**Families’ Attitudes and Mental Illness**  
**Literature Review**

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**Introduction**

“People with serious mental illness are not ill in isolation. Their families, extended whanau, and significant others, whatever they think about the illness, cannot escape being affected by it. The lives of people with serious mental illness are inextricably involved with the lives of those they love and care for, and the lives of those who love and care about them.” (Mental Health Commission 1998 p9)

Families and whanau may play an important role in the lives of people with experience of mental illness. People with experience of mental illness often rely on family members as part of their support mechanisms. The relationships with family members may be the closest relationships that we have. A recent survey of discrimination against people with experience of mental illness in New Zealand (Peterson, Pere et al. 2004), however, showed that more people reported discrimination occurring from their friends and family than from any other source. This means that while families are an important feature in our lives, their attitudes and behaviours, whether they intend them or not, are not always effective in supporting people with experience of mental illness.

The aim of this literature review is to explore family attitudes towards people with experience of mental illness further – to look at the views and attitudes held by families of people with experience of mental illness, family beliefs about the cause of mental illness, the exact nature of discrimination perpetuated by family members, what is known about the effectiveness of different strategies to reduce discrimination,
and to look at the best way forward in terms of further research into the area of discrimination by family members.

**Views of families of people with experience of mental illness**

Traditionally families have been seen as contributing to mental illness - either as causing it or aggravating it (Riebschleger 2001; Marshall, Solomon et al. 2003; Rethink 2003). They have, at various times in the history of mental illness supported institutionalisation (by sending their relatives to psychiatric institutions (Jones 2002)), or been major players in deinstitutionalisation (more recently). Many families have assumed a caring role for people with experience of mental illness (Mason 1996).

Many mental health professionals view families as an ‘irritation’ (Angermeyer, Schulze et al. 2003). Families are considered by mental health professionals to be interfering and over-protective (Rethink 2003), and are regarded as being uninformed about mental illness and treatment (Riebschleger 2001). Family members also report a strained relationship with mental health professionals, who are perceived as being discriminatory towards family members (Angermeyer, Schulze et al. 2003). This may be because family are perceived by health professionals to be contributing to their relative’s mental illness.

There is a large number of stereotypes about families of people with experience of mental illness including their being dysfunctional, incompetent, burdened or brave (Banks 2003). The British Columbia Minister of Health’s Advisory Council on Mental Health (2002) reports that these stereotypes have an impact - families of people with experience of mental illness have strained relationships with others, and experience fear, violence, anxiety, conflict, lowered self-esteem and guilt. While mental health services have changed in the last ten years or so, the ‘burden’ placed on family members has not lessened (Ostman, Hansson et al. 2000). Angermeyer, Shulze et al. (2003) state succinctly that family members of people with experience of mental illness are characterised by ‘responsibility’. That is “they act as the major caretaker, and have a special emotional closeness” (Angermeyer, Shulze et al. 2003, p602)
The caring role that family members sometimes find themselves in has certain implications. People report a reduction in income (Dore and Romans 2001) – this study was limited to those with bipolar disorder, and major costs were incurred as a result of this mental illness, as well as family members needing to take time off work. Dore and Romans (2001) also found that there were difficulties in the relationship with families and their family member with experience of mental illness. Family members often feel ashamed and helpless (Angermeyer, Schulze et al. 2003), and feel guilty, as if they are the cause of a person’s mental illness. They may feel that they somehow have to compensate for their family member’s difficulties and social deficits (Perlick, Rosenheck et al. 2001).

Families’ perceptions of the causes of mental illness

When deciding on what they believe to be the causes of mental illness, family members tend to think specifically about their own situation and that of their relative - taking an individual approach - rather than the causes of mental illness in general (Magliano, Fiorillo et al. 2004). There are differing views as to how families perceive the causes of mental illness. Some researchers believe that families are strong proponents of a medical model of mental illness (Jones 2002) – that mental illness is caused by a brain disease. Other researchers state that families more frequently adhere to a psychological model of mental illness (Magliano, Guarneri et al. 2001; Magliano, Fiorillo et al. 2004). Marshall, Solomon et al. (2003) report that family members hold both biological and family causations beliefs about mental illness simultaneously, with families tending to blame themselves in the early stages of the recovery of their relative. Scheurich (2002) comments that family members tend to believe in the ‘power of positive thinking’ as a way of dealing with mental illness, implying that people are able to control their symptoms and behaviour.

There is a lack of information available in a New Zealand context that describes the beliefs that family members have about the causes of mental illness. The available research cited here about family beliefs of causation of mental illness comes from the UK and Italy (Marshall, Solomon et al. 2003; Magliano, Fiorillo et al. 2004), and there are possibly different cultural influences that may be at play in New Zealand.

Discrimination against people with experience of mental illness
Discrimination against, and the stigma of, people with experience of mental illness is widespread (Sayce 1998; Crisp, Gelder et al. 2000). It has an impact on the self-esteem (Link, Struening et al. 2001) and recovery (Perlick 2001) of people with experience of mental illness, as well as affecting all aspects of people’s lives (Penn and Wykes 2003).

Discrimination occurs when a person is treated differently from another person in the same or similar circumstances. It is a result of belief in the stereotypes of people with experience of mental illness leading to prejudice, which in turn leads to discrimination (Schumacher, Corrigan et al. 2003). For discrimination to occur however, the person with the prejudice must be in a position of power, which must then be exercised (Link and Phelan 2001). It is clear from the literature that any understanding of stigma and discrimination must include an analysis of power.

Whilst many people in this world face discrimination (on the basis of gender, race, disability amongst others), Gordon, Tantillo et al. (2004) report that discrimination against people with mental illness or intellectual disability seems to evoke the most negative attitudes out of all the disabilities surveyed. Findings from the New Zealand discrimination survey (Peterson, Pere et al. 2004) suggest that discrimination against people with experience of mental illness is an issue no matter what ethnic or cultural group the person identifies with.

**Families and discrimination**

Families share much of the discrimination that people with experience of mental illness face, by being associated with them (Angermeyer, Schulze et al. 2003) – this is discrimination by association (BC Minister of Health's Advisory Council on Mental Health 2002; Ostman and Kjellin 2002). Many families tend to treat mental illness as a source of shame and embarrassment (Wahl 1999). When talking about discrimination and mental illness, Angermeyer, Schulze et al. (2003) report that families tend to talk about their relatives’ experiences of discrimination, rather than their own.

Some of the literature has recognised that not only are families discriminated against due to their relative’s experience of mental illness, they are also an important source
of that discrimination (Wahl 1999a; De Ponte, Bird et al. 2000; Dickerson, Sommerville et al. 2002; Peterson, Pere et al. 2004). Tsang, Tam et al. (2003) concluded in their study based in Hong Kong, that “Stigmatization of patients’ families and ‘blaming the victim’ were so prevalent that even the relatives themselves held those beliefs” (Tsang, Tam et al. 2003 p127) The figures range from 51 percent of people with experience of mental illness reporting discrimination from family (De Ponte, Bird et al. 2000), to 21 percent (Dickerson, Sommerville et al. 2002). Wahl (1999a) found that discrimination from family was the second most cited cause of discrimination. The New Zealand discrimination survey (Peterson, Pere et al. 2004) found that 59 percent of people with experience of mental illness reported discrimination from friends and family. Good, Berenbaum et al. (2000) report that not all families are discriminatory – that those with high levels of ‘expressed emotion’ are more likely to have negative interactions with their family member. It seems clear, however, that a significant amount of discrimination against those with experience of mental illness comes from family members.

**Issues for Māori**

In any discussion on mental health issues in New Zealand, it is important to focus on issues for Māori, in part due to obligations under the Treaty of Waitangi (recognising that New Zealand is a bicultural society), and partly because Māori are over-represented in mental health statistics (Dyall 1997, Durie 1994)

There are several models that have been developed that describe a Māori view of health including ‘Te Whare Tapa Wha’, ‘Te Wheke’, and ‘Ngā Puo Mana’ (Dyall 1997). All of these models emphasise the importance of the well being of the whānau. The implication is that unless the whānau is strong or healthy, then the individual will not be.

In New Zealand today, there is no single definition of family or whānau (Durie 1997). The experience of being in a family may be both positive and negative. The family or whānau is a core structure of society. In Māori society “whānau as a primary source of identity, confidence and pride, has the ability to assume responsibilities on behalf of its members, and to assign responsibilities to them. At the same time, whānau has the potential to be an environment for nurturing, support, protection and safety on the
Peterson, Pere et al (2004) showed that discrimination is a significant issue for people with experience of mental illness who identify as Māori (tāngata whai ora). Tāngata whai ora reported being discriminated against most commonly from whānau and friends (57 percent). Tāngata whai ora may also face discrimination which is multi-level – that is not only due to their experience of mental illness, but is also racially based.

**How do families discriminate?**

Magliano, Fiorillo et al’s study (2004) shows that family members of people with experience of mental illness do not acknowledge those people’s civil rights to the same extent as the general public and mental health professionals do. This could mean that families are less likely to recognise and uphold those rights, placing people with experience of mental illness at risk of discrimination.

Both Bower (1998) and Phelan, Bromet et al (1998) report from their respective studies, that family members often try to conceal their relative’s mental illness or hospitalisation. This is more likely to happen if the person is not living with them, or when the disclosure is avoidable (Phelan, Bromet et al. 1998). The implications of this are that family members in this situation may be more likely to withdraw social contact and are less likely to support their relative with their experience of mental illness (Phelan, Bromet et al. 1998).

Discrimination from family members towards people with experience of mental illness occurs in different forms. De Ponte, Bird et al. (2000) mentions the most common forms that this takes. They include distancing themselves, inappropriate or hurtful comments, name calling, behaving as if mental illness is contagious, providing unhelpful or flippant instructions, showing a lack of interest in mental illness and avoiding the topic, not wanting others to know, considering people with experience of mental illness as stupid or unreliable, treating people as children, and blaming the individual for family problems. Tsang, Tam et al. (2003) report people being distanced by friends and relatives, whilst Wahl (1999a) talks of people being treated
as less competent, patronised, devalued and demoralised or experiencing outright rejection. People perceived that their family members lacked confidence in people with experience of mental illness as capable human beings (Wahl 1999).

In Peterson, Pere et al (2004), people with experience of mental illness reported being rejected by friends and family, being called names, being treated as if they were incapable or incompetent, and having family members trying to take control of their lives.

Magliano, Guarneri et al. (2001) surveyed relatives of people with experience of mental illness in Italy and discovered that 68 percent believed that a person with experience of mental illness should be able to vote, 29 percent thought they should be able to have children, and 45 percent that they should be able to work as a babysitter. Forty percent thought that their relative would not recover further. In another study, Ostman and Kjellin (2002) found that 18 percent of respondents thought that, at times, their relative would be better off dead.

De Ponte, Bird et al. (2000) also reported that in terms of disclosing their experience of mental illness, people found family members easier to talk to if they had similar experiences, some knowledge of mental distress, or if the person’s experience of mental distress had happened some years ago.

**Interventions to reduce discrimination**

Several interventions were suggested in the literature regarding reducing discrimination. Angermeyer, Schulze et al. (2003) make several suggestions. These include communication measures (increasing people’s knowledge of mental illness), providing support for people with experience of mental illness and their relatives, changing mental health care (improving the quality of care, as mental health services are also discriminatory) and education and training (including mental health professionals, at school level, and lawyers and judges). Phillips, Pearson et al. (2002) state that it is the job of mental health professionals to tackle discrimination.

The study by Corrigan, River et al (2001) tried three different approaches to reducing discrimination. These were education (about stigma), contact (with people with
experience of mental illness), and protest (treating mental health discrimination as a human rights issue). Education and contact were perceived to be effective, whilst protest was not. Reinke, Corrigan et al. (2004) explore contact further, and discover that not all contact is effective – contact with people who are regarded as high achievers, or those who are perceived to fit the stereotypes of people with experience of mental illness is not effective. Contact with these types of people was deemed to be ineffective, as people targeted either do not perceive the anti-discrimination messages as credible because the people expressing them are the ‘exception to the rule’ (high achievers) or because they see the stereotypes of people with experience of mental illness played out in front of them.

In a literature review undertaken by Gordon (2005), several conditions regarding the effective use of contact in reducing discrimination against people with experience of mental illness are listed. These are equal status, the chance for individuals to get to know each other, information challenging negative stereotypes, active participation, and pursuit of a mutual goal. It can be argued that family members of people with experience of mental illness fit all of these requirements, yet discrimination still remains a major problem (Gordon 2005 p3).

**Attribution theory**

A theory mentioned by Corrigan, Bodenhausen et al (2003) that may be relevant to unpacking discrimination against those with experience of mental illness, is attribution theory. To sum it up, this theory states that when people are viewed to be in control of their perceived negative behaviour, they are likely to be held responsible for their actions, and that this elicits angry reactions from others. On the other hand, if people are not perceived to be in control - that their behaviour is out of their own hands, they evoke pity from others. This may explain the differing reactions that people with experience of mental illness report from family members – some people are told to pull themselves together, while others are treated as if they are incapable, or of low intelligence. There may be some cultural differences – the New Zealand survey (Peterson, Pere et al. 2004) suggested that statements such as ‘pull yourself together’ were more likely to be made to people with experience of mental illness who identified as NZ European or Pākehā, rather than Māori or Pacific people.
Implications for further research
This literature review shows that while families are considered to play an important role in the lives of most people with experience of mental illness, their attitudes and behaviour can cause problems. Discrimination from their families is a significant component of the discrimination that people with experience of mental illness may face.

In terms of what to do to reduce discrimination against people with experience of mental illness, education about discrimination and contact with people with experience of mental illness are the two strategies that appear the most effective. How this applies to discrimination by family members is unclear, however – families have more contact with people with experience of mental illness than most other people, yet still discriminate. They also know more about discrimination, because they experience it themselves, yet they still discriminate. This suggests that other types of interventions may be needed to prevent discrimination by family members.

Some researchers have tried to identify what families perceive to be the root cause of mental illness. The beliefs as to the cause of mental illness seem to differ depending on the country the family member is in, or the cultural group they belong to. The fact that discrimination from family occurs, however, does not appear to differ. This means that while family beliefs as to the cause of mental illness may be interesting, and may predict certain behaviours (pity or anger, according to attribution theory), they have no impact on the overall incidence of discrimination itself.

What is missing in this analysis of discrimination by family members is a power analysis. People can hold whatever beliefs in stereotypes, or maintain whatever prejudices they have, but without power over a person with experience of mental illness, discrimination cannot occur. That is, a person can think what they want about another individual, and this may amount to prejudice against them, but unless they hold some sort of power over that person, the person will not feel discriminated against, as this prejudice can not be translated into action.

For discrimination from family members to impact against people with experience of mental illness there must be a power imbalance present. There are two aspects to a
power imbalance – one party must take the power, the other must give it up. Any discussion of discrimination by family members must look at this power imbalance – how and why it occurs, its fluctuating nature, and the implications it has for the ongoing relationship between people with experience of mental illness and their family members. The implications, as far as interventions are concerned for preventing the discrimination between people with experience of mental illness and their family members, also need to be explored.
References


