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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.