefits of releasing essential information to them. Responsibility for encouraging the client of the benefits of involving his/her family should be the responsibility of the mental health professional. When a mentally ill client is approached by a mental health professional who *believes* in the value of involving families most clients are willing to grant a degree of access to certain information (Zipple et al. 1990; Bogart & Solomon, 1999).
- The provision of evidence based psychoeducation training would empower family caregivers to cope with the diverse and complex issues surrounding living with mental illness in the family. The models of training mentioned in this thesis require the attendance and participation of both mental health professionals and family caregivers. Knowledge and skill-based learning would ease the burden for caregivers as they also learn to become part of the treatment team during these courses and become respected and valued for the care they provide.
- Finally more in-depth research will be required to further explore the perceptions, attitudes and difficulties faced by mental health professionals including psychiatrists, when involving families in New Zealand. There is also a need for research to evaluate the strategies and plans put together by District Health Boards and mental health services when implementing Ministry of Health policies in relation to involving families, to ensure that these documents become *living* documents providing specific guidance to mental health professionals and family caregivers.

Limitations.

The researchers first-hand experience in this area of research has already been discussed in the methodology and much care was taken to be respectful of the difficulties mental health professionals have described when dealing with families of clients.

The sample of both mental health professional and family caregiver participants were a self-selected small group of six family caregivers (FCGs) and seven mental health professionals (MHPs) one of whom had been a family caregiver. These participants were recruited from only two District Health Board areas in New Zealand.

Family caregivers agreeing to participate were all women and in one geographic area were all supported by the local community family support group. Family members had all been given diagnoses a number of years prior to the interviews and were aged between 20 and 30. Family caregivers, even though they were encouraged to participate by the local support group, may also have agreed to participate due to the negative nature of their relationship with mental health professionals rather than because of a positive perception of this relationship. However, the negative factors that influence this relationship have been described in research and other literature for twenty years. Family caregivers have a right to be heard until changes are instigated that grant them the support and involvement they require to ease the burden of caring for a mentally ill family member.

Three out of four public community mental health team leaders including one Maori mental health team leader granted permission. One leader stated that she might not have agreed to my interviewing team members up to twelve months prior to this research. The reason this leader gave for this response was that she was now confident that due to changes implemented in that service, any prospective mental health professional participants would probably be able to share a more positive perspective on the nature of their relationship with family caregivers in that area. However when exploring the relationship between mental health professionals and family caregivers both positive *and* negative factors affecting this relationship needed to be discussed.

Concluding comments.

The purpose of this study was to explore the relationship between family caregivers and mental health professionals who care for 18-30 year olds diagnosed with a serious mental illness in two District Health Boards of New Zealand. Most of the findings were supported by a large number of overseas and local research studies.

The mental health professional themes revealed awareness of the needs of the family in spite of difficulties they faced within mental health services, with some families and

confidentiality issues. However the family caregiver themes reflected a lack of mental health professional response to their needs, resulting in feelings of frustration, fear, anger, abandonment and powerlessness. It would appear from the caregiver perceptions in this study that a chasm exists, which prevents effective communication occurring, therefore, from the family caregiver's perspective there is no relationship. It would also appear from the mental health professional's perspective that although there is awareness of the family's need for contact and communication and there is an intention to build a positive relationship, a true working relationship does not exist.

A relationship requires regular positive contact, effective communication and a relationship built on trust and mutual respect for the equally important roles the mental health professional and family caregiver provide in the care of the mentally ill family member/client. Narrowing the chasm between both groups of caregivers will require that the above recommendations be addressed to enable the mental health professionals and the family caregivers to build a relationship that will provide a balance of care for the mentally ill client/family member in the community. Intention must be followed by action, by mental health professionals and by *all* those involved in planning and implementing more and better mental health services for the *whole* family.

APPENDICES

APPENDIX ONE

Letter of introduction and Information sheet (MHP)



School of Health Sciences
Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
Facsimile: 64 6 350 5668

Elizabeth Nicholls,
School of Health Sciences,
Massey University,
Private Bag 11 222,
Palmerston North.
21/2/03

Dear _____,

Thankyou very much for offering to becoming a participant in my Massey University research project.

I am Elizabeth Nicholls. I completed my Postgraduate diploma in Rehabilitation in 1999 and I am currently enrolled as a student to do a Masters degree in Rehabilitation at Massey University, Palmerston North.

As one member of my family has experienced a psychotic illness, I have been interested in the factors that influence the relationship between caregivers and mental health professionals. There has been much written about the benefits and difficulties of involving families in the treatment and recovery process of the mentally ill person. Therefore I am very interested in exploring how you, as community mental health key workers, experience the relationship with family caregivers in N.Z. I am also interested in how family caregivers experience that relationship with community mental health key workers in N.Z.

I am enclosing the **information sheet** to provide you with more details on :

- The nature and purpose of the research,
- The requirements if you decide to participate, and on
- Your rights if you agree to participate in this study.

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/117. If you have any concerns about the conduct of this project, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics committee: Palmerston North, telephone 06 350 5249,
email S.V.Rumball@massey.ac.nz

I really appreciate you taking the time to read through this material and considering being a participant. If you agree to participate in this research could you please complete the enclosed Consent form? On receipt of your signed

consent form I will contact you and make an appointment to meet with you at a place convenient to us both.

I look forward to hearing from you and meeting you soon.

Yours sincerely,

Elizabeth Nicholls.



School of Health Sciences
Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
Facsimile: 64 6 350 5668

INFORMATION SHEET FOR KEY WORKERS.

Nature and purpose of the study.

My research involves exploring the experience of the relationship between family caregivers and community mental health key workers who care for 18 – 30 year olds diagnosed with a mental illness involving psychosis (psychotic disorder).

I hope to gain a clearer picture of how that relationship is experienced from your perspective by interviewing you at a time and place that is convenient to you. The interview will involve asking you to share the experience of your relationship with families during the treatment and recovery of your clients. I will be asking your permission to tape the interviews and therefore will be asking you to choose a pseudonym that will be used in the transcription of these tapes to safeguard your anonymity.

By interviewing community mental health key workers and family caregivers, I hope to gain an understanding of how that relationship is being experienced by you both, and identify some of the factors that influence that relationship. The outcome would be to provide some suggestions to both groups as to how the relationship could be enhanced. I hope to publicise the results as widely as possible through journals and speaking with interested groups.

Community mental health key worker's participation

- I am looking for key workers who care for clients/consumers, between the ages of 18 - 30 who have been diagnosed with a mental illness involving psychosis (psychotic disorder).
- I am looking for key workers who are involved with family caregivers, and whose clients/consumers either live at home or have regular contact with their family caregivers.

What will you have to do?

If you agree to take part:

1. You need to sign the enclosed **consent form** and return to me in the reply paid envelope **within ten days**. (Can email consent if this is more convenient).
2. You will be asked to give me a **pseudonym** so that when I transcribe the tapes I will replace your real name with that pseudonym. No reference will be made to your geographic location as I am interviewing in two geographic areas. Also any real names mentioned during the interview will receive pseudonyms to further preserve your anonymity when analysing and reporting the results.
3. On receipt of your (signed) consent form I would then **contact you by phone to arrange a convenient date, time and place where we could meet for the interview**. This interview may take place at your own home or office or at another convenient place for us both. The approximate duration for the interview will be **1 – 2hours maximum**. I would need you to be available for that interview some time between **March 10th and 14th, 2003**.
4. I will be requesting your permission to tape the interview, as what you have to say is really important to me. Taping what you say will ensure accuracy and enable me to listen more closely, rather than having to write down your answers as I try to listen.
5. Also I will send you a summary of the findings at the completion of the study.

Anonymity and confidentiality.

As stated above you will be asked to provide a pseudonym which I will use in the transcription of the tape and documentation, so that your real name will not be identifiable. Pseudonyms will be given to any other real names mentioned during the interview. I will be transcribing all tapes myself to ensure your confidentiality.

Your real name with contact phone number/email will only be available to myself. It may be made available to my two supervisors if necessary. Also, if you agree, my own professional support person living in your geographic location, will be given your name and the venue of our interview. This person will sign a confidentiality agreement. All tapes and written references will be stored securely during collection and transcription in a locked cabinet or briefcase. At the completion of the data collection the tape will be kept in secure storage at Massey University and either destroyed after transcription or returned to you.

Your rights.

If you choose to participate you have the right to:

- Decline to participate;
- Decline to answer any particular question;
- Withdraw from the study any time until two weeks after the interview;
- Ask any questions about the study at any time during participation;

- Provide information on the understanding that your name will not be used unless you give permission to the researcher;
- Be given access to a summary of the project findings when it is concluded.

Further questions

Any questions that you may have regarding this study may be directed to either one of my supervisors or myself. Our names, phone numbers and email addresses are listed below. Please do not hesitate to contact any of us by post, phone or email at:

School of Health Sciences,
Massey University
Private Bag 11 222,
Palmerston North.

Dr. Regina Pernice,
(06) 350 5799 Extension 2242.

Mr Martin Woods,
Ph: (06) 350 5799 Extension 2241

R.E.Pernice@massey.ac.nz

M.Woods@massey.ac.nz

RESEARCHER

Elizabeth Nicholls
Ph: (06) 350 5799 Extension 7383.
E.A.Nicholls@massey.ac.nz

I am available from
9. 30.am to 1.30.pm, Monday – Friday

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/117. If you have any concerns about the conduct of this project, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics committee: Palmerston North, telephone 06 350 5249,
email S.V.Rumball@massey.ac.nz

Your experience as a community mental health key worker working alongside clients and their families is very valuable, and would increase the awareness of the factors that influence the relationship between families and mental health services. Ultimately, it could contribute to the enhancement of client/consumer mental health. If you decide to participate I would be very grateful, and I warmly invite you to send me the enclosed informed consent form.

I look forward to your reply.

Kind regards,
Elizabeth Nicholls

APPENDIX TWO

Letter of introduction and Information sheet (FCG)



School of Health Sciences

Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
Facsimile: 64 6 350 5668

Elizabeth Nicholls,
School of Health Sciences,
Massey University,
Private Bag 11 222,
Palmerston North.
21/2/03.

Dear _____,

Thank you very much for offering to become a possible participant in my Masters research project.

I am Elizabeth Nicholls. I completed my Postgraduate diploma in Rehabilitation in 1999 at Massey and I am currently enrolled as a student to do a Masters degree in Rehabilitation at Massey University Palmerston North.

As one member of my family has experienced a psychotic illness, I have been interested in the factors that influence the relationship between caregivers and mental health professionals. There has been much written about the benefits and difficulties of involving families in the treatment and recovery process of the mentally ill person. Therefore I am very interested in exploring how you, as family caregivers experience the relationship with community mental health key workers in N.Z. I am also interested in how Community mental health key workers perspective of the relationship with family caregivers in N.Z.

I am enclosing an **information sheet** to provide you with more details on :

- The nature and purpose of the research,
- The requirements if you decide to participate, and on
- Your rights if you agree to participate in this study.

I really appreciate you taking the time to read through this material and considering becoming a participant. If you agree to participate in this research could you please complete the enclosed Consent form? On receipt of your signed consent form I will contact you and make an appointment to meet with you at a place convenient to us both.

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/117. If you have any concerns about the conduct of this project, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics committee: Palmerston North, telephone 06 350 5249, email S.V.Rumball@massey.ac.nz

Te Kunenga ki Pūrehuroa

I look forward to hearing from you and meeting you soon.
Yours sincerely,

Elizabeth Nicholls.



School of Health Sciences
Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
Facsimile: 64 6 350 5668

INFORMATION SHEET FOR FAMILY CAREGIVERS.

Nature and purpose of the study.

My research involves exploring the experience of the relationship between family caregivers and community mental health key workers who care for 18 – 30 year olds diagnosed with a mental illness involving psychosis (psychotic disorder).

I hope to gain a clearer picture of how that relationship is experienced from your perspective by interviewing you at a time and place that is convenient to you. The interview will involve asking you to share the experience of your relationship with community mental health key workers during your family member's treatment and recovery. I will be asking your permission to tape the interviews and therefore will be asking you to choose a pseudonym that will be used in the transcribing of these tapes, to safeguard your anonymity.

By interviewing family caregivers and community mental health key workers I hope to gain an understanding of how that relationship is being experienced by you and identify some of the factors that influence that relationship. The outcome would be to provide some suggestions to both groups as to how the relationship could be enhanced. I hope to publicise the results as widely as possible through journals and speaking with interested groups.

Family caregiver's participation

I am looking for family caregivers who care for a family member, between the age of 18 and 30, who has been diagnosed with a mental illness involving psychosis (psychotic disorder).

I am looking for family caregivers who have contact with community mental health workers and whose mentally ill family member either lives at home and/or has regular contact with you, the family caregiver.

What will you have to do?

If you **agree** to take part:

1. I need you to complete the enclosed **consent form** and return to me in the reply paid envelope within ten days.
2. You will be asked to give me a **pseudonym** so that when I transcribe the tapes I will replace your real name with that pseudonym. No reference will be made to your geographic location as I am interviewing in two geographic areas. Also any other real names mentioned during the interview will receive pseudonyms to further preserve your anonymity when analysing and reporting the results.
3. When I receive your signed consent form I will contact you by phone to arrange a convenient date, time and place where we could meet for the interview. This interview may take place at your own home or at another convenient place for us both. The approximate duration for the interview will be **1 – 2 hours maximum**. I would need you to be available for that interview during **March, 2003**.
4. I will be requesting your permission to tape the interview, as what you have to say is really important to me. Taping what you say will ensure accuracy and enable me to listen more closely rather than having to write down your answers as I try to listen.
5. Also I will send you a summary of the findings at the completion of my study.

Anonymity and confidentiality.

As stated above you will be asked to provide a pseudonym that I will use in the transcription of the tape and documentation of the results, so that your real name will not be identifiable. Pseudonyms will be given to any other real names mentioned during the interview. I will be transcribing all tapes myself to ensure your confidentiality.

Your real name with contact phone number/email will only be available to myself. It may be made available to my two supervisors if necessary. Also, if you agree, my own professional support person, living in your geographic location, will be given your name and the venue of our interview. This person will sign a confidentiality agreement. All tapes and written references will be stored during collection and transcription, in a locked cabinet or briefcase. At the completion of the data collection the tape will be kept in secure storage at Massey University and either destroyed after transcription or returned to you.

Limitations to this anonymity would be if two members from the same family agree to participate. In this case I cannot guarantee complete individual anonymity, even though I would be interviewing each family member separately.

Your rights.

If you choose to participate you have the right to:

- Decline to participate;
- Decline to answer any particular question;
- Withdraw from the study any time until two weeks after the interview;

- Ask any questions about the study at any time during participation;
 - Provide information on the understanding that your name will not be used unless you give permission to the researcher;
- Be given access to a summary of the project findings when it is concluded.

Further questions

Any questions that you may have regarding this study may be directed to either one of my supervisors or myself. Our names, phone numbers and email addresses are listed below. Please do not hesitate to contact any of us at:

School of Health Sciences,
Massey University
Private Bag 11 222,
Palmerston North.

Dr. Regina Pernice,
(06) 350 5799 Extension 2242.

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R.E.Pernice@massey.ac.nz

M.Woods@massey.ac.nz

RESEARCHER

Elizabeth Nicholls

Ph: (06) 350 5799 Extension 7383.

E.A.Nicholls@massey.ac.nz

I am available from

9. 30.am to 1.30.pm Monday – Friday

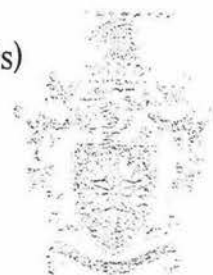
This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/117. If you have any concerns about the conduct of this project, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics committee: Palmerston North, telephone 06 350 5249, email S.V.Rumball@massey.ac.nz

Your experience as a family caregiver working alongside community mental health key workers is very valuable, and could increase awareness of the factors that influence the relationship between families and mental health services. Ultimately it could contribute to the enhancement of client/consumer mental health. If you decide to participate I would be very grateful, and I warmly invite you to send me the enclosed Consent form. I look forward to your reply.

Kind regards,

Elizabeth Nicholls.

APPENDIX THREE
Consent form (MHPs and FCGs)



School of Health Sciences
Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099
Facsimile: 64 6 350 5668

CONSENT FORM

RESEARCH TITLE

Exploring the relationship between community mental health key workers and family caregivers.

I have read the information sheet and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any time.

I understand that I am free to withdraw from the study at any time and to refuse to answer any particular questions. I also understand my other rights outlined in the Information Sheet.

I agree to provide information to the researcher on the understanding that I will not be identified in any parts of the research. Also that the information given will only be used for this research, and any publications or meetings where the sharing of these results may benefit people who are diagnosed with a mental illness and their families.

Conditions. Please tick the appropriate boxes.

- I agree I do not agree to be interviewed by Elizabeth Nicholls.
- I agree I do not agree to the interview being audio taped.
- I agree I do not agree to having the information shared in the interview used for the purposes set out in the information sheet.
- I do I do not wish to have a Kuia/ Kaumatua to support me during the interview.

I also understand that I have the right to ask for the audiotape to be turned off at any time during the interview.

At the conclusion of the study I wish my audiotapes to be:

- returned to me
- destroyed

I agree to participate in this study under the conditions set out in the Information Sheet and this consent form.

My name _____

Signature and date _____

As the researcher, I declare to adhere to the conditions set out in the Information Sheet and this Consent Form.

Name of researcher _____

Signature and date _____

Signatures of supervisors.

1. Name _____

Signature and date _____

2. Name _____

Signature and date _____

Please fill out your chosen pseudonym below for use following the interview. Thankyou.

Participant pseudonym:

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APPENDIX FOUR

Interview guide for MHPs

Clarify the participant's rights.

Go over the research title with the participant.

1. Tell me about the process of how you came to work in the mental health area?
2. In your experience what kinds of factors make for a positive relationship with family caregivers?
3. (a) What kinds of factors contribute towards a negative relationship with family caregivers?
(b) Is there discussion about this among key workers?
4. (a) When family caregivers contact you what are the general reasons for that contact?
(b) How do you feel about the reasons for being contacted?
(c) Is there discussion about the reasons for being contacted, amongst keyworkers?
5. (a) Tell me about some reasons why you contact family caregivers?
(b) How do you feel about contacting them?
6. (a) In your experience what sort of factors make for a good relationship between a family caregiver and his/her recovering family member?
(b) What kinds of factors contribute to a difficult relationship?
7. Would you like to involve family caregivers more in the treatment of your clients if you were able to do so?
8. (a) What do you know about policies that encourage involvement of the families of your clients?
(b) How did you find out about that information?
(c) Where would you go to find out this information?
9. Are there any other issues that you would like to raise about your involvement with family caregivers?

APPENDIX FIVE

Interview guide for FCGs.

Clarify the participant's rights.

Go over the research title with the participant.

1. I'd like to start by you telling me about how your family member's illness developed?
How is that person coping now?
2. In what ways have you been involved in the care of your family member – both formally and/or informally?
3. In what ways would you like to be more or less involved with your family member's treatment and care?
4. When you have had to contact your family member's key worker
 - (a) What reasons were there for contacting him/her?
 - (b) How did you make the decision to contact him/her?
 - (c) How did you feel about contacting the key worker?
 - (d) How did this affect your relationship with your family member or other members of the family?
5. Have there been times when the key worker has had to contact you?
 - (a) What were the reasons for that?
 - (b) What was that contact like?
6. (a) What kinds of things contribute towards a good relationship with your family member's key worker?
 - (b) What kinds of things contribute to difficult relationship with your family member's key worker?
7. What do you know about policies that encourage involvement of families?
Where would you go to find that information?
8. What kind of support do you feel that you need to help you, as you care for your family member?
9. Is there anything else that we have not covered that you would like to tell me about?

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