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# **The Effectiveness of a Brief Psychoeducational Intervention for People With Schizophrenia and Their Families**

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# Abstract

In an attempt to replicate and extend previous research, the present study conducted a brief psychoeducational intervention through community organisations designed to overcome methodological shortcomings of past studies. The two session intervention (one session with follow-up phone call) sought to establish if a brief community intervention was effective in both improving family members' knowledge about schizophrenia and various other indicators linked to improved client functioning. People with schizophrenia and their family members (N = 50) were recruited into a controlled trial of a brief educational intervention. Clients and their corresponding key family members were randomly allocated to a treatment group or a wait-list control group. Measures included those reflecting knowledge about schizophrenia, expressed emotion, perceived coping ability, burden of care and distress. Analyses showed that knowledge increased significantly after the intervention and not after the control condition and was maintained at a nine-month follow-up. Family members' and clients' expressed emotion ratings significantly decreased from pre- to post-test with changes in total expressed emotion scores improving across treatment by over twice the magnitude compared to the control condition. All gains were maintained at the nine-month follow-up, with continuing improvement seen in family members' intrusiveness ratings. A similar pattern of findings was reflected on other indices, with significant improvements in burden of care, coping and distress that were more a function of intervention than the control condition. All gains were maintained at the nine-month follow-up. Additionally, assessment of relapse rates at this follow-up interval indicated that no client had relapsed. Overall the results suggested that although knowledge increased as a result of education, the improvements in all indicators other than knowledge appeared to be due to education combined with some non-specific factors. These non-specific factors may have included expectancy effects, setting effects, sampling bias and other possibilities. These issues are considered in terms of implementation of brief programs in supportive community settings and in terms of future research.

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# Introduction

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**“Myths, like ignorance can lead to troubling consequences – stigma and denial. The best way to contend with ignorance is by education”  
(Reddy & Keshavan, 2006, p.3).**

Schizophrenia is a disorder most people are familiar with, yet it is widely misunderstood. The term has been used to sensationalise and has become distorted in everyday language, the media, and in popular culture.

It is presently common for someone to use the term schizophrenic “to describe a state of contradictory or incompatible elements” (Mueser & Gingerich, 1994, p.4). For example, in his weekly humour column in Miami Herald, Dave Barry wrote (when describing an incident with a snake), “So I had no choice but to pick up the tongs again and chase the snake around the edge of the pool, in that schizophrenic way that you chase a critter when you are actually terrified of it” (Barry, 2003, p.B6).

The Collins English Dictionary states that the informal definition of schizophrenia is “contradictory behaviour or attitudes” (Collins, 2002, p.484) and in everyday usage an individual may describe someone who they see as “two-faced” (presenting different facets of themselves), or as someone who appears to want mutually exclusive things at the same time (Schizophrenia Fellowship [NZ] Inc., 1998).

“In the popular media the word schizo is often used to describe any person with psychotic symptoms, such as hallucinations or delusions, or who is ‘out of touch’ with reality” (Mueser & Gingerich, 1994, p.4-5). The media also often assume that anyone who has a lasting mental illness has schizophrenia. It is very rare for the media to portray someone diagnosed with schizophrenia as someone with an illness who is functioning adaptively.

This assumption or stereotype that almost anyone who is severely mentally ill has schizophrenia is further compounded when the media focus on individual cases of violence committed by psychiatric patients. This includes the attempted assassination of US President Ronald Reagan by John Hinckley and suicide committed by the man who entered the lion’s den at London Zoo and was then mauled to death (Reddy & Keshavan, 2006). The resulting media attention is often extensive and helps perpetuate the negative stereotype that all individuals diagnosed with schizophrenia are violent. What the media does not usually broadcast is that

individuals such as John Hinckley are rare and not representative of the approximately 1% of the population suffering from schizophrenia. In fact, there is little compelling data demonstrating that violent behaviour is more common in people with schizophrenia than in the general population (Reddy & Keshavan, 2006)

Research shows that most people diagnosed with schizophrenia are not violent but that a small proportion are (Mueser & Gingerich, 1994), and that those who do become violent have usually become noncompliant with their psychiatric medication or have become abusers of alcohol and/or drugs (Raine, 2005).

Popular media such as television and movies often further compound the confusion and fear about schizophrenia and mental illness. In the movie industry there exists a genre called the schizophrenic drama (Halliwell, 1997), observed in the films *The Three Faces of Eve*, *Lizzie* and *Vertigo*. The trend in these films is to present case histories of schizophrenia with no hope or solution offered (*Repulsion*, *Spider*; Halliwell, 1997), psychological (or schizophrenic) horror (*Psycho*, *The Shining*, *Misery*), and homicidal sociopath films (*Silence of the Lambs*, *Kalifornia*, *Natural Born Killers*; Fleming & Manvell, 1985).

Advocacy groups have argued (see Noll, 1992; Torrey, 1995) that these trends in popular media have unfairly emphasised the “homicidal maniac” stereotype of people suffering from schizophrenia, and contribute to maintaining a negative stereotype about schizophrenia for the general public (Prawer, 1980). There is little media exposure that informs the public that “Not all people with psychotic symptoms have schizophrenia, and people with schizophrenia are not always psychotic. Similarly, not all people with schizophrenia are chronically ill, nor do all chronic psychiatric patients have schizophrenia.” (Mueser & Gingerich, 1994, p.5). Although the New Zealand ‘Like Minds Like Mine’ public health campaign promoted through various media outlets aims to counter stigma and promote awareness and acceptance of mental illness through various means, such as challenging stereotypes and ‘debunking’ myths (Jackson, 2008).

Given all this exposure and conditioning about stereotypes of schizophrenia that the general public receive, it is likely that loved ones of the diagnosed may also share these beliefs: “If they do have these beliefs, then how do they reconcile these to their loved one who has just been diagnosed with schizophrenia?” (Moxon, 1999, p.2).

When someone develops schizophrenia, it has an impact on everyone in their environment. They may develop odd or bizarre ideas and perceptions, enhanced anxiousness and restlessness, inexplicable rituals or belief systems, a disregard for personal hygiene, an indifference to other people or previously enjoyable activities and erratic, sometimes disruptive behaviour. The despair and anxiety family members may feel at these times is often increased by guilt and worry about how they may have contributed to the development of schizophrenia in the individual.

Most families struggle to adjust to the changes in the personality of their loved one and have difficulty reconciling their previous knowledge about schizophrenia with the client. Attempts to reconcile these two things may lead to guilt, family isolation, or compensatory over-involvement and protectiveness in some family members. In other family members, attempts to support and help the client regain their former level of functioning can deteriorate and be replaced by criticism and hostility, or antipathy and rejection: “These feelings may be exacerbated by other severe consequences for the family in particular stigma, embarrassment, financial hardship and a significant level of tension which can erupt into arguments and recrimination” (Birchwood, Hallett, & Preston, 1989, p.11).

For reasons like these, the provision of information to people diagnosed with schizophrenia and their loved ones may help to correct misplaced beliefs about the illness, increase awareness and understanding, and promote healthy environments linked to better outcomes (Moxon & Ronan, 2008).

# Chapter 1

## Literature Review

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**“Of all mental illnesses schizophrenia is the most feared, and the most fascinating, and it is the model for the layman’s concept of madness”  
(Gregory, 1987, p.679).**

## **HISTORY OF SCHIZOPHRENIA**

The cluster of symptoms now known as schizophrenia can be argued to have existed for centuries. Accounts of individuals exhibiting key symptoms of modern-day schizophrenia can be traced through history to Babylonian times and Ancient Greece.

Biblical figures such as Ezekiel the Prophet had visual and auditory hallucinations (Smith, A., 1982), Nebuchadnezzar ate grass as if a goat for seven years (Humphrey, 1991; Torrey, 1995) and Royal family members such as Christian VII of Denmark had a range of symptoms, most notably incomprehensible speech, delusions of grandeur, of killing people and talked of noises in his head (Williamson, 1988). Charles VI of France had a belief that he was made of glass and about to break at any moment and thus inserted iron rods into his clothing (Green, V., 1993). All of these historical figures appeared to demonstrate bizarre behaviours indicative of the symptoms of schizophrenia (Bos, 2002).

Scholars argue that people who might have met the criteria for schizophrenia in medieval times were often seen as being imbued with divine powers or possessed by the devil (Lieberman, Stroup, & Perkins, 2006) and, depending on the era, were seen as sages, shamans, burnt as witches, confined at home, left as destitute beggars or put into institutions such as Bethlem Hospital (Linter, 1996).

Researchers and scholars continue to debate as to when schizophrenia first appeared, but it was not until the 18<sup>th</sup> century that cases of schizophrenia appeared in a documented form that would be classifiable according to modern nosologies (Reddy & Keshavan, 2006). At the turn of the 18<sup>th</sup> century, Philippe Pinel in France and John Haslam in England described symptomologies of patients that were unmistakably cases of schizophrenia.

Pinel was a pioneer in the field of psychiatry for the many reforms he introduced into the field. These included dismissing the popular theory that mental illness was a result of demonic



possession or a punishment from God. Instead he theorised that mental illness was a result of extreme exposure to social and psychological stresses, heredity and physiological damage (Whitiker, 2003). In 1798, he published a book called *Nosographie Philosophique* where he defined a variety of disorders and psychoses which included the symptoms of hallucinations, social withdrawal and delusional behaviour (Pinel, 2009).

During this same time, Haslam (1798) published his second edition of ‘Observations on Insanity’ which described in depth hallucinations, delusions and disordered thinking in patients. This was followed in 1810 by ‘Illustrations of Madness’ (Torrey, 2001; Portor, 1988), which described case studies, in particular a patient of Bethlem Hospital, James Tilly Matthews (1770-1815). Matthews believed that outside Bethlem, a gang of villains skilled in ‘pneumatic chemistry’ were controlling his mind and tormenting him with rays from a machine called the ‘Air Loom’ (Jay, 2003; Scull, Mackenzie, & Hervey, 1996). He displayed a complex array of hallucinations, disordered thinking, delusional beliefs and behaviours which would likely be today classifiable as schizophrenia.

Based on such evidence, it appears clear that the disorder existed, but it did not yet have a formal name. It was called, amongst other things, ‘Folie Circulaire (cyclical madness) by Falvet in 1851, ‘Hebephrenia’ (silly, undisciplined mind) by Hecker in 1871 after Hebe the goddess of youth and frivolity, and Catatonia and Paranoia by Kahlbaum in 1874 (Shean, 2004; Walters, 2009).

In 1878 Emil Kraepelin merged these various concepts together into a singular and distinct disease entity, which he named ‘Dementia praecox’ – progressive intellectual deterioration of early onset. Kraepelin put emphasis on the progressive intellectual deterioration (dementia) and early onset (praecox) as the core of the disease now known as schizophrenia. This was reflected in the four types of schizophrenia that he described: 1) Simple, marked by a slow social decline coupled with apathy, 2) Paranoid, marked by fear and persecutory delusions, 3) Hebephrenia, where the patient may act silly or bizarre with disorganised speech and behaviour, and, 4) Catatonic, marked by poverty of movement, waxy flexibility and fear with possible verbigeration (obsessive repetition of meaningless words and phrases), echolalia and echopraxia (Firth & Johnstone, 2003; Green, B., 2007; Stone, Faraone, & Tsuang, 2004).

Kraepelin grouped these subtypes together as diverse symptoms of a progressive disease that would deteriorate steadily to a chronically impaired condition. If there was improvement, it was thought to result in only partial recovery. Kraepelin himself recognised that the condition appeared diverse and was difficult to define, measure and clarify (Firth & Johnstone, 2003; Stone et al., 2004). He maintained that dementia praecox and its symptoms had a specific pathology in the brain and a specific origin, although nothing had yet been discovered regarding pathology or causation.

It wasn't until 1908 that this concept was challenged. Eugene Bleuler, a Swiss Psychiatrist criticised this concept with the argument that there was no evidence supporting a global dementing process (Davison & Neale, 1996). Bleuler emphasised the “breaking of associative threads” between the different functions of the mind (cognitive, emotional, volitional and perceptual) as the core of the disorder (Firth & Johnstone, 2003; Moxon, 1999; Stone et al., 2004).

Bleuler reformulated Kraepelin's dementia praecox into *schizophrenia* from the Greek words *schizein* (to split), *phren* (mind) and the suffix *-ia* which indicates a disease. Bleuler believed that this term better explained the split between perception and reality (Torrey, 1995) and affect and intellect (Shean, 2004) that someone with schizophrenia displays. He chose the term ‘schizophrenia’ to reflect the idea of “a mind that is torn asunder” (Hales, Yudofsky, & Gabbard, 2008).

Bleuler's disorder was additionally defined by four characteristics (known as the “4 A's”). These were: blunted affect – referring to a restricted or diminished emotional response to stimuli; loosening of associations – referring to a disordered thought pattern; ambivalence – referring to an apparent inability to make decisions; and lastly autism – referring to a preoccupation with one's inner world, to a loss of awareness of external surroundings, and to an apparent “preference for fantasy over reality” (Tsuang, Stone, & Faraone, 2000, p.1041; Walters, 2009). These characteristics reflected what Bleuler saw as the ultimate defect of schizophrenia – the fragmentation between the normally harmonious integration of the four mental functions of thinking, feeling, perception and behaviour (Bleuler, 1950; Watkins, 1988).

These definitions – Kraepelin's narrow definition focused on description, classification, onset, course and prevalence and Bleuler's broader definition with an emphasis on core features

and prognosis (Kraepelin, 1981) – contributed formatively to the current definition of schizophrenia, both defining characteristics of the disorder which are still largely incorporated in modern nosological systems.

With the advent of the 21<sup>st</sup> century, while earlier views are still incorporated, the concept of schizophrenia has also been refined in many ways, as reflected in DSM-IV-R (American Psychiatric Association [APA], 2000). First, specific diagnostic criteria are required; second, those who meet the criteria for a mood disorder are excluded; third, some symptoms of the disorder must be apparent for at least six months prior to diagnosis and the disorder may include a prodromal or residual phase. It also now excludes those with acute psychotic reactions to stress. Finally, what used to be considered mild forms of schizophrenia have now been reclassified as personality disorders – such as schizotypal and schizoaffective disorders. The disorders of schizophrenia and psychosis are currently being researched and targeted for change under the review process for the DSM-V (Reiger, 2007) which is due for release in 2012 with a “renewed focus on the validity of diagnoses” (p.2).

## **THE SYMPTOMS AND CHARACTERISTICS OF SCHIZOPHRENIA**

**“One way to understand a disease is to describe what it is...the alternative is to describe what it is not” (Torrey, 1995, p.105).**

As discussed in the previous section, schizophrenia-spectrum disorders are a class of psychological disorders marked by major disturbances in perception, thinking, emotion, and behaviour. Acute sufferers often lose touch with reality and can suffer from hallucinations, extreme cognitive distortions and paranoia, which can isolate them from the world and, amongst other things, trigger intense anxiety and depression (Bassett, Chow, & Hodgkinson, 2008; Birchwood, Iqbal, & Upthegrove, 2005).

There are of course many symptoms common to schizophrenia, yet those diagnosed with schizophrenia can differ widely in the specific symptoms that they exhibit (Strauss & Carpenter, 1981; Watkins, 1988). The range of symptoms is so extensive that it is highly

unlikely for an individual to exhibit all of the possible symptoms of schizophrenia at one time. It is more likely that an individual will exhibit a cluster of possible symptoms varying in frequency, intensity and duration (Burton & Davison, 2007; Weiten, 1992).

### **Positive Symptoms**

The major symptoms of schizophrenia are typically characterised as either positive or negative (Andreasen, Flaum, Swayze, Tyrrell, & Arndt, 1990). A symptom characterised as positive means that there is an excess or distortion in behavioural, perceptual, emotional and thought processes. Those characterised as positive symptoms are: disturbances in thinking, delusions, and hallucinations (Andreasen & Olsen, 1982).

#### **Disturbances in thinking**

Disturbances in thought processes are possibly the most debilitating symptom of schizophrenia as they prevent logical thinking, and are what Bleuler referred to when he originated the term schizophrenia ('split-mind').

Cognition may be affected in a number of ways: thoughts may seem to slow down, speed up, or disappear – leaving the mind completely blank (e.g., thought blocking; Friedman, 2000). Some clients have difficulty following one train of thought, changing topics in mid-sentence (to unrelated topics is referred to as derailment; to related topics, loose associations), appearing confused, using made up words (neologisms) or speaking in an incoherent manner ("word salad"; Freudenreich, 2008).

A common symptom for those diagnosed with schizophrenia manifests itself in conversation where the individual may be easily distracted by external stimuli (such as a vehicle going past or hearing a snippet of another's conversation). This may then trigger a new train of conversation incorporating these elements. This tangential manner of conversing can alternately be seen by the individual as stimulating and exciting, or confusing and overwhelming (Friedman, 2000; Linter, 1996).

## Delusions

Delusions are a deviance in the content of thought. They are beliefs that are not in touch with reality and are sometimes not coherent. They may also be bizarre, and tend to be persistent and unshakeable. Delusions are usually held to be true despite (a) other people not sharing the belief and (b) evidence to the contrary (Mueser & Gingerich, 2006).

Thus, a delusion is a ‘false belief’, that the individual may have which is held firmly in the absence of all evidence and which is not shared by others of the same culture or religion. They vary greatly in the way they are manifested, ranging from well organised with logical connections between ideas to non-systematised (Reddy & Keshavan, 2006).

Some core delusions are related to thinking that an outside source is influencing one’s thoughts. These include: thought insertion where thoughts are inserted into one’s head which are not one’s own – they may appear to come from other people in the form of radio waves or by telepathy; thought withdrawal where thoughts disappear from one’s head, as if they are being taken out, or stolen by someone – one’s mind is quite blank and he or she is unable to think about anything (this is not the same as when a thought is forgotten, or when one is nervous and loses track of thoughts); thought broadcasting where one’s thoughts seem to be spoken out loud as if somebody close by could hear them – in this way, it appears that everybody knows what he or she is thinking and no thoughts are private.

Other common delusions in schizophrenia are:

- Paranoid (or persecutory) delusions, where the individual believes that they are being unfairly persecuted, besieged, conspired against, taken advantage of, or threatened.
- Grandiose delusions, where the individual believes they are famous, superior, important, special or imbued with magical powers.
- Delusions of control, where the individual believes that an outside force is manipulating or controlling their body, thoughts or feelings.
- Delusions of reference, where the individual believes that people or things in the environment are making a specific reference to them (Freidman, 2000).
- Depressive delusions, where the individual believes that they are guilty of a terrible crime or may be responsible for gruesome world events (Linter, 1996).

- Other less common delusions include amongst others: somatic delusions where there may be a belief of physical abnormality or deformity with oneself; erotomanic delusions where the individual believes that an inaccessible person is in love with them, and nihilistic delusions where the individual may believe that they no longer exist, are about to die or that objects or people no longer exist (Burton & Davison, 2007; Woo & Keatinge, 2008).

## **Hallucinations**

Hallucinations are false perceptions – sensory experiences that the individual has in the absence of a stimulus. This means that the person hears, sees, smells, tastes or feels things that do not exist in the current surroundings and are not shared by others. These are referred to as auditory, visual, olfactory, gustatory or tactile hallucinations, respectively (Barrowclough & Tarrier, 1992).

Auditory hallucinations are most often experienced in the form of ‘voices’ (Sartorius, Shapiro, & Jablonsky, 1974; Tarrier, 2008). Voices may direct the person to do something, talk about them, narrate their every move, repeat their thoughts out loud (Watkins, 1987), mock them, insult them, or entertain them (Lintner, 1996). The voices may sound familiar or be alien to the individual. They may seem to come from their brain, another body part, from an animal, from the television, or from another room.

Robert Miller suggests that it is “very difficult to understand hallucinations. Perhaps they are exaggerations of normal sensations. The voices may be exaggeration of a persons’ normal thoughts (Many of us experience our thoughts as tiny “voices”, and this is quite normal)” (1995, p.28).

It is approximated that roughly 70% of those diagnosed with schizophrenia experience auditory hallucinations; a further 25%, visual hallucinations; and a further 10%, other types of hallucinations such as somatic and olfactory (Mueser & Gingerich, 1994).

These major positive symptoms are often accompanied by a significant difficulty in managing everyday activities and interacting socially, possibly manifested as grossly disorganised behaviour. This is most obvious in self-initiated, goal-directed activities, where the

individual may be so absorbed in their hallucinations or delusions that they are unable to follow a task through to its logical conclusion.

### *Negative symptoms*

Negative symptoms are those symptoms which indicate an absence or deficit in “what would be considered normal behaviour” (Corcoran & Walsh, 2008, p.161). These include blunted affect, alogia, avolition and anhedonia.

Blunted affect is also known as affective flattening (Mueser & Gingerich, 1994) and refers to a restricted range and intensity of emotional responsiveness. This is seen mostly in facial expressions and tone of voice where the person, when discussing something that would usually cause some animation, may instead speak in a flat and toneless voice and stare vacantly with expressionless eyes. It is important to note that a lack of facial expression is not indicative of inner experiences at the time. Flat affect only refers to the client’s “outward expression of emotion” (Davison & Neale, 1996, p.393). It is quite likely that the individual is feeling emotion but is merely unable, or perhaps unwilling to reflect that feeling outwardly (Blanchard, Kring, & Neale, 1994).

Alogia refers to a poverty of speech and poverty of content of speech. Poverty of speech is common to schizophrenia and refers to a reduction in the amount of spontaneous speech and replies to conversational prompts or questions. Clients struggle to hold conversations, initiate conversations and reply to others with more than single word answers (Lieberman et al., 2006). Poverty of content of speech is less common and means that although the amount of speech is adequate, it does not make sense, often contains little information and can be excessively vague and repetitive (Davison & Neale, 1996).

Avolition (or apathy) refers to a lack of motivation and energy and for some a lack of interest in routine activities. This can be one of the most debilitating symptoms of schizophrenia as it may affect every aspect of the client’s life (Tsuang & Faraone, 1997). Grooming, personal hygiene, basic self-care activities such as cooking for oneself, washing clothes, doing chores can all be affected as can more complex skills such as budgeting, being able to go to and maintain work, studying or going on outings with friends and family. The individual may have

difficulty initiating or following through with tasks. This symptom may lead the client to avoid tasks, situations, or people by staying at home or sleeping excessively. It may be further reflected in the person's mood where "apathy reflects discouragement and a sense of helplessness about the future, while for others it is simply a genuine state of not caring" (Mueser & Gingerich, 1994, p.35).

Lastly, anhedonia refers to a decrease or an inability to experience pleasure (Bassett et al., 2008). It is reflected in a lack of interest in recreational activities, lack of interest in friendships or even sex. Further, the client may not enjoy activities that used to be enjoyable such as going to the movies, playing sport or talking with others.

It is worth noting that negative symptoms have been associated with poorer prognosis and poorer quality of life than positive symptoms (Katschnig, 2000; Kirkpatrick, Fenton, Carpenter, & Marder, 2006) and have been significantly correlated with later impaired ability to enjoy activities, maintain a job and relationships, and having a financial dependence on others (Ho, Nopoulos, Flaum, Arndt, & Andreasen, 2004).

## **TYPOLGY**

Currently the most widely used tools used in clinical practice for diagnosing schizophrenia are the World Health Organisation's ICD-10 (International Classification of Diseases, 10<sup>th</sup> Revision; WHO 1992) and the American Psychiatric Association DSM-IV-TR (Diagnostic and Statistical Manual – text revision, 2000).

The two classification systems have much in common with respect to the diagnosis of schizophrenia. However a significant difference is in the requirement for the duration of symptoms before diagnosis, which is only one month for the ICD-10 in comparison to six months for the DSM-IV-TR. Also, not required for the ICD-10, the DSM-IV-R specifies that deterioration should be present from a premorbid degree of functioning.



Both systems require evidence of psychosis with at least one characteristic positive symptom present (hallucinations, thought disorder, delusions) with any specific delusions or hallucinations listed. Both systems also specify that other symptoms including negative symptoms be present for a diagnosis and require that affective symptoms are not pre-eminent. Both systems also exclude schizoaffective or mood disorder, substance use and organic conditions. Only the DSM requires there to be evidence of social or occupational dysfunction.

### **Subtypes of Schizophrenia**

The subtypes of schizophrenia as defined in DSM-IV-R and ICD-10 are undifferentiated, residual, disorganised (hebephrenic in ICD-10), catatonic and paranoid. The ICD-10 also includes the subtype of simple and another related category, post-schizophrenic depression.

Undifferentiated schizophrenia is diagnosed when the individual does not meet the criteria conclusively for any of the subtypes, but rather demonstrates a combination of symptoms from other subtypes. Residual schizophrenia is a state where the individual is not currently experiencing severe psychotic symptoms, but still demonstrates limited symptoms of the illness. Disorganised (hebephrenic) schizophrenia is characterised primarily by inappropriate affect, disorganised speech, inappropriate behaviour and neglect of self-care. Catatonic schizophrenia is characterised by motor disturbance and negativism which can range from immobility to disproportionate meaningless activity. Paranoid schizophrenia is marked by delusions of persecution and/or grandeur and auditory hallucinations. Individuals who fall into this subtype generally do not display the degree of disorganisation of speech or behaviour seen in other subtypes.

The subtypes of schizophrenia have considerable overlap between types, exhibit low diagnostic reliability, and have limited predictive validity. Most people with schizophrenia exhibit a mixed symptom picture and do not always fit precisely into one of the categories of schizophrenia (Maier, 2006). As discussed earlier, this is currently being targeted for revision in DSM-V.

## **PREVALENCE, DEVELOPMENT AND COURSE OF ILLNESS**

### **Prevalence**

The prevalence rate of schizophrenia is reported as the proportion of the population per 1000 people surveyed within a one year period (Lieberman et al., 2006; Tsuang & Faraone, 1997). Schizophrenia has a worldwide prevalence of approximately 1% (Murray, Jones, Susser, Van Os, & Cannon, 2003) but has a range of 0.5% to 1.6% (Jablinsky, 1995) across different geographical areas.

The U.S. National Institute of Mental Health (NIMH) Epidemiological Catchment Area study of mental illness found the lifetime prevalence rate of schizophrenia to be 1.3% across several U.S. cities (APA, 2000), whilst the 1994 British study OPCS Survey of Psychiatric Morbidity found an incidence rate of 0.4% for people aged between 16 and 64 years of age. A recent New Zealand study found a prevalence rate of 0.2% (Lieberman et al., 2006).

The following facts related to prevalence help to give some perspective to the illness;

- 1) In comparison, about one in every two hundred people develop bi-polar disorder (0.5% of the population); (Lintner, 1996).
- 2) The number of people suffering from schizophrenia is equal to the numbers who suffer from rheumatoid arthritis (Firth & Johnstone, 2003; Lintner, 1996; Stone et al., 2004).
- 3) More hospital beds are filled by people with schizophrenia than any other psychiatric disorder (Mueser & Gingerich, 1994).
- 4) More hospital beds in Canada are filled by those with schizophrenia (8%) than any other medical condition (Lintner, 1996; Long, 2008), and in 1997 it was estimated that 25% of hospital beds in the United States were occupied with those diagnosed with schizophrenia (Chouinard & Albright, 1997).
- 5) There are nearly a quarter of a million people with schizophrenia in the U.K. at any one time and in the U.S. there are between 2 and 3 million people with the illness (Mueser & Gingerich, 1994).
- 6) One fifth of all chronic disability (including mental and physical illness) is estimated to be due to schizophrenia (Mueser & Gingerich, 2006).

- 7) The World Health Organisation has placed it on the list of the 10 most disabling medical illnesses (Murrey and Lopez, 1996).
- 8) “Approximately 30% of people with the disease are hospitalised at one point in their lives” (Lieberman et al., 2006, p.187).

These facts serve to illustrate the prevalence and magnitude of the disorder and one of the reasons why it is referred to as a major psychiatric illness.

### **Development**

Schizophrenia is an illness that usually develops during late adolescence or early adulthood. It affects men and women with equal frequency although the peak age of onset varies between men and women, 18-25 and 25-35 years of age, respectively. The median age of onset is 23 years in men and 28 years in women (Lieberman et al., 2006).

Schizophrenia can develop at any time but rarely develops before age 16 or after age 35 (Mueser & Gingerich, 1994). There is an illness called childhood-onset schizophrenia (COS) which develops before age 12, but it is extremely rare and is thought to be separate from adulthood schizophrenia (Mueser & Jeste, 2008). Onset can also occur after age 45 (late onset) but is also quite uncommon, and it is extremely rare to develop after age 65 (very late onset; Ebert, Loosen, Nurcombe, & Leckman, 2008).

In a landmark long-term follow-up study by Ciompi (1980), it was found that the onset of schizophrenia typically followed one of two different patterns with 50% of the sample having an acute onset and the remainder 50% following a longer prodromal period leading up to the first psychotic episode. A 1990's study of the prodromal period by Hafner and colleagues found that the onset of negative symptoms tended to be present roughly five years before the first psychotic episode (Hafner, Meurer, Loffler, Heiden, & Stein, 1999).

### Course

Schizophrenia is an episodic illness with clusters of symptoms which vary in frequency, intensity and duration at different times of the illness. When having a psychotic episode, core symptoms may further deteriorate and symptoms which have been mild or non-existent may become chronic. This may require time in a hospital to help regulate symptoms.

Research shows that roughly 20% of all diagnosed persons have only one episode of the illness with no further episodes and no resulting impairment in personality or functioning. About 35% of diagnosed continue to have episodes of the illness but experience no impairment between episodes. About 10% of all diagnosed individuals will continue to have multiple episodes but will also experience a degree of personality impairment and loss of functioning. Finally, 35% of those diagnosed will also have multiple episodes of the illness but will also experience increasing levels of impairment in personality and functioning (Green, B., 2007).

The Huber and colleagues study (Huber, Gross, Schuttler, & Linz, 1980) which followed up 502 individuals with schizophrenia found that after 22 years, 31% of the sample group had significantly improved while 26% had achieved full recovery in not needing further treatment (Silverstein, Spaulding, & Menditto, 2006).

Similarly, a study by the World Health Organisation (Harrison, 2001) found that out of the 1633 individuals followed, roughly 50% of the surviving cases had positive outcomes, with about 16% achieving full recovery. This has led some researchers to conclude that “schizophrenia does not seem to be a disease of slow progressive deterioration. Even in the second and third decades of illness, there is still potential for full or partial recovery” (Silverstein et al., 2006, p.9).

## **AETIOLOGY**

**“Virtually all schizophrenia researchers agree that genes play some role in the development of schizophrenia, but precisely what role remains in dispute”**

**(Torrey, 2001, p.160)**

Despite more than a century of research into what causes schizophrenia, the exact aetiology and pathophysiology is yet to be discovered. Nevertheless, research indicates that the disorder is neurodevelopmental in derivation (Mueser & Jeste, 2008; Woo & Keatinge, 2008) and appears to require the interaction of a number of factors (genetic, biological, and environmental) that modify the course of normal brain development and functioning (Corcoran & Walsh, 2008). Research on psychosocial stressors also suggests that “aspects of the social environment may heighten an existing risk for the disorder or effect illness course” (Woo & Keatinge, 2008, p.496).

A wealth of research over the last century has been able to demonstrate in a convincing body of evidence the importance of a genetic predisposition to schizophrenia (Gottesman, 1991; Smoller, Sheidley, & Tsuang, 2008). Schizophrenia is certainly a disorder with a genetic component (Gottesman, 1991; Green, B., 2007; Kendler & Diehl, 1993) but it is not a fully genetic condition such as Huntington’s disease or cystic fibrosis, where a single formative gene has been isolated as being the cause. Rather, schizophrenia appears to involve the actions and interactions of multiple independent genes “that cumulatively, make a person more or less vulnerable to developing the illness” (Burton & Davison, 2007, p.11) with a statistically high heritability at 80% - 87% (Cardno, Marshall, Coid, Macdonald, Ribchester, Davis et al., 1999; Green, B., 2007).

A number of sources (Burton & Davison, 2007; Reveley, 2006) use the analogy of heart disease to explain the inherited genetic predisposition of schizophrenia, as the illness appears to cluster in particular families. However, it does not follow Mendelian principles of inheritance (McGue & Gottesman, 1989), and it has been determined that other risk factors must be involved (Woo & Keatinge, 2008).

Current research on the determinants of schizophrenia is being conducted through molecular genetics and family, twin and adoption studies. Thus far, the research has demonstrated that people inherit a genetic susceptibility to develop the disorder rather than a certainty of developing it. Research also supports the theory that schizophrenia is a neurodevelopmental disorder, due to the disproportionately high percentage of specific and observable brain abnormalities among those diagnosed (Hales et al., 2008; Tsuang & Farone, 1997). Brain abnormalities include deficits linked to the prefrontal areas of the brain, decreased overall brain volume, decreased volume of the prefrontal cortex and hippocampus and enlarged ventricles compared to healthy individuals (Hill, Mann, Laws, Stephenson, Nimmo-Smith, & McKenna, 2004; Powchik et al., 1998; Steen, Hamer, & Lieberman, 2005; Zipursky, Lim, Sullivan, Brown, & Pfefferbaum, 1992). All of these findings suggest a deterioration or atrophy of brain tissue.

Yet despite visible abnormalities, there is still no identified pathological characteristic common to all those diagnosed with schizophrenia. These abnormalities are not found in all, or even a majority of those diagnosed, and it remains unclear whether this is a direct cause of schizophrenia, an indirect predisposing factor, or a consequence of the disorder (Andreasen, 1985; Suddath, Christisan, Torrey, Casanova, 1990). Current models support a diathesis-stress approach:

“Current information on the etiology of schizophrenia supports a diathesis-stress model. That is, the behavioural expression of the biological vulnerability for schizophrenia is influenced by exposure to stress” (Stone et al., 2004, p.117).

Having been first presented by psychologist Paul Meehl in his presidential address to the American Psychiatric Association in 1962, the view most widely accepted amongst researchers (Gleeson, Killackey, & Krstev, 2008; Noll, 1992; Tarrier & Barrowclough, 1986) and mental health professionals is that schizophrenia results as a combination of two conditions: 1) a mix of heritability and biological influences in the working of the brain (‘diathesis’), and 2) stressful situations (Murry & Jones, 2003) such as, “insults to the brain, threatening physical environments, emotionally intrusive or demanding experiences, and emotional deprivation” (Corcoran & Walsh, 2008, p.168).

Further, there is evidence (Zubin, 1986) that stress may not only blend together with a schizophrenic diathesis to trigger the initial onset of schizophrenia but may also induce episodes or exacerbate symptom severity once developed (Hirsh & Weinberger, 2003), and may increase the risk of relapse (Stone et al., 2004). Stressful situations have “an impact on the individual’s social perceptions, emotional reactions, coping skills and self-efficacy. These in turn affect symptoms and problem behaviour which further affect vulnerability” (Atkinson & Coia, 1995, p.22).

The diathesis-stress model proposes that there is an inverse relationship between the degree of intrinsic vulnerability and the degree of stress required for the emergence of an episode of schizophrenia (Birchwood et al., 1989). Thus, it is thought that “the greater the genetic load, the less psychosocial stress needed to trigger the illness” (Reddy & Keshavan, 2006, p.147).

To conclude this section, it has been demonstrated that some people are born with a genetic predisposition for developing schizophrenia. The development of schizophrenia depends not only on genetic predisposition but also on risk and protective factors that increase and decrease the chance of developing the disorder. These factors include neurodevelopmental problems, neurochemistry and psychosocial stressors. The influence of such factors has been expressed by way of metaphor: “Risk factors for schizophrenia are akin to striking out in baseball: One needs to accumulate a certain number of strikes, and the exact number depends on the amount of one’s predisposition. People who have experienced some risk factors for schizophrenia will not develop the illness if they can avoid accumulating the requisite number of “strikes” for their level of predisposition” (Green, M., 2003, p.28).

Attention now turns to a prominent stress-related risk factor examined in the current study, Expressed Emotion.

## **EXPRESSED EMOTION**

**“EE is a term that represents a set of mechanisms underlying interpersonal relationships and communication patterns” (Gumley & Schwannauer, 2006, p.48).**

## **History of EE**

Expressed Emotion (EE) is a construct which describes the “quality of a relative's relationship with one particular person rather than a general tendency toward everyone” (Gottschalk & Keating, 1993. p.899). It was developed in the early 1950s following Brown and colleagues (Brown, Carstairs, & Topping, 1958) series of studies observing the outcome of releasing chronic schizophrenic patients into the London community (Brown, Andrews, Harris, Adler, & Bridge, 1986). The initial finding was that those who were discharged to hostel accommodation, to live alone, or returned home to live with working mothers, were notably less likely to relapse than those who went home to live with mothers who stayed in the home (Brooker, 1990).

As a result of this work, Brown et al. (1958) hypothesised that the emotional atmosphere at home was directly related to relapse. Because of the ‘close emotional ties of family life’, the client with schizophrenia might be more prone to become overstimulated, causing an elevation of physiological arousal, resulting in the client’s ability to cope becoming compromised (Weardon, Tarrier, Barrowclough, Zastowny & Armstrong Rahill, 2000).

## **What is EE?**

Family stress or tension in living with someone diagnosed with mental illness can manifest itself in a variety of ways: as denial of the illness, bewilderment, criticism of the client’s behaviour, emotional overinvolvement or overprotectiveness of the client (Anderson, Reiss & Hogarty, 1987; Barrowclough, Tarrier, Watts, Vaughn, Bamrah, & Freeman, 1987).

Often expressed as a family member’s concern for or reactions to the client and their symptoms, these behaviours can include becoming overinvolved, critical or hostile. These three behaviours are at the core of what is known as Expressed Emotion. More specifically, it is the amount of hostile and critical comments, emotional overinvolvement and intense or emotional-laden comments directed from family members to the individual with schizophrenia (Glynn, Cohen, Dixon, & Niv, 2006).



Expressed Emotion was “initially formulated as an index of the emotional climate within the home environment, an attempt to assess the quality of the relationship between client and relative” (Tarrrier, 1996, p.272). The make-up of this emotional climate was seen as potentially significant in the course and prognosis of schizophrenia.

Brown and colleagues refined the construct of Expressed Emotion (Leff & Vaughn, 1985) by developing the Camberwell Family Interview (CFI), used to interview the family members of client’s with schizophrenia whilst the client was in hospital after or during an acute episode of schizophrenia, in order to measure EE.

The CFI assesses events leading up to the most recent hospital admission and questions the family members about the behaviours of the client, how they respond to and feel about the symptoms, and about how they feel the illness has affected family relationships.

Scores are obtained on three scales (hostility, critical comments and emotional overinvolvement) based on the number of critical comments and the extent of emotional overinvolvement or hostility shown towards the client. Then, depending on whether the thresholds are met on the scales, the family member is then classified as low or high in EE.

### ***An Initial Comparison of Low-EE and High-EE Relatives***

This comparison been researched in significant depth over the last four decades (further information to be found in subsequent sections) with Barrowclough and Tarrrier (1992) finding that “High-EE relatives tend to be locked into a series of negative interactions” (p.22) with the client, while Hahlweg and colleagues (Hahlweg, Goldstein, Nuechterlein, Doane, Miklowitz, & Snyder, 1989) found that low-EE family members appear to be more able to ‘go with the flow’. For example, a high-EE family member might state in response to an ungroomed client “you look filthy and you stink, don’t you have any pride in your appearance, you disappoint me”. A low-EE family member might notice this but choose not to say anything believing that the client will achieve this when they can. This indicates that high-EE relatives tend to be more intolerant of symptomatic behaviour and become impatient with impaired performance in contrast with low-EE family members who tend to accept and tolerate these impairments.

By definition, high-EE families tend to be hostile, highly critical, overinvolved or controlling of their family members lives, and their response pattern tends to be marked by anger, distress, “intolerance to patient problems, intrusiveness, and inappropriate and inflexible methods of solving problems” (Barrowclough, Johnston, & Tarrier, 1994, p.68). They are not likely to allow the client a sense of autonomy and rather than the low-EE family member’s respect and acceptance of client social distance, they are likely to try and enforce social interactions (Bland, 1989).

It has also been found that families high in EE appear to communicate and listen less effectively than low-EE families (Kuipers, Sturgeon, Berkowitz, & Leff, 1983). Hooley and Campbell (2002) found that high-EE family members act more independently, tending to believe that they can manage their own problems with little, if any outside help, leaving them more isolated with little external support. Whereas, families low in EE appear to be more tolerant, warm and understanding, and their characteristic response pattern is “controlled concern”, broad-minded, non-intrusive, open to their family members needs, and flexible in coping with problems (Barrowclough, et al., 1994; Bland, 1989).

The research into EE has diversified over the last four decades. One of the areas coming under focus is the extent to which EE is malleable. The question here is does it represent a fixed and enduring state that families are ‘stuck’ in or is it a construct that is open to influence, change and adjustment?

### ***Expressed Emotion as an Interactionist Concept***

In the original research studies, Brown and colleagues suggested that Expressed Emotion was “a two-way relationship, each depending on the other” (Brown et al., 1972, p.254). This idea of a variable circular relationship has intrigued researchers and caused much debate over the last 35 years, leading to studies specifically designed to investigate the direction of causality of EE effects.

Is it that the disturbed or withdrawn behaviour of the client leads burdened and strained family members to become more critical or emotionally over-involved, or is it that living with a critical and emotionally over-involved (high-EE) family member impacts on the client in a way

which leads to an exacerbation of symptoms? Alternatively, is it a combination or subtle blend of the two?

To sum up the research on this area, it appears likely that EE and relapse do not have a linear relationship but rather they have a “complex circular relationship, with the patient’s behaviour leading to changes in the relative’s EE and the relative’s in turn affecting the course of the patient’s illness” (Wearden, TARRIER, Barrowclough, Zastowny, & Armstrong Rahill, 2000, p.636) each supplying the stress that operates on the inherent vulnerabilities of the other (Hooley & Richters, 1995).

This suggests that the construct of Expressed Emotion is not stable over time but is part of a process involving adjustment and adaptation (Gumley & Schwanneuer, 2006; Hogarty, Anderson, Reiss, Kornblith, Greenwald, Java, & Madonia, 1986; Stirling, Tantam, Thomas, Newby, Montague, Ring, & Rowe, 1993). In fact, research has supported that high-EE family members can indeed lower, or raise, their ratings over time (Dulz & Hand, 1986; Goldstein, Miklowitz, Strachan, Doane, Nuechterlein, & Feingold, 1989; Leff, Berkowitz, Shavit, Strachan, Glass, & Vaughn, 1990; TARRIER et al., 1988a).

A 1992 study (Moore, Ball, & Kuipers) investigating EE in 35 professional staff working with 61 long-term mentally ill adults in three residential hostel units and a specialised day centre in Camberwell (England) found in their sample that EE was more dependent on the patient attributes than on the staff member. Based on this finding, the researchers suggested that EE does not represent a “stable, enduring, trait-like quality in the carer” (p.806).

This indicates that EE, and in particular high-EE, can be modified. A rating of EE may not be a stable, enduring state, but more a ‘snapshot’ of a single period in time in an interactive relationship between family member and client (Birchwood & Preston, 1991; Hahlweg et al., 1989; Miklowitz et al., 1988). Thus one’s EE rating may be on a continuum of sorts which is likely influenced by daily stressors, accumulating stress, personality traits and behaviours of both the client and family member (Weisman, Nuechterlein, Goldstein, & Snyder, 1998), and the increased level of physiological and emotional arousal that living in a stressful environment produces. This idea that EE can be modified also provides encouragement including the idea that lowering EE might also contribute to lower relapse.

### **The EE-Relapse Relationship**

Early research by both Brown, Birley, & Wing (1972) and Vaughn and Leff (1976a) found that approximately 92% of people diagnosed with schizophrenia, and living with high-EE families with more than 35 hours of face-to-face contact per week, relapsed over a nine month period. This was in direct contrast with client's who lived with low-EE families with the same amount of face-to-face contact, where only 15% relapsed. This pattern of findings has have been replicated by other researchers including Bebbington and Kuipers (1994), Falloon, Boyde, and McGill (1985), and Kavanagh (1992). TARRIER and Barrowclough (1990) found that a total of 53% of client's living with a family member who had high-EE relapsed, in comparison to 23% living with a low-EE family member, independent of all other factors assessed.

Bebbington and Kuipers (1994) conducted an in-depth aggregate analysis using 25 studies linking Expressed Emotion and schizophrenia and found that 50.1% of clients residing in high-EE households relapsed within a nine month period in comparison with 21.2% from low-EE households. Further, the amount of face-to-face contact time with high-EE family members was a risk factor for relapse yet was a protective factor for clients residing in low-EE families. This same pattern of findings has also been substantiated in a meta-analysis by Butzlaff and Hooley (1998).

A later meta-analysis by The Cochrane Collaboration (Pharaoh, Mari, Rathbone, & Wong, 2006) examined family interventions across Europe, Asia and North America and included psychosocial interventions of more than five sessions with family members of those diagnosed with schizophrenia. One of the outcome criteria was expressed emotion (amongst others such as suicide, relapse and quality of life). They found that a number of studies obtained 'equivocal' results but nevertheless many demonstrated statistically significant decreases in EE post intervention. In other words, while equivocal, the fact that a number of studies did find decreases again provides encouragement in light of the protective role of low-EE.

As an example of studies in this meta-analysis, a seminal study in this area was the 1986 Hogarty and colleagues study (Hogarty et al., 1986; Hogarty, Anderson, Reiss, Kornblith, Greenwald, Ulrich, & Carter, 1991) which compared four treatment conditions; family intervention and medication; social skills training for the client and medication; family management as well as a control group. Spread across these four groups, were 103 clients and

their high-EE family members. At the 1-year mark of treatment, the relapse rate for the control group was 41%, social skills training/medication was 19% and the group of combined family intervention and social skills training had 0% relapse (excluding drop-outs). In relation to EE, elevated relapse rates were found in households who had retained their high-EE status at the 12-month mark (42% in the control group, 33% family management group, 21% social skills only), with no relapse in the combined treatment group or in households that changed from high- to low-EE during the intervention.

To summarise, roughly four decades of research has substantiated that EE is a well-replicated predictor of client outcomes (Butzlaff & Hooley 1998; Pharoah, Mari, Rathbone, & Wong, 2006). This research has also authenticated the predictions that high Expressed Emotion plays a role in the likelihood of the client relapsing (Bebbington & Kuipers, 1994; Falloon, Boyde, & McGill, 1982; Harrison, Dadds, & Smith, 1998; Vaughn & Leff, 1976b).

The findings around this construct are now increasingly robust: findings now include those from research on the effect of EE on client outcomes and psychiatric relapse in other disorders and across different cultures and countries (e.g., Eisner & Johnson, 2008; Gumley & Schwannauer, 2006; Peris & Baker, 2000; Weardon, Ward, Barrowclough, & Tarrier, 2006). The next section focuses on cross-cultural research in relation to EE.

### **Cross Cultural Research on EE**

**“In everyday life, culture is something people come to take for granted – their way of feeling, thinking, and being in the world – the unself-conscious medium of experience, interpretation, and action” (Jenkins & Karno, 1992 p.10).**

Over the last three decades a significant number of studies investigating the association between EE and schizophrenia have been conducted in a host of different countries and cultures and in a number of different disorders. While it is not the purpose of this study to discuss this line of research in depth, it is worth briefly highlighting these areas to show the breadth and robust quality of this construct.

Research has been conducted in such diverse countries as – Australia (Francis & Papageorgiou, 2004; Harrison et al., 1998; Vaughn, Doyle, McConaghy, Blaszczyński, Fox, &

Tarrier, 1992), Germany (Buchkremer, Klingberg, Holle, Schulze-Monking, & Hornung, 1997; Kronmuller, Buckenstrass, Victor, Postelnicu, Schenkenbach, Joset, Fiedler, & Mundt, 2008), Brazil (Kymalainen & Weisman de Mamani, 2008), Czechoslovakia (Mozny & Votypkova 1992), Switzerland (Barrelet, Ferrero, Szigethy, Giddey, & Pellizzer, 1990), England (Jenkins, 1990; MacMillan, Gold, Crow, Johnson, & Johnstone, 1986; Nuechterlein, Miklowitz, Ventura, Gitlin, Stoddard, & Lukoff, 2006; Tarrier, Barrowclough, Porceddu, & Watts, 1988b), Denmark (Jeppesen, Petersen, Thorup, Abel, Oehlenschlaeger, Christensen, Krarup, Hemmingson, Jorgensen, & Nordentoft, 2005), Italy (Cazzullo, Bressi, Bertrando, Clerici, & Maffei, 1989; Magliano, Fiorillo, Malangone, DeRosa, Maj, 2006), France (Barrelet, Pellizzer, & Ammann, 1988), Germany (Bachmann, Bottmer, Jacob, & Schroder, 2006; Kottgen, Sonnichsen, Mollenhauser, & Jurth, 1984), Taiwan (Chen, Yang, Liao, Lee, Yeh, Chen, 2004; Jou, Wen, Kleinman, Kleiman, Wu, Chiu, & Schiller, 1989), India (Leff, Wig, Ghosh, Bedi, Menon, Kuipers, Korten, Ernberg, Day, Satorius, & Jablensky, 1987; Wig, Menon, Bedi, Leff, Kuipers, Ghosh, et al., 1987; Moran, 2008), Japan (Mino, Inoue, Shimodera, & Tanaka, 2000; Yamaguchi, Takahashi, Takano, & Kojima, 2006) as well as in North America amongst Anglo-Americans (Vaughn, Snyder, Jones, Freeman, & Falloon, 1984), Mexican-Americans (Karno, Jenkins, de la Selva, Santana, Telles, Lopez, & Mintz, 1987; Kopelowicz, Zarate, Gonzalez, Lopez, Ortega, Obregon, & Mintz, 2002) and African Americans (Moline, Singh, Morris, & Meltzer, 1985).

Despite the cultural differences in defining and interpreting the terms, criticism, hostility and emotional overinvolvement, the EE research across cultures shows a definite trend. Barrowclough and Hooley (2003) state the following “Although high-EE relatives can be found in all countries and cultures, it is generally true that high-EE attitudes tend to be less prevalent in developing or more traditional cultures than they are in more industrialised or developed parts of the world” (p.865). For example, this low-EE trend has been found in Mexican-American families of schizophrenia sufferers (Jenkins & Karno, 1992; Kopelwicz et al., 2002), in Indian families (Leff et al., 1987) and in Japanese families of those diagnosed with a mood disorder (Mino et al., 2000).

The results of those studies, despite difficulties in translation, differing measurement tools and methodological limitations, are consistent with the research found by the World Health Organisation’s (WHO) International Study of Schizophrenia (ISoS) demonstrating that individuals with schizophrenia in developing countries, less industrialised societies, or more traditional societies such as Asian countries and cultures are more likely to have a lower

proportion of high-EE households and a better prognosis than clients residing in more industrialised or westernised societies (Jablinsky, Sartorius, Ernberg, et al., 1992).

While this remains an active research topic and theories to explain why this result is so consistent are still being established, it has been speculated that more traditional cultures have cultural values that might support a more tolerant and benign environment (low-EE) for a client in comparison to ‘developed’ nations (Barrowclough & Hooley, 2003; Barrowclough, Tarrier, Humphreys, Ward, & Gregg, 2003). Also it has been theorised that the role of extended family in developing countries and their greater involvement in family daily life may also be creating an environment conducive to low-EE and recovery.

In more industrialised countries, the role of “extended family” may be partially to completely filled by professional staff members. When admitted to in-patient services or residential care facilities, the client’s level of contact with family members decreases whilst their level of contact with professional carers increases. The focus then “shifts toward staff assuming a significant place in the social network” (Mckeown, McCann, & Forster, 2002, p.222).

### **EE in Professional Staff**

Research has found that staff in professional caring relationships, and family caretakers share many characteristics, as staff also care for clients, often full-time in a long-term care facility (Kuipers, 1992; Moore et al., 1992). As such they also face similar client behaviour disturbances and challenges exhibited by clients (Creer, Start, & Wykes, 1982). Thus, despite professional training it is no real surprise that many early studies in this area have found the full range of EE present in relationships between staff and clients (Ball, Moore, & Kuipers, 1992; Moore & Kuipers, 1992; Moore et al., 1992; Nuechterlein, Dawson, Gitlin, Ventura, Goldstein, Snyder, Yee, & Mintz, 1992; Oliver & Kuipers, 1996; Siol & Stark, 1995; Synder, Wallace, Moe, & Lieberman, 1994; Herzog, 1992; Willetts & Leff, 1997).

The Moore et al. (1992) study (introduced in a prior section) interviewed 35 staff working in long-term care settings and obtained a total of 61 interviews about different service users the staff worked with on a daily basis. Based on these interviews, 43% of the 35 staff members

were rated as high-EE, similar to the proportion of family members shown in the family intervention EE studies (Leff & Vaughn, 1985).

A later study by Tattan and Tarrier (2000) conducted a naturalistic study which assessed clinical outcomes, including EE, for clients after a minimum of three months working with a case-manager. Approximately 158 clients participated in the study and were assigned to two years of either intensive case management, or standard case management via 18 case managers, resulting in 120 client-case manager dyads for assessment. Clients rated 73% of case managers as low-EE and 27% as high-EE. They also found that there were many similarities between staff and family members in terms of their processing of and reactions and attitudes to symptomatic behaviours. High-EE staff found many of the same types of behaviours difficult to deal with that high-EE family members did, such as disruptive behaviour, socially embarrassing behaviour and the social withdrawal aspects of the negative symptoms. They found prompting clients to attend to the activities of daily living frustrating and struggled to show empathy for the client, whereas low-EE staff were more realistic about progress and could show empathy and warmth for the client (Kuipers, Leff, & Lam, 2002; Tattan & Tarrier, 2000).

Other studies (e.g., Oliver & Kuipers, 1996; Snyder et al., 1994) have also shown that high-EE in staff can also be associated with poor client outcomes. However, even for those staff lower in EE, it is not difficult to picture the struggle someone might have remaining empathic, tolerant and understanding on an everyday basis, particularly for some level of care staff who have minimal training and ongoing supervision to call on. For this reason, education programmes might have the same potential benefit for professional staff as they do for family members and may help staff to engage more fully and positively with their clients.

## **THE ATTRIBUTIONAL MODEL AND EE RELATIONSHIP**

Although the EE construct is now firmly established, it is still not fully understood why some family members are high-EE and others low-EE. In an attempt to provide a theoretical framework for this question and to pinpoint the processes that differentiate high-EE from low-EE family members, the attribution theory was developed (Hooley, 1987).



The attributional model explores why different families, as well as different family members, can differ in their responses and attitudes to those with schizophrenia. This model proposes that the attributions family members make about the causes of symptoms and behaviours of the client are linked with the emotional feelings and responses they have toward them, which then impacts on family members' subsequent ability to cope effectively (Harrison & Dadds, 1992).

Hooley (1985) suggests that as positive symptoms are the most tangible and easily recognised signs of mental illness (e.g. hallucinations or delusions), they are more likely to be perceived as uncontrollable and unintentional, are more likely to be attributed to a legitimate illness, and those exhibiting them are subsequently less likely to be held accountable for this behaviour. By contrast, negative symptoms (behavioural deficits, particularly social withdrawal, self-neglect and apathy) are more likely to be attributed as controllable personality characteristics or deficits in behaviour and the client seen as merely unwilling to behave in an appropriate manner (Vaughn & Leff, 1981). This may be because behaviours such as poor hygiene or social withdrawal are seen as those which one could reasonably expect to be improved with effort by the client.

This theory was expanded upon by Weiner (1986) who suggested that emotions of anger, guilt, pity, and shame occur because of prior attributional beliefs about the causes of client behaviour: "In relation to Expressed Emotion, his theories about anger have particular relevance, as highlighted in the following example - if Ben attributes Meg's negative behaviour to causal factors that are seen as internal and thus controllable by Meg, then Ben will become angry at Meg and be less inclined to help Meg with her negative behaviour (Brewin, 1994)" (Moxon, 1999, p.19). A client's symptoms and negative behaviours may therefore elicit anger and subsequent hostility and critical comments in family members who see the symptoms as controllable. If this pattern continues, it would then be thought to result in high-EE and cumulative stress for the client leading to an increased chance of relapse (Lopez, Nelson, Snyder, & Mintz, 1999; Wendel, Miklowitz, Richards, & George, 2000).

In support of this model, research has consistently found that family members who are high in EE make different attributions to those who are low in EE (see review by Barrowclough & Hooley, 2003). The available studies support the utility of an attributional model in attempting to understand the determinants of levels of EE. In studies predicting that those high in EE would have less knowledge of schizophrenia and have a poorer understanding of negative

symptoms, the results have corroborated the predictions (Barrowclough, et al., 1994; Brewin, MacCarthy, Duda, & Vaughn, 1991; Harrison & Dadds, 1992; Weisman et al., 1998).

As an example of one study here, Weisman et al. (1998) conducted a study with 40 family members of 40 Anglo American clients diagnosed with schizophrenia to test the hypothesis that the differences between the attributions that high-EE and low-EE family members make are related to the differences between their knowledge and understanding of particular symptoms. In this study, 29 family members were rated through the CFI as high-EE and 11 as low-EE. The major finding of this study was that negative symptoms reflecting behavioural deficits, such as poor hygiene, apathy and social withdrawal were criticised at almost six times the rate of criticism directed at positive symptoms.

This particular study also highlighted that high-EE relatives tend to see symptoms on the behavioural deficit spectrum as controllable personality characteristics rather than the symptoms of a legitimate illness. This then appears to contribute to them expressing more critical, negative and hostile attitudes and comments towards the client. They suggest that research supports the view that high-EE relatives are in general less informed about schizophrenia than their low-EE counterparts (Cozolino, Goldstein, Nuechterlein, West & Snyder, 1988) and that they have “a poorer understanding of the negative symptoms in particular” (p.358). Thus, it can be suggested that education about the behavioural deficit spectrum might help to reduce these critical attributes.

In addition to the positive versus negative symptom attributions, a number of additional studies have examined a related idea that high-EE in family members is related to attributing symptoms to the client and/or their personality rather than to the disorder (Barrowclough, Johnson, & Tarrier, 1994; Brewin et al., 1991; Greenly, 1986; Hooley, 1985; Hooley & Licht, 1997; Hooley, Richters, Weintraub, & Neale, 1987; Licht, 2000; Lopez et al., 1999; Tarrier, Barrowclough, Ward, Donaldson, Burns, & Gregg, 2002; Weisman, Lopez, Karno, & Jenkins, 1993). Vaughn and Leff (1981) first suggested that high-EE family members have unrealistic expectations that cause them to believe that the client’s symptomatic behaviour is within their volitional control. Viewing this behaviour as intentional is then thought to result in anger, hostility, exasperation and annoyance, making them less sympathetic toward both the illness and the client, possibly resulting in the family member using intrusive methods or criticism in an attempt to restore or change the client’s behaviour (Barrowclough & Hooley, 2003; Lopez et al., 1999; Wendel et al., 2000). In contrast, low-EE family members are thought to believe that

the client suffers from a legitimate illness and has little or no volitional control over their symptomatic behaviours, prompting them to be more tolerant and understanding (Hooley & Gotlib, 2000; Lopez, Hipke, Polo, Jenkins, Karno, Vaughn, & Snyder, 2004).

The research that has evaluated this hypothesised difference has tended to provide supportive findings. For example, a 2003 review (Barrowclough & Hooley) lists 11 separate studies<sup>1</sup> spanning between 1991 and 2003 that have all confirmed the hypothesis that hostility and criticism (high-EE) in family members reflects the “underlying beliefs that patients could do more to control their symptoms and problems” (p.861). Across all the studies, relatives who were rated as high-EE because they are critical were also consistently found to attribute more control to clients for their symptoms and problems than relatives who were rated low-EE and rarely criticised.

The research highlighted here shows that high-EE family members tend to make different attributions about client’s symptoms and behaviour than do low-EE family members. Low-EE family members tend to attribute the causes of symptoms and behaviours to factors more outside of the client’s discretionary control. Alternately, family members high in critical comments and/or hostility attributed more causes to factors inside of the client’s discretionary control (e.g., Hooley et al., 1987).

Based on these overall findings, most research in the attribution field suggests that the more information families have about schizophrenia, in particular about behavioural deficits of the negative symptoms and the impact the disorder has on clients, the less distress and burden of care they will feel. It also suggests that increased understanding, perhaps combined with an increased sense of empowerment, may also help them “to modify their expectations of patient’s and temper their attributions of control” (Hooley & Gotlib, 2000, p.140).

Subsequent sections build on these findings and suggestions with further examination of constructs including those used along with EE as additional dependent variables in the current

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<sup>1</sup> Brewin et al., 1991; Weisman et al., 1993; Brewin, 1994; Barrowclough, Tarrrier, & Johnston, 1994; Barrowclough, Tarrrier, & Johnston, 1996; Hooley & Licht, 1997; Weisman et al., 1998; Lopez, Nelson, Snyder, & Minz, 1999; Weisman, Nuechterlein, Goldstein, & Snyder, 2000; Wendel, Miklowitz, Richards, & George, 2000; Barrowclough, Lobban, Hatton, & Quinn, 2001; Tarrrier, Barrowclough, Ward, Donaldson, Burns, & Gregg, 2002; Bolton, Calam, Barrowclough, Peters, Roberts, Weardon, & Morris, 2003.

study: distress, burden of care and capacity and ability to cope on a daily basis with a family member diagnosed with schizophrenia.

## **DISTRESS AND BURDEN OF CARE**

The emphasis on deinstitutionalisation and community care has meant more clients are being accommodated within a family setting and with overburdened hospital systems with restricted bed usage and reduced inpatient stays, the burden on and distress of family members is increased (Boye, Bentsen, Ulstein, Notland, Lersbryggen, Lingjaerde, & Malt, 2001; Fadden, Bebbington, & Kuipers, 1987; Ostmann, Hansson, & Anderson, 2002). While the construct burden of care will be defined more clearly further on in this section, in brief it can be defined as an impact of care on family members requiring them to place the needs and wishes of their mentally unwell family member above those of their own (Maurin & Boyd, 1990). While used often colloquially, the term distress in the context of caregiving for someone diagnosed with schizophrenia itself has been defined more specifically as a global form of negative affect that may not be “specifically attributed to the presence of the patient, but to one’s overall life situation” (Maurin & Boyd, 1990, p.99). Thus, distress may result from a combination of factors including life strain, the family member’s mental health, social supports and a number of other related factors.

As introduced in the previous sections, the impact on families who care for someone with schizophrenia has been extensively researched over the last 50 years, resulting in a general consensus that living with someone with schizophrenia produces significant financial, emotional and practical burdens (Carpentier, Lesage, Goulet, Lalonde, & Renaud, 1992; Jung, 2000; Kuipers & Raune, 2000; Lowyck, De Hert, Peeters, Gilis, & Peuskens, 2001; Maurin & Boyd, 1990; McDonell, Short, Berry, & Dyck, 2003; Teshinsky, 2000). In fact, a 2002 study (Magliano, Marasco, Fiorillo, Malangone, Guarneri, & Maj, 2002) found that up to 83% of family members of people diagnosed with schizophrenia experience considerable burden of care.

This Italian study recruited 709 people diagnosed with schizophrenia and their key family members across 30 different mental health departments. Information was gathered on the level of disability and clinical status of the client, the social and professional support family members receive, their level of burden and the interventions received by both clients and family members. They found families perceived significant burden and that this burden was associated

in part with the clients' level of disability and the social and professional support network around the family.

When family members are thrust into the caregiving role of someone diagnosed with schizophrenia, they are often unaware of the supportive resources and specialist knowledge available (Pond, 2004). When family members assume the caregiving role, it is likely that they will suffer increased levels of distress, anxiety, stress (Kuipers & Raune, 2000) and exhaustion (Noh & Turner, 1987). For example, Fadden et al. (1987) found that family members who have taken on the caregiving role develop depression and anxiety at three times the rate of the normal population (Sartorius, Leff, Lopez-Ibor, Maj, & Okasha, 2005).

Many studies have researched the detrimental impact of schizophrenia on the family unit and their lives, with findings on self-report scales such as the General Health Questionnaire that between 30% and 60% of family members suffer significant distress (Barrowclough & Parle, 1997; Birchwood & Cochrane, 1990; Fadden et al., 1987; Magana, Ramirez Garcia, Hernandez, & Cortez, 2007; Oldridge & Hughes, 1992; Winefield & Harvey, 1993). With these levels being higher than those in the general population, it follows that the elevated levels at least in part are related to the stress and strain of caring for someone with schizophrenia.

Research has consistently found that the particular behaviours which cause the most burden for family members are the behavioural deficit symptoms such as social withdrawal, apathy and self-neglect as well as bizarre, disturbing or socially embarrassing behaviour (Creer & Wing 1974; Dyck, Short, & Vitaliano, 1999; Grad & Sainsbury, 1968; Hoeng & Hamilton, 1966; Lefley, 1987; Mills, 1962). As defined earlier, burden of care can relate to a number of different effects. For example, in the Magliano and colleagues study (Magliano, Fadden, Madianos, Caldas de Almeida, Held et al., 1998), it was found that being a caregiver of someone with schizophrenia led to the caregiver restricting their own social activities, adverse effects for the family unit, and feelings of loss and grief. These findings are also consistent with previous research (Fadden et al., 1987; Maurin & Boyd, 1990).

Of course, as may be evident from this review of findings, distress and burden of care – and a number of other constructs - are not orthogonal. In fact, research has indicated that distress is itself related to the following constructs: a perceived burden of care (Oldridge & Hughes, 1992), inadequate family support (Boye et al., 2001), caregiver depression (Magana et al., 2007), high-EE (Barrowclough & Parle, 1997), a belief that client's could control their

psychosis and were choosing not to (Fortune, Smith, & Garvey, 2005) and a concern of family members when they “perceived there to be greater negative consequences for the client from the illness, they showed greater distress and subjective burden” (Sartorius et al., 2005, p.5). With respect to burden of care, as introduced in this section, it too has been linked to a number of negative outcomes. The next section reviews research in more depth delineating between objective and subjective burden.

### **Objective & Subjective Burden**

Hoenig and Hamilton (1967) were the first researchers to distinguish between two dimensions of burden – objective and subjective. Objective burdens are the tangible, observable costs to the family of mental illness and can be measured, such as financial costs, disruptions to the daily routine of family life, and physical care. Subjective burdens stem from the individual’s own perception and assessment of the impact of caring for their family member and the degree to which they see the caretaking experience as a burden. It has been found that measures of burden of care and Expressed Emotion are more dependent on family members’ assessment and perception of the client condition rather than on the client’s actual deficits (Scazufca & Kuipers, 1996).

Schene (1990) suggested that objective burden relates to the additional caregiving tasks that the family carries out (such as supervising, financial aid and direct helping) in addition to the loss of their own activities and hobbies (such as work and social interests) which they can no longer commit to because of their caregiving duties. By contrast, subjective burden relates to the experiences and responses of a caregiver in response to symptomatic behaviour or potentially distressing situations.

Objective and subjective burden are not mutually exclusive nor is it necessary to have equivalent levels of both. However, many families differ in the type or amount of burden experienced with some who have high levels of objective burden not reporting high levels of subjective burden. With respect to objective burden, comparative studies (Chakrabarti & Kulhara, 1999) illustrate that across a broad range of psychiatric illnesses, objective burden scores were highest in families with schizophrenia clients. In terms of subjective burden, it has been found that families reporting high levels of subjective burden, irrespective of their objective burden, report feeling less able to cope (Birchwood & Cochrane, 1990).

In terms of the type of subjective burden experienced, a 2004 study (Lowyck, DeHert, Peeters, Wampers, Gilis, & Peuskens) found that respondents reported perceived burdens such as a tense family atmosphere, arguments and loss of contact with some family and friends. Only 2% of 150 respondents in this 2004 study reported not feeling emotionally burdened in coping with their family member's symptoms (Kuipers, 1993; Provencher, 1996). A more recent review of the literature (Mueser & Jeste, 2008) has reported that up to two-thirds of caregivers experience subjective burden as a direct consequence of their care-giving role.

In general, caution is advised in interpreting the levels of burden associated with mental illness (Maurin & Boyd, 1990; Sartorius et al., 2005) due to inconsistencies in findings resulting from methodological differences (Magliano et al., 1998), inconsistent and differing use of operational definitions (Maurin & Boyd, 1990) as well as the complications that can arise from self-report assessments (Wise & DeMars, 2003). However, despite these methodological problems, there are a number of well-replicated findings in this area, including that women generally assume the main caregiving responsibilities and thus bear a greater level of burden (Cook & Pickett, 1988; Noh & Turner, 1981; Schene, Van Wijngaarden, & Koeter, 1998), that those who live with the client have a higher level of burden (Jacob, Frank, Kupfer, & Carpenter, 1987; Maurin & Boyd, 1990), client's inappropriate or disturbing behaviours result in a higher level of burden (Creer et al., 1982; Fadden et al., 1987; Noh & Turner, 1987; Provencher, 1996; Quinn, Barrowclough, & Tarrier, 2003), that poor client social functioning results in higher levels of burden (Magliano et al., 1998) and that longer duration of the illness and a higher number of hospitalisations are related to higher levels of burden (Rose, Mallinson, & Gerson, 2006). Finally, and importantly, the negative symptoms of schizophrenia (such as apathy and social withdrawal) appear to be seen as the most burdensome behaviours (Runions & Prudo, 1983; Dyck et al., 1999; see also Fadden et al., 1987; Hooley et al., 1987; Velligan & Alphas, 2008).

A number of studies have also found that families characterised by high Expressed Emotion also report higher levels of subjective burden and family stress (Kavanagh, 1992; Scazufca & Kuipers, 1996), report higher levels of disturbed behaviour in clients, and perceive themselves less able to cope effectively with their increased burden (Smith, Birchwood, Cochrane, & George, 1993).



Research into burden of care and EE, as research into EE alone, shows that low-EE families still report burden of care but that they perceived it as less problematic (Kuipers, 1993). They also appear to use more problem focused coping strategies (versus emotion-focused strategies, see next section for further detail), seek out more social support and use poor coping strategies such as avoidance less often than their high-EE counterparts (Sartorius et al., 2005; Scazufca & Kuipers, 1996).

By contrast, Barrowclough and Parle (1997), Raune, Kuipers, and Bebbington (2004) and Scazufca and Kuipers (1999) have all found that high-EE is associated with higher subjective burden, more avoidance coping strategies, lower perceived client functioning, and higher distress. Smith, Birchwood, Cochrane and George (1992) also found that high-EE family members perceived themselves as being less able to cope with the client's illness as compared to low-EE family members. By contrast, it has been found that low-EE family members are associated with a higher degree of perceived coping ability and less distress than their high-EE counterparts (Harrison & Dadds, 1992).

It has been concluded (Birchwood & Tarrier, 1998; Smith et al., 1993; Scazufca & Kuipers, 1996; Wykes, Tarrier, & Lewis, 1998) that burden of care in family members, like EE, is more dependent on family members appraisal of the client's (or situational) problems than on actual problems or client deficits. In addition to perceptions, burden of care also appears to be related to social support and coping. In fact, across all levels of EE, it has been found that subjective burden tends to be lower when families have a supportive social network or have a large array of coping skills to draw on (Birchwood & Cochrane, 1990; Magliano, Veltro, Guarneri, & Marasco, 1995; Noh & Turner, 1987; Solomon & Draine, 1995).

## **COPING**

As discussed in earlier sections, up to 60% of individuals diagnosed with schizophrenia live with their families (Kuipers, 1993) and up to 60% (Woo & Keatinge, 2008) return to live with their families upon discharge. Research has reflected that upon discharge from inpatient services, families often report that they feel unprepared for the client's return to the family (Bernheim & Switalski, 1988; Gantt, Goldstein, & Pinsky, 1989; Hatfield, 1978).

Following the Lazarus and Folkman (1984) interactional theory of stress and coping, coping refers to the “constantly changing thoughts and behaviours that people use in order to manage stressful situations” (Scazufca & Kuipers, 1999, p.154). As it relates to coping with the burden of looking after the needs of a family member diagnosed with schizophrenia, research has indicated that coping ability is influenced by the type, severity and frequency of the stressor, the personality traits and behaviour patterns of both clients and family members. Coping ability is also influenced by the specific coping strategies available to the individual, the individual’s assessment of the supports accessible to them to assist with coping and their perception and appraisal of not only the situation but the perception of their ability to cope with the situation (Sartorius et al., 2005).

Research examining the coping effectiveness of people with mental illness and their families has become more prevalent in the past decade or so (Barrowclough & Parle, 1997; Magliano, Fadden, Economou, Held, Xavier, Guarneri, et al., 2000; Quinn et al., 2003; Scazufca & Kuipers, 1999). Overall, this line of research has found that the majority of families use a broad array of coping styles that are applied in response to different situations and behavioural changes in clients (Birchwood & Cochrane, 1990).

However, some coping strategies appear to be used more often than others. Magliano et al. (1998) and Solomon and Draine (1995) both found that one of the most commonly used and most effective coping strategies was an ‘ignore/accept style’ (Sartorius et al., 2005). Other commonly used strategies appear to be related to social factors: seeking out social activities, seeking support and increased social support (Sartorius et al., 2005). All of these coping strategies have been shown to be associated with lower burden and distress (Magliano et al., 2000; Magliano, Fadden, Fiorillo, Malangone, Sorrentino, Robinson, & Maj, 1999; Noh & Turner, 1987). On the other hand, passive and emotionally focused coping styles such as avoidance, resignation, and self-blame have been found to be associated with increased distress and burden in family members (Bibou-Nakou, Dikaiou, & Bairactaris, 1997; Dyck et al., 1999; Magliano et al., 2000; Scazufca & Kuipers, 1999).

As also discussed in relation to other constructs, Barrowclough and Parle (1997), Quinn et al. (2003), and Scazufca and Kuipers (1999) found that the family members’ perceived ability to cope is more dependent on their perception and assessment of the client’s’ problems than the actual problems themselves. In relation to schizophrenia, the appraisal process would include the causal attributions made about problematic behaviours or symptoms related to

schizophrenia, and it would also quite likely include or be influenced by the circular and interactive construct of EE combined with burden of care. According to Lazarus and Folkman's theory (Haley, Levine, & Brown, 1987), the appraisal that a person (i.e., the family member) makes about a situation (i.e., situations linked to living with or caregiving for a diagnosed family member), along with its unconscious determinants, is the key factor that then helps shape the resulting coping strategy.<sup>2</sup>

Further, it has been reasoned that if a situation is appraised as open to change, then coping responses of family members tend more often to be approach- and problem-focused (Scazufoa & Kuipers, 1999), whereas in a situation perceived as unchangeable, coping responses of family members tend to be more avoidance-based. Therefore, if a situation with the client is appraised as too problematic or threatening in some way, and family members do not believe that they have the resources needed available to them to cope with the client/situation, then they are more likely to avoid rather than deal directly with the problem (Sartorius et al., 2005).

It can be seen from the previous sections that the caregiving role can have many demands and stressors. It is also the case that both knowledge and support have been found to reduce features related to these demands and stressors. Thus, supportive educationally-based interventions that provide information about illness and simple means of coping may assist in modify appraisal processes and resultant reaction to stressors. Such modification may then help improve relatives' ability to cope and reduce the stress and subjective (and perhaps objective) burden linked to the caregiving role. The next section examines intervention strategies.

## **TREATMENT**

### **Rationale**

There have been important social changes in the decades since the 1950s which, alongside the advent of neuroleptics, have contributed to an improved future for those diagnosed with schizophrenia. Instead of staying in hospital for prolonged periods of time, clients now tend to

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<sup>2</sup> Lazarus and Folkman delineate between problem- and emotion-focused coping strategies in that emotion-focused coping strategies include distancing, minimization and avoidance whereas problem-focused strategies focus on defining and analyzing a problem, weighing the options and then acting.

be released as soon as possible. While this may be desirable in many instances, it can also for some create a 'revolving-door' pattern of admission, discharge and readmission. In fact, over the past three decades, research has found rehospitalisation rates of 40-50% after one year (since onset) and 75% upwards after two years (Anthony, Rogers, & Farkas, 1986; Paul & Menditto, 1992). Specific American rehospitalisation rates have been found in Illinois where 30% of clients with schizophrenia discharged from psychiatric hospitals were rehospitalised within one month, and in New York, 60% of those discharged were rehospitalised within one year (Torrey, 2006).

As discussed in previous sections, this potentially creates an increased burden of care for the families supporting the clients. As introduced in previous sections, research shows that between 46% (Bland & Harrison, 1995) and 65% (Intagliata, Willer, & Egri, 1986) of clients hospitalised return on discharge to live with their families and approximately 25% of people with schizophrenia live permanently at home with their families (Torrey, 2006).

The return of the client can cause a major upheaval in both the individual's life and those of his or her family. The client may feel hurt, angry or even resentful for not being understood or helped and for being admitted to hospital or to have their rights restricted through being subject to mental health legislation (i.e., in New Zealand, the Mental Health Act; Ministry of Health, 2009).

Family members may feel a sense of loss and grief for the person the client was before the illness developed, and as Moxon (1999) found:

anxious because they do not know what to expect and they may feel helpless and depressed because they can not change the illness or make it 'all better' as parents particularly may want and try to do. They may feel angry at the difficult behaviour of the client and resentful at having to provide more care (p.23).

In some cases, they may sacrifice part of their own lives to provide care, more than is typical for a person of the client's age (Schene et al., 1998). Family members may also feel guilty for any negative feelings or doubt themselves and question their parenting style (Anderson, Reiss, & Hogarty, 1986; Bernheim & Lewine, 1979; McFarlane, 1983). Both clients and families may feel stigmatised, embarrassed or ashamed and socially isolate themselves (Gonzales-Torres,

Oraa, Aristegui, Fernandez-Rivas, & Guimon, 2007; Wahl & Harmon, 1989). Underneath all of these feelings, grief can usually be found for the “loss of health, personality and vitality in the person they love” (Miller, 1995, p.51).

When someone in a family is diagnosed with schizophrenia, it is difficult for family members to support the client in addition to attending to various responsibilities including trying to keep the household stable for the rest of the family. As documented in previous sections, family members may find this struggle and the extra burdens placed on them tiring and stressful (Clark, 1994; Schene, Tessler, & Gamache, 1996). Smith (1982) has encapsulated the plight of families with a family member diagnosed with schizophrenia:

The families feel burdened, ill-understood by the professional services, and bewildered by the patient’s behaviour. They have in the past been offered little help except the admission of the patient when life was intolerable, and now the emphasis on community care outside institutions means that disturbed patient’s remain at home while the supposed care may be scanty. Informed advice about illness and its disabilities, about social over- and under-stimulation and reducing the intensity and duration of contact within the family when the patient’s condition shows signs of relapse, about the drugs and about the services available, has been lacking and sorely missed (p.159).

As discussed in earlier sections, those with schizophrenia have a lower tolerance for stress. Returning to the family home where their symptoms and behaviours may adversely affect the family, particularly in those families with high-EE, may then lead to increased stress and sense of burden (Kuipers, 1983). Therefore, interventions aimed at reducing stress and EE have been developed to be used in conjunction with standard treatment of care.

## **CURRENT TREATMENT MODELS**

### **Medications**

Prior to the 1950's, most clients with schizophrenia spent much of their lives in institutions or hospitals where they underwent a number of radical treatments such as insulin coma therapy (Sakel, 1938), fever therapies, prefrontal lobotomies (Moniz, 1936) and electroconvulsive therapy (Cerletti & Bini, 1938). These treatments were largely abandoned after the 1950s when long-stay asylums began closing (Reveley, 2008) after the effects of antipsychotic medications, such as phenothiazines (neuroleptics) were discovered and became widely accepted as the first-line of treatment for schizophrenia (Tsuang & Faraone, 1997).

During the course of his work, French surgeon Hénery Laborit found chlorphenithiazine (a derivative of phenothiazine) had a calming effect on people and suggested that psychiatrists trial it (Mueser & Gingerich, 1994; Shean, 2004). Trials found that the derivative chlorpromazine (trade name Thorazine) could, in some people, have a dramatic effect in reducing or eliminating the psychotic symptoms of schizophrenia (Davison & Neale, 1996; Kalat, 1995). As a result, it “prompted the huge exodus of patient’s from state hospitals in the 1950s” (Keefe & Harvey, 1994, p.145).

The body of evidence for the efficacy of antipsychotic medications in symptom management and reduction in relapse is impressive (Dixon & Lehman, 1995). Across almost 100 randomised clinical trials, it was found that 75% of client’s improved<sup>3</sup> on antipsychotic medications compared to improvement in 25% of placebo client’s (Lehman, 1999).

Since the 1950's, many antipsychotic medications have been developed and used with impressive efficacy in relation to positive symptoms and relapse prevention. However, they are still considered as less effective for the withdrawal spectrum of the negative symptoms such as alogia, anhedonia, social withdrawal apathy and affective flattening (Shean, 2004). Additionally, these medications typically also produce side-effects. These may include dry mouth, drowsiness, sedation, dizziness, blurred vision, excess salivation, akathisia, constipation, weight gain, increased appetite, restlessness (akathisia), muscle rigidity, tardive dyskinesia and Pseudoparkinsonism among others.

The current six classes of typical antipsychotics available include phenothiazines, thioxanthenes, butrophenones, dibenzoxapines, dihydroindolones and dibenzodiazepines (Shean, 2004). They have all been shown to reduce psychotic symptoms and to prevent or

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<sup>3</sup> Improvement was defined as a reduction of positive symptoms.

reduce the chance of further psychotic relapses (Insel & Scolnick, 2006). At the neuronal level, they all share the common property of inhibiting dopaminergic transmission in neuron systems in the brain by blocking the postsynaptic dopamine receptors (Shean, 2004; Snyder, Banerjee, Yamamura, & Greenberg, 1974; van Praag, 1977).

A recent summary of medications (Lieberman et al., 2006) has concluded the following: “For the great majority of patients, medications help with symptom control but do not clearly preserve or restore premorbid levels of social and vocational functioning and do not lead to normal functioning. Moreover, 20% or more of schizophrenic patients have psychotic symptoms that do not respond to antipsychotic medications, and many other patients have residual symptoms” (p.327).

As a result, psychosocial interventions are seen as an essential component of intervention to be used often in conjunction with medications (Falloon, 1999). The next sections focus on family-based interventions, the focus of the current study. However, prior to focusing on these interventions and related research in depth, a brief overview of the full range of psychosocial interventions is provided.

### **Psychosocial Family Interventions**

**“Call it a clan, call it a network, call it a tribe, call it a family: whatever you call it, whoever you are, you need one”. Jane Howard (1935-1999)**

**From Reddy & Keshavan 2006, pg 86**

Not all treatments for schizophrenia involve the use of drugs. Psychological treatment is a broad term used to describe any therapeutic approach seeking to modify thoughts and behaviour without medicine. They are not necessarily an alternative to drug therapies; the two may be used in conjunction. Indeed, this seems to be the ideal treatment plan for many schizophrenic patients (Tsuang & Faraone, 1997, p.112).

A meta-analysis (Pilling, Bebbington, Kuipers, Garety, Geddes, Orbach, & Morgan, 2002) found that the average client with schizophrenia who received psychosocial treatment in

addition to medication was more improved than 65% of clients who received medication only, and that these gains were maintained across a median 12-month follow-up period. Such findings indicate quantitatively the value of psychosocial treatment. Of all the psychosocial interventions available, the current evidence favours family interventions as one of the two treatments seen to have the most support, the other being cognitive behavioural therapy (Woo & Keatinge, 2008).

### **Evidence-Informed Recommendations**

In 1992, the Agency for Health Care Policy and Research and the National Institute of Mental Health in the America funded and formed the Schizophrenia Patient Outcomes Research Team (PORT) “to develop and disseminate recommendations for the treatment of schizophrenia based on existing scientific evidence” (Lehman & Steinwachs, 1998, p.1). The PORT collaboration recommended family interventions be used in the treatment of schizophrenia for a duration of at least 9 months and focus on family support, education about the illness, crisis management and behavioural problem solving (Lehman et al., 2004). The World Schizophrenia Fellowship (1998) has identified similar key elements of an effective family intervention but further recommends goal setting, conflict resolution, communication and problem solving training (Beebe, 2007).

PORT further recommended that “family interventions should not be restricted to patients whose families identified as having high levels of Expressed Emotion” (Lehman & Steinwachs, 1998, p8). This is based on research showing “no differences in outcome studies between studies which only include high Expressed Emotion families and those with broader inclusion criteria” (Mihalopoulos, Magnus, Carter, & Vos, 2004, p.517). As discussed in previous sections, low-EE families are still impacted by the caregiving role and may well obtain benefit from such interventions.

The National Institute for Clinical Excellence (NICE; 2002) in the United Kingdom also recommended that psychological interventions should be “an indispensable part of the treatment options available for service users and their families in the effort to promote recovery” (p.16) and states that the intervention should be of at least 6 months duration. The NICE recommendations confirmed that family interventions have proven efficacy in reducing client relapse rates.



Further, the most recent review of family intervention for schizophrenia (The Cochrane Collaboration; Pharoah et al., 2006) states that psychosocial interventions are specifically designed to reduce the level of EE within families by “decreasing stress within the family as well as the rate of relapse” (p.2) and that these interventions serve often as adjuncts to drug treatments (see also next section).

Within New Zealand, the New Zealand Code of Family Rights state that the family/whanau has the right to “information about a family member’s illness, the diagnosis, treatment and possible side-effects of treatment” (SF New Zealand, 2009) , while the New Zealand Treatment Guide for Consumers and Carers in relation to Schizophrenia (*Schizophrenia*, 2007) outlines different forms of treatments available for schizophrenia in the country, including medications, psychosocial treatments including psychoeducation, family/whanau therapy, cognitive-behavioural therapy, vocational and social rehabilitation, group activities and self-help groups. It explains psychosocial treatment as that which aids the individual in becoming accustomed to psychosis and helps the individual to have a recovery focus in achieving their goals, despite the illness.

### **Principles, Goals and Findings**

Family interventions are packages of interventions with different components, guided by a set of overall principles (Mari & Streiner, 1994). As the previous section describes, there are many family intervention components available, with different packages differing widely in their content and mode of delivery. The most frequently used components of family interventions are psychoeducation, cognitive-behavioural therapy, behavioural family management and family intervention. Additional interventions such as social skills training and vocational rehabilitation are available as supplementary components (Shean, 2004).

Family-based interventions also differ in how they are conducted: in the home or in the hospital; with multi-family groups or with individual families; with the client included and seen with the family, included but seen separately, or excluded; and stage of illness of the client linked to the timing of intervention (Dixon & Lehman, 1995). While family-based interventions may have differing components, they almost all follow a set of guiding overall principles (“common features which appear to be crucial for their effectiveness” Fadden, 1998, p.116; Lam, 1991; Mari & Streiner, 1994; Pharoah et al., 2006) and include an education component (Wykes et al., 1998) : 1) schizophrenia is seen as an illness, 2) the family is not blamed for the

development of the illness, 3) an alliance is established with the family, 4) EE and the tension in the environment of the family home, family burden, effective communication, problem solving, anger, guilt and family members behaviour and belief systems is all targeted, 4) reasonable and achievable expectations are set, 5) interventions are part of a treatment package which includes regular medication and attendance at additional outpatient services (e.g., support, skills-training), and 6) maintenance of gains is encouraged.

Family interventions attempt to reduce or prevent client relapse and reduce symptomology as well as improve client functioning. This is done in part through targeting the family environment by increasing insight, awareness and understanding, helping to decrease the EE level, family burden and improve overall family functioning.

For this review, and as examples of family therapy programmes developed in this area, the intervention package highlighted is the psychoeducational based family intervention (often also referred to as a psychosocial family intervention in the available literature) developed by Anderson, Reiss, and Hogarty (1986). This model has been chosen as it has been described as possibly the most comprehensive family intervention model available (Atkinson & Coia, 1995; Shean, 2004).

Leading researchers Michael Goldstein, Ian Falloon in New Zealand, Carol Anderson, Gerry Hogarty (Hogarty et al., 1986) and colleagues spent much of the 1970's and 1980's developing family intervention models (Marley, 2004) which culminated amongst other works, in the publication of 'Schizophrenia and the Family: A Practitioner's Guide to Psychoeducation and Management' (Anderson, Reiss, & Hogarty, 1986) and was adapted to multi-family settings in Australia by William McFarlane (McFarlane, Lukens, Dushay, Deakins, Newmark, Dunne, et al., 1995).

The goal of the first of four phases of this family intervention model is to connect and establish a relationship with the family, enlisting their co-operation and reducing their guilt, anxiety, emotionality, frustration and negative reactions to the illness. The Survival Skills Workshop (phase two) is usually a one-day multi-family educative workshop which provides families with information about schizophrenia and its management as well as providing practical techniques such as communication and problem solving skills. It aims to increase the family's understanding of the illness. One of the most important parts of the workshop is the

multi-family aspect with families encouraged to establish support networks with the other families.

The third phase is the family therapy stage and re-entry of the client into the family or community environment. Individual family sessions are held every 2-3 weeks for a minimum of six months. Sessions focus on maintaining community connections, gradual resumption of responsibility for the client, and increasing family tolerance for the client's' symptomatic behaviours as well as the development of more achievable family expectations.

The final phase of the treatment involves gradual continued treatment, or disengagement. Once the original goals have been achieved, the family can choose to either: a) attend gradually decreasing periodic supportive maintenance sessions, or b) attend more traditional family focused sessions to resolve any remaining long term family conflicts. The focus of this phase is on providing support for the gradual re-integration of the client into the community and maintenance of family problem solving and this phase can last for 1-2 years.

There have been a large number of psychosocial family interventions developed over the past 30 years (refer to Brooker, 1990; Dixon & Lehman, 1995; Pharaoh, Mari, Rathbone, & Wong, 2006; Pitschel-Walz, Leucht, Bauml, Kissling, & Engel, 2001 for reviews), including four seminal interventions (Anderson et al., 1986; Barrowclough & Tarrier, 1992; Falloon, Laporta, Fadden, & Graham-Hole, 1993; Kuipers, 1992). Most psychosocial interventions work through the goals outlined earlier although they may vary in what they do within each phase, given that they may follow a cognitive behavioural or behavioural focus.

Research on this model as previously indicated, has demonstrated that psychosocial programmes aimed at lowering EE in family environments can also reduce the rate of client relapse (Dixon & Lehman, 1995; Gamble & Midence, 1994). A 2002 meta analysis (Pilling et al.) of randomised clinical trials found that single and multi-family interventions were more effective at the one year follow up than standard care comparison conditions (such as medication alone).

A review of some specific findings highlights the effect of these interventions on relapse rates. This has been substantiated by Falloon and colleagues (Falloon, Hahlweg, & Tarrier, 1990) who reported relapse rates, within the first year of intervention of 8% to 19% for clients

receiving psychosocial family treatment as an addition to standard treatment, but 41% to 60% for clients receiving standard care alone.

Leff and colleagues (Leff, Kuipers, Berkowitz, Eberlein-Vries, & Sturgeon, 1982; Leff, Kuipers, Berkowitz, & Sturgeon, 1985) also compared individual standard care with psychosocial family interventions which involved four home-based educational lectures, a fortnightly relatives' group for nine months, and between one and twenty-five home-based family sessions. They found that at the nine month follow-up period, 50% of the standard care group had relapsed in comparison with only 9% of the family intervention group. At the two year follow up, 78% of the standard care subjects had relapsed in comparison with 40% of the family intervention group, demonstrating that family intervention was superior to standard care, at least across two-year follow-up. Vaughn et al. (1992) conducted a brief family intervention involving 10 weekly counselling sessions for family members with a focus on education, problem solving and communication skills compared with standard care. They found at the nine month follow up that 65% of the standard care group had relapsed in comparison to only 41% of the family intervention group.

Sartorius et al. (2005) concluded that in combination with routine care, family interventions decrease relapse rates (refer also to Pharaoh et al., 2006 for review) across the variables of age, sex, culture, and length of treatment. These results have also been generalised across different countries such as Australia, Europe, the UK and USA, Italy and the People's Republic of China.

In following some overseas developments, this study has chosen and adapted this evidence-based family psychoeducation and intervention model to a brief psychoeducational format. Psychoeducation programmes centre around the provision of information and support to families and are briefer than full intervention packages.

### **Psychoeducation Programmes**

**“The psychoeducational model firmly believes that knowledge is power”**

**(Marley, 2004, p.109)**

“Family Psychoeducation for the management of schizophrenia has been extensively studied and is currently considered a best practice in the treatment of schizophrenia among adults” (Hazel, McDonell, Short, Berry, Voss, Rodgers, & Dyck, 2004, p.35; Lehman & Steinwachs, PORT recommendations, 1998).

Family psychoeducation assumes that inaccurate information about schizophrenia and client’s symptomatic behaviour is held by families and subsequently, place an “emphasis on educating relatives about schizophrenia to the extent that some reviewers have subsumed all family intervention under the category ‘psychoeducation’” (Barrowclough, 2005, p.13).

The New Zealand Treatment Guide for Consumers and Carers in relation to Schizophrenia (Schizophrenia, 2007) explains psychoeducation as a therapy that provides education to clients and caregivers about the illness, in individual or group sessions which works to increase understanding of symptoms and available treatment and services.

Designed as a model to help families learn how to support the client, psychoeducation is today an umbrella term (Bertrando, 2006) representing a collective designation (usually within a standardised and empirically-based model) for an intervention which includes several different ways of combining the dissemination of information with therapeutic elements and is an internationally acknowledged term (Pitshel-Walz et al., 2001) which can even be found on the internet encyclopedia Wikipedia.

The term ‘psychoeducation’ can be misleading. As McFarlane and colleagues (McFarlane, Dixon, Lukens, & Luckstead, 2003) aptly put it “family education includes many cognitive, behavioural, and supportive therapeutic elements, often utilizes a consultative framework, and shares key characteristics with other types of family interventions (p.224). What this means is that at times it can be confused with other models of family intervention.

As with the fuller psychosocial interventions that were the topic of the previous section, there are a variety of different psychoeducational approaches (for reviews refer to Mari & Streiner, 1994; Penn & Mueser, 1996; Pharaoh et al., 2006; Pilling et al., 2002; Pitshel-Walz et al., 2001): lecture-based (Leff et al., 1982; Smith & Birchwood, 1987), video presentations (McFarlane et al., 1995; Smith, J., 1984), written pamphlets, work-shops (Anderson, Hogarty, & Reiss, 1981), multi-family groups (McFarlane et al., 1995; Smith, J., 1984), and individual

family groups (Falloon, Boyd, McGill, Razani, Moss, & Gilderman, 1982; Hogarty et al., 1991; Leff et al., 1982; Tarrier et al., 1988b). In New Zealand, information and education can be provided via support groups, videos, pamphlets, websites, meetings, workshops, early intervention services or through discussions with a case-manager or GP.

Psychoeducation programmes typically have a standardised approach (Pollio, Brower, & Galinsky, 2001), that combines elements of education, support, training in cognitive-behavioural strategies, problem solving and communication skills (Falloon et al., 1985), management and coping strategies, all designed to increase knowledge, skills, lower the emotional climate of the family home, increase coping, promote recovery and reduce relapse risk. The integral part of these programmes is the education component, where clients and family members are provided relevant information on diagnosis, symptomology, aetiology, treatment, and course of schizophrenia (Anderson, Hogarty, & Reiss, 1981; Falloon, Liberman, Lillie, & Vaughn, 1981), as well as information on the importance of self-care for family members, the provision of information on available formal and informal services (Pollio, 2000; Smith, Majeski, & McClenny, 1996) and information on how to support the recovery process (*Schizophrenia*, 2007).

The interventions focus on providing factual information about schizophrenia to the family. Based on an extensive review, the information provided tends to be similar across programmes. Despite minor variations, most approaches (Barrowclough et al., 1987; Berkowitz, Eberlein-Vries, Kuipers, & Leff, 1984; Falloon, 1985) provide information on the following common themes: 1) nature of schizophrenia, including symptoms, diagnosis, aetiology, and course of illness, 2) treatment, including medication, 3) prognosis and practical management advice, including about the interaction between family members and client, 4) additional information or strategies that can help, including available services, 5) reducing family members' sense of guilt and self blame, 6) encouraging realistic expectations regarding the future (Atkinson & Coia, 1995). Thus, the components of psychoeducation packages have much in common. They are brief, generally involving between 2-16 sessions (Barrowclough et al., 1987; Bauml, Frobose, Kraemer, Rentrop, & Pitschel-Walz, 2006; Berkowitz et al., 1984), each session usually one-two hours in duration (Falloon et al., 1985).

The information given is concise, and only the most relevant and helpful information is included (Tarrier & Barrowclough, 1986). Regardless of the specific programme, it tends to be provided in an interactive manner which allows opportunities for the participant to relate the

information to their own experiences and ask questions (Mueser & Jeste, 2008). This process has been recommended as research (Ley, 1979) has supported the idea that in doctor-patient type communications, only a small amount of information is remembered by recipients. To this end, many education programmes also provide easy-to-read summary pamphlets (Barrowclough et al., 1987; Smith & Birchwood, 1987).

Many clinical trials have demonstrated the superiority of the longer duration psychoeducational interventions in comparison to standard treatments (Penn & Mueser, 1996; Pharaoh, Rathbone, Mari, & Streiner, 2003; Pilling et al., 2002; Pitschel-Walz, Leucht, Bauml, Kissling, & Engel, 2001; Wiedemann, Klingberg, & Pitschel-Walz, 2003) in improving the short-term prognosis (and possibly long-term prognosis) of schizophrenia as measured by relapse (Anderson, Reiss, & Hogarty, 1986; Falloon et al., 1982; Leff, Berkowitz, Shavit, Strachan, Glass, & Vaughn, 1989; McFarlane et al., 1995; North, Pollio, Sacher, Hong, Isenberg, & Bufe, 1998; Tarrier, Barrowclough, Porceddu, & Kitzpatrick, 1994; Tarrier, Barrowclough, Vaughn, Bamrah, Porceddu, Watts, & Freeman, 1989). Differences between psychoeducation and standardised care can be encapsulated in the length of time between hospital admissions. At the two-year follow up, Leff et al. (1990; Leff & Berkowitz, 1996) found relapse rates over time for family intervention groups of 9.2 months for standard care, and 14.2 months for family intervention groups. The Mental Health Foundation of New Zealand states on its website that with medication and some form of support, 30% of people diagnosed with schizophrenia will relapse per year, but this falls to 15% when psychoeducation is combined with medication and support (“Schizophrenia”, 2008).

In addition to a reduced relapse rate (a narrow clinical definition of beneficial outcome), several studies have also demonstrated a number of other beneficial effects as summarised below:

- An improvement in knowledge about schizophrenia (Barrowclough et al., 1987; Bauml, Pitschel-Walz, & Kissling, 1996; Birchwood, Smith, & Cochrane, 1992; Cozolino et al., 1988; Fowler, 1992; Liberman, Wallace, Falloon, & Vaughn, 1981; Pakenham & Dadds, 1987; Pitschel-Walz 1997; Posner et al., 1992; Smith & Birchwood, 1987; McGill, Falloon, Boyd, & Wood-Silverio, 1983).
- A decrease in Expressed Emotion from high-EE to low-EE (Hogarty et al., 1986; Leff et al., 1982; MacCarthy, Kuipers, Hurry, Harper, & LeSage, 1989; Randolph, Eth, Glyn, Paz, Leong, Shaner, et al., 1994; Rund, Moe, Sollien, Fjell, Borchgrevink,

Hallert, & Ness, 1994; Snyder & Liberman, 1981; Tarrier et al., 1988b; Vaughn et al., 1992).

- Better medication compliance (Bauml et al., 1996; Falloon et al., 1982; Goldstein, 1994; Mari & Streiner, 1994; McFarlane et al., 1995; Xiang, Ran, & Li, 1994; Zhang, Wang, & Phillips, 1994).
- Reduced psychiatric symptoms (Leff et al., 1982; Tarrier et al., 1988b).
- Improved client social adjustment (Anderson et al., 1986; Barrowclough & Tarrier, 1992; Bauml et al., 1996; Falloon et al., 1985; Falloon, McGill, Boyd, & Pederson, 1987; Hogarty et al., 1991; Leff et al., 1985; Tarrier et al., 1988b, 1989; Vaughn et al., 1992; Xiang et al., 1994).
- Improved social and family adjustment for the caregiver (Leff et al., 1982; Levene, Newman, & Jeffries, 1989; McFarlane, Dunne, Lukens, Deakins, Newmark, et al., 1993; McFarlane et al., 1995).
- A decrease in family burden and increase in coping (Abramowitz & Coursey, 1989; Birchwood et al., 1992; Lam, 1991; McFarlane et al., 1995; Pakenham & Dadds, 1987; Pollio, North, & Osborne, 2002; Solomon, 1996; Solomon & Draine, 1995; Zastowny, Lehman, Cole, & Kane, 1992).

McFarlane et al. (1995) found that after participating in a psychoeducation programme, family members' mental health and global functional knowledge about schizophrenia increased significantly, as did communications between family members and client, EE was reduced and expectations were lowered. Improvements were also seen in client's personal functioning and social adjustment.

The psychoeducational model has potential to empower families with knowledge and basic skills, which in turn better enables them to cope with the client's symptomatic behaviour as well as the daily frustrations and burdens of caring for someone diagnosed with schizophrenia. Given the potential in these programmes, a "current concern" in the field revolves around whether these programmes can be usefully transported to more routine care settings while at the same time be subjected to rigorous empirical scrutiny.



## Use in Routine Care

A number of psychosocial interventions for problems linked to schizophrenia have been shown to be successful and efficacious, but despite their effectiveness, their use is not yet widespread in clinical practice (Gamble & Brennan, 2000, McFarlane et al., 1993). It was 1984 when Kuipers and Bebbington first concluded that “family intervention as a treatment modality in schizophrenia should move from the research environment to influence clinical practice” (Anderson & Adams, 1996, p.505) Yet two decades later the availability of these interventions in routine clinical practice and the community is uncommon (Beebe, 2007; Fadden, 1998; Magliano et al., 2006; McFarlane, McNary, Dixon, Hornby, & Cimett, 2001; Sartorius et al., 2005) and research on the effectiveness of psychoeducation interventions in “real-world settings” is sparse (Barrowclough, Tarrier, & Lewis et al., 1999; Cardin, McGill & Falloon, 1985; Magliano, Fiorillo, Fadden, Gair, Economou, Kallert, et al., 2005; Magliano et al., 2006; Mak, Wong, & Ma, 1997; Rund et al., 1994).

There are many reasons suggested for why dissemination is not more widespread. The programmes, although comprehensive, can be extremely lengthy, and may not be applicable to the clinical or real-world settings where time is often at a premium, and resources are often over-booked. It can be difficult to source qualified providers of such a service (Beebe, 2007), there is limited training and supervision available (Beebe, 2007; Magliano et al., 2006), there may be difficulty in disseminating such a service into the mental health services available due to the way they are configured (McFarlane et al., 2003; Magliano et al., 2006; Sartorius et al., 2005). Families themselves can also be reluctant to participate in a family intervention. For example, Barrowclough and colleagues (Barrowclough, Tarrier, Lewis, Sellwood, Mainwaring, & Quinn, 1999) found that only 50% of carers participated in a family intervention when it was made available to them. It has been suggested that “family intervention still attracts hostility from families who see it as blaming them for the illness or its exacerbation” (Hemsley & Murray, 2000, p.2) and that some family members have little contact with their ill relative due to the emotional, physical and/or financial toll it has taken on them (Woo & Keatinge, 2008).

One possible way to overcome some of these problems is to deliver brief educational programmes in settings where clients and carers can be made to feel comfortable and where the time commitment is not seen as overly onerous. Tarrier and Barrowclough (1986) suggested that a brief education component might be quite easily integrated as a short-term programme in community settings. If done, the introduction of such interventions into routine mental health services or community support settings would of course need the full support of policymakers,

area mental health managers and senior clinicians to increase the likelihood that they are offered in a comprehensive and effective manner (Mihalopoulos, Magnus, Carter, & Vos, 2004). However, prior to such a move, this policy direction needs to be assisted by research findings that test whether the delivery of these programmes in day-to-day settings can be effective.

### **Brief Education Interventions**

As introduced in the previous section, a significant drawback for families to many types of psychoeducation is the long-term commitment required (Smith & Birchwood, 1990). The difficulties family members experience trying to cope with caregiving for someone with mental illness whilst still working and maintaining other family commitments as well as possible prior negative experiences with mental health services may make families reluctant to commit to a lengthy intervention.

In a 1991 review (Lam, 1991), the efficacy of brief and standard educational interventions in schizophrenia were reviewed, resulting in Lam's suggestion that apart from gains in knowledge and, in some studies, an alleviation of family members' burden and distress, brief education programmes had no real beneficial effects when not part of a larger psychoeducational intervention. This is a view generally agreed upon by researchers who have emphasised the idea that brief education programmes have been shown to have no appreciable impact on relapse (Reilly, Rohrbaugh, & Lackner, 1988; Silverstein et al., 2006; Tarrier et al., 1988a; Vaughn, 1989). On the other hand, Tarrier et al. (1988a) have focused on a wider array of potential benefits and suggest that an education programme may have enough benefits to make it a worthwhile effort. McGill et al. (1983) agreed with this view, stating that "family members can effectively enhance their knowledge of this illness by participating in a brief educational intervention...and that such knowledge results in better understanding" (Tarrier & Barrowclough, 1986, p.459). Thus, while perhaps not impacting on relapse (Barrowclough & Tarrier, 1992; Pitschel-Waltz et al., 2001; Silverstein, et al., 2006), these programmes in fact may be quite useful for engaging the family in treatment and helping them to conceptualise the illness and its problems from a stress-vulnerability framework (Moxon, 2008; see also Barrowclough et al., 1987).

If one then broadens the definition of ‘beneficial effect’ from reduction in relapse to an increase in knowledge, skills, understanding and engagement, evaluations of brief family education programmes (1 to 8 sessions) have reported supportive findings including increases in knowledge about schizophrenia and the treatment and recovery process, improved coping, reduced distress and self-blame, and increased satisfaction with services (Abramowitz & Coursey, 1989; Posner, Wilson, Kral, Lander et al., 1992). Such findings support a role for brief psychoeducation programmes as being a conduit through which to provide clients and families with useful support (Gleeson, Jackson, Stavely, & Burnett, 1999). Related to the current study, this would also include a safe forum through which clients and families can have their concerns heard and be provided with potentially helpful strategies for coping.

To illustrate the potential of some of these shorter duration programmes, Cassidy, Hill and O’Callaghan (2001) conducted an 8 week psychoeducational programme with 55 clients and their 101 family members. They found that after this brief programme, family members’ knowledge about the illness increased and concluded that such a programme informs and assists the family members and clients to recognise early signs of relapse, manage a relapse in a more empowered and less traumatic fashion for all involved and may help to foster a stronger and more supportive alliance with their mental health service.

An Australian brief multiple-family group psychoeducational study with clients experiencing first episode psychosis also had beneficial results (Mullen, Murray, & Happell, 2002). They conducted an education programme of 4 two-hour sessions running one night a week for 4 weeks. Approximately 24 participants began the programme and 15 completed each session with the researchers not gathering identifying data about whether participants were clients or family members, although clients were encouraged to attend. They found similar results to Linszen, Dingemans, Ven der Does, Nugter, Scholte, Lenior and Goldstein (1996) in that the brief intervention was found to lead to increased awareness and understanding of mental illness, how it develops and the role stress plays in mental illness. Based on these findings, they concluded that brief programmes are ‘highly suitable’ for family members of those experiencing first episode psychosis. A number of limitations reduces the strength of this conclusion. The sample was small, attendance by some participants was sporadic, demographic information was not sufficiently gathered and there was no delineation between clients and family members. This study also did not test for distress, burden of care or an improvement in coping strategies and use, all constructs which Linszen et al. (1996) suggest should be targets in these type of interventions.

Research has also examined programmes that are more brief than those reviewed to this point. In their research Barrowclough and Tarrier (1992) describe a collaborative approach underpinning their two session intervention. That is, to promote gains over such a brief intervention, they suggested that “an understanding of the relatives’ beliefs and attitudes about the illness in general and the symptoms of the client in particular is a necessary precondition to establishing an interactive mode of information presentation rather than delivering a lecture about schizophrenia” (cited in Atkinson & Coia, 1995, p.76). Thus, in their two session education programme<sup>4</sup> (1987), information is gathered and assessed at the outset of the first education session using the Knowledge About Schizophrenia Interview (KASI; Tarrier & Barrowclough, 1992) which reflects six core and separate areas of schizophrenia: Diagnosis, Symptomology, Aetiology, Medication, Prognosis, and Management.

Information conveyed in the programme is then structured around family members’ knowledge, beliefs and misconceptions about the illness. Specific attention is paid to the assimilation of knowledge, notably where family member beliefs are contradicted by new information. The KASI is re-administrated at the close of the second session after any questions participants may have had are answered with both family members and client seen together. This helps assess change and “where further attitude or belief change will be important, since it is unlikely that family members, particularly those where patient’s have a long history of illness, will change all their views after a brief education component” (Barrowclough & Tarrier, 1992, cited in Atkinson & Coia, 1995, p.77). Through the use of a single group pre-test post-test design, they found that this brief education intervention was successful in improving family members’ knowledge which might be used in the home environment to support clients. However, they also concluded that brief education is limited as they found their intervention did not affect relapse rates. In addition, in this study and other research of this type (Birchwood et al., 1992; MacPherson, Jerrom, & Hughes, 1996; Mullen et al., 2002; Pollio, North, Reid, Miletic, & McCleadon, 2006; Reilly et al., 1988), methodological shortcomings (including lack of a control group, randomisation and use of single group pre-test post-test designs) limit conclusions. This study was also limited in terms of ecological validity as it was not carried out in a community setting.

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<sup>4</sup> This educational intervention was part of the larger Salford Family Intervention Project (Tarrier, Barrowclough, Vaughn, et al., 1988) which evaluated their brief two session educational intervention against two versions of a nine-month behavioural family intervention.

In following a number of the ideas of Barrowclough and Tarrier et al. (1987) brief intervention approach, Moxon and Ronan (2008) carried out a similar study in New Zealand for those with schizophrenia and their families for the author's Masters thesis. One of the intentions of this study was to improve on aspects of the previous study through the introduction and use of randomised, controlled trial. Another improvement was to carry it out through a community support setting. The study recruited 19 clients and 20 key family members through two regional branches of Schizophrenia Fellowship and provided a 2 session education programme. The first session attended by clients and family members separately, consisted of providing information on diagnosis, symptomology, etiology, medication, course and prognosis of schizophrenia, management and coping strategies and optional relaxation training. The second session conducted 2 weeks later brought the key family member and client together to allow time for questions, feedback and a summary. Results included a significant increase in knowledge post-intervention which was maintained at the three-month follow-up with no changes following the control condition, significant reductions in EE in both the client and family member groups that were largely a function of intervention and which were also maintained at the three-month follow-up (with a further decrease in family members' attitudes toward illness). However, this study did not report on formal relapse rates though reports suggested that it assisted (with only one report of relapse over a nine month interval following intervention, see Moxon, 1998). This study also did not evaluate a number of key instrumental outcomes, including family members' burden of care, distress and coping ability. Additionally, the intervention itself included an optional relaxation exercise, taken up by some and not by others. While that reflects a flexibility of intervention approach on the one hand, it also reflects a lack of stringency with respect to the application of the independent variable. On the other hand, the intervention itself was carried out without using Tarrier and Barrowclough's recommendation to use findings on the KASI to individualise and inform intervention. Finally, gains in EE were not only a function of intervention, modest gains were also seen across the wait-list, to the extent that it could not be concluded that changes in EE were due exclusively to the intervention. Given such findings overall, future research is needed to replicate and extend this research. Some minimal needs include the following: assessment and reporting of relapse rates, use of a wider array of outcome variables including distress, burden of care and coping, use of a follow-up interval longer than 3 months, application of the intervention in an increasingly standardised, and individualised, fashion and, as a consequence of that application, testing of whether the intervention itself can produce significant benefits compared to the control condition on EE and other indicators.

## **THE PRESENT RESEARCH: AIMS AND HYPOTHESES**

In an attempt to replicate and extend previous research, the present study conducted a brief psychoeducational intervention applicable to routine care settings which aimed to enhance family members' knowledge about schizophrenia and Expressed Emotion resulting in a reduction in EE, burden of care and distress as well as an increase in perceived ability to cope.

With a larger sample base gathered from a number of different cities and through various regional branches of two different support organisations in New Zealand, the present study attempted to rectify methodological shortcomings found in earlier research. As introduced in the previous section, these improvements included the retention of a RCT design, a larger battery of outcome indicators including distress, burden of care and coping ability, an increased collection of demographic information such as the amount of support sourced through each agency on a regular basis, a reduction in face-to-face contact hours required between clients and family members to participate in the study from 35 to 20 hours, a longer follow-up period of 9-months and improvements to the intervention itself. These included the replacement of the follow-up feedback/questions session with clients and family members together with a follow-up phone call to each participant asking if they had spoken with their family member and if they had any questions from the education session and an extended wait-list control period of up to two weeks longer than the previous intervention. It also included a more standardised and individualised approach, involving removing the optional relaxation exercise, instead replacing it with a discussion and description of different relaxation strategies as part of the coping strategy component delivered to all participants within the second half of the intervention. The education programme itself was delivered in a more flexible manner to allow a more individualised approach based on pre-test information. This flexibility allowed the author/educator to assist each participant to identify their preferred methods of coping and relaxation as well as limited problem solving and the provision of practical management strategies based on identified issues. Also, and unusually for brief education, but based on feedback from participants in previous research (Moxon & Ronan, 2008), the intervention was constructed to allow each participant to receive the education separately. In addition, previous research as articulated in the literature review has tended to focus on longer duration interventions which are typically, but not always, conducted in hospital settings. The present study deviated from this trend and, as in Moxon and Ronan, conducted the study and the intervention itself in community settings. Additionally, these community settings were more diverse than in the previous study, both in terms of another agency being involved and an

increased number of community support settings being involved that were also across a wider geographic spread.

Overall, it was hypothesised that the provision of brief education about the illness and its management would alter the knowledge and related attributions that family members make about the causality of the client's unusual, difficult or socially withdrawn behaviour. Alongside these changes, it was hypothesised that an increase in understanding and tolerance would also occur reflected in a reduction in criticism, hostility, emotional overinvolvement, distress, and burden of care compared to a randomly assigned wait-list control condition. It was also expected that providing knowledge about the illness and its course would give family members a sense of hope and mastery about the situation which would allow them to begin to understand and accept the illness and assist them to develop a more supportive and realistic expectations. These improvements in turn were then expected to contribute to the client's adjustment, all of which would then be reflected in low rates of relapse across a nine-month follow-up interval.

# Chapter 2

## Method

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## **DESIGN**

A mixed factorial, randomized controlled design was used in the present study. The family units were randomly allocated using a computer generated programme to either the experimental or wait-list control group. This was done to raise the probability that each group contained a random mixture of families high and low in Expressed Emotion (EE) as well as random allocation on demographics and other variables.

As will be described in the following sections, in addition to the two main groups of experimental and wait-list control in the present study, the sample has at different stages of the analyses also been further subdivided into the following groups: high-EE families versus low-EE families (based on a median split) and family members versus clients.

## **PARTICIPANTS**

Clients were aged 17-65 and met the following inclusionary criteria:

- had a diagnosis of schizophrenia according to DSM-IV which could be confirmed by the agency with which they were affiliated;
- provided informed consent to participate in the education programme and have a family member agree to participate in the education programme;
- were on prescribed, psychiatric medication which was taken as prescribed;
- had no evidence of an organic brain syndrome or substance use-induced condition which would explain the psychopathology as confirmed by their medical records held by the community agency they belonged to.

A key family member (or members) was also included in the study if they met the following criteria:

- gave informed consent;
- resided with or spent more than 20 hours of face-to-face contact a week with the client.<sup>5</sup>

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<sup>5</sup> Previous research (Moxon & Ronan, 2008) was based on 35 hours of face-to-face contact but it was found in the preliminary stages of the present research that the majority of families were not spending 35 hours a week with the

- the family members were nominated by the client as the people who were seen to be the most influential and important people in their lives as well as the main provider of emotional support on a regular basis.

The identification of the key family member/s was made independently by the client. As a consequence, in a few cases ( $n = 3$ ), they were not biological family members.

It is worth noting that less than one sixth of those initially contacted eventually participated in the study. That is, 143 clients who met the inclusionary criteria were approached and 22 (15%) agreed to participate. This was for a variety of reasons, with the most predominant being: the client was disinclined to participate ( $n = 45$ ), the client was not taking psychiatric medication as prescribed ( $n = 14$ ), the client wanted to participate but their family members did not ( $n = 38$ ) amongst other reasons ( $n = 24$ ).

As summarised in Table 1, 14 of the 22 participating clients were male (64%). The client's average age across both sexes was 27.95 years ( $SD = 5.68$ ) and the range was 20-43 years. All 22 clients identified themselves as New Zealanders despite being given the option of identifying themselves as various cultures residing in New Zealand. The majority of clients came from Palmerston North ( $n = 12$ ) with 1 from Timaru, 2 from Wellington, 3 from Blenheim and 4 from Christchurch. Twelve clients were living in the family home, 3 were flatting with others, 2 were living by themselves and 5 were residing in supported accommodation. Of the client sample, 16 listed High School as their highest education, 3 Polytechnic, 1 University and 2 an Apprenticeship. Sixteen clients were unemployed at the time of the intervention, 1 was a student, 1 was self-employed, 2 were employed and 2 listed volunteer work as their vocation. Nineteen clients listed themselves as single, 2 as married and 1 listed themselves as 'other'.

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individual diagnosed with schizophrenia. The criterion was dropped to 20 hours to maximise the number of potential participants.

**Table 1: Demographic Information of Clients**

<b>Characteristics of Clients (n = 22)</b>		
<b>14 Male</b>	<b>8 Female</b>	
<b>Age in Years:</b>		
<b>Mean</b>	27.95	<b>SD = 5.68</b>
<b>Median</b>	27.50	
<b>Range</b>	20-43	
<b>Ethnicity Identified with:</b>		
<b>New Zealander</b>	22	
<b>City of Residence:</b>		
<b>Palmerston North</b>	12	
<b>Timaru</b>	1	
<b>Christchurch</b>	4	
<b>Blenheim</b>	3	
<b>Wellington</b>	2	
<b>Research Condition:</b>		
<b>Experimental</b>	10	
<b>Wait-list control</b>	12	
<b>Expressed Emotion Level:</b>		
<b>Low EE</b>	10	
<b>High EE</b>	12	
<b>Where Client Residing:</b>		
<b>Home with family</b>	12	
<b>Flatting with others</b>	3	
<b>Flatting with self</b>	2	
<b>Supported accommodation</b>	5	
<b>Education Level of Client:</b>		
<b>High school</b>	16	
<b>Polytechnic</b>	3	
<b>University</b>	1	
<b>Trade/Apprenticeship</b>	2	
<b>Employment Status of Client:</b>		
<b>Student</b>	1	
<b>Unemployed</b>	16	
<b>Self-employed</b>	1	
<b>Employed</b>	2	
<b>Volunteer</b>	2	
<b>Marital Status of Client:</b>		
<b>Single</b>	19	
<b>Married</b>	2	
<b>Other</b>	1	

In contrast as summarised in Table 2, in the family member sample, initially 30 agreed to participate. However, after signing consent forms, two dropped out leaving n = 28 who participated in assessment and the intervention. The majority of participants were female at 71% (20 out of 28) and the overall mean age was 51.66 ( $SD = 8.99$ ) with a range of 25-65 years. Twenty-four family members were parents, of whom 17 were mothers, one was a sibling, one a spouse and two were friends/staff members. Like client participants, all 28 family members identified themselves as New Zealanders despite being given the option of identifying

themselves as various cultures residing in New Zealand. The majority of family members came from Palmerston North (n = 16), with one from Timaru, six from Christchurch, three from Blenheim and two from Wellington. Of the family member sample, 16 listed High School as their highest education, two Polytechnic, seven University and three an Apprenticeship/Trade. Two family members were unemployed at the time of intervention, six were self-employed, 19 employed and one listed volunteer work as their vocation.

**Table 2: Demographic Information of Family Members**

<b>Characteristics of Family Members (n = 28)</b>		
<b>8 Male</b>	<b>20 Female</b>	
<b>Age in Years:</b>		
<b>Mean</b>	51.68	<b>SD = 8.99</b>
<b>Median</b>	53	
<b>Range</b>	25 – 65	
<b>Ethnicity Identified with:</b>		
<b>New Zealander</b>	28	
<b>City of Residence:</b>		
<b>Palmerston North</b>	16	
<b>Timaru</b>	1	
<b>Christchurch</b>	6	
<b>Blenheim</b>	3	
<b>Wellington</b>	2	
<b>Research Condition:</b>		
<b>Experimental</b>	13	
<b>Wait-list control</b>	15	
<b>Expressed Emotion Level:</b>		
<b>Low EE</b>	13	
<b>High EE</b>	15	
<b>Relationship with Client:</b>		
<b>Mother</b>	17	
<b>Father</b>	7	
<b>Sibling</b>	1	
<b>Spouse</b>	1	
<b>Friend</b>	2	
<b>Education Level of Family Member:</b>		
<b>High school</b>	16	
<b>Polytechnic</b>	2	
<b>University</b>	7	
<b>Trade/Apprenticeship</b>	3	
<b>Employment Status of Family Member:</b>		
<b>Unemployed</b>	2	
<b>Self-employed</b>	6	
<b>Employed</b>	19	
<b>Volunteer</b>	1	

In summary, 16 clients had only one family member participate in the research, six had more than one family member participate, and no clients had more than two family members participate. Ten clients (and their 13 family members) were randomly allocated to the experimental group with 12 clients (and their 15 family members) randomly allocated to the wait-list control group.

Tables 3 and 4 show the agency the participant received support from, as well as the amount and type of support accessed on a regular basis (information gathered at the outset of the study in the Patient and Family History Interview).

**Table 3: Support Accessed by Clients**

<b>Support Accessed by Clients (n = 22)</b>	
<b>Previous Education on Schizophrenia:</b>	
Yes	2
No	20
<b>Agency of Support:</b>	
Schizophrenia Fellowship	18
Richmond Fellowship	4
<b>Length of Support in Years:</b>	
Mean	3.32
Median	3
Range	0 – 10 <b>SD = 2.48</b>
<b>Support Accessed:</b>	
2x weekly	6
Weekly	10
Fortnightly	6
Monthly	0
6 monthly plus	0
<b>Main Form of Support:</b>	
Face-to-face	22
Phone contact	
Other	

**Table 4: Support Accessed by Family members**

<b>Support Accessed by Family Members (n = 28)</b>	
<b>Previous Education on Schizophrenia:</b>	
Yes	12
No	16
<b>Agency of Support:</b>	
Schizophrenia Fellowship	22
Richmond Fellowship	6
<b>Length of Support:</b>	
Mean	3.00
Median	2
Range	0 –10 <i>SD = 2.43</i>
<b>Support Accessed:</b>	
2x weekly	4
Weekly	1
Fortnightly	2
Monthly	12
6 monthly plus	9
<b>Main Form of Support:</b>	
Face-to-face	13
Phone contact	14
Other	1

Table 5 shows the composition of the respective households which are represented here by one family member and one client for all but six households which are represented by two family members each, and one household represented by two clients. Of those who were included in the study, no participants later refused to complete any of the measures.

**Table 5: Composition of family households – Family members participating**

Households	<u>High-EE</u>		<u>Low-EE</u>	
	Experimental	Control	Experimental	Control
<b>Mother</b>	3	6	5	3
<b>Father</b>	2	1	2	2
<b>Sibling</b>	1			
<b>Spouse</b>		1		
<b>Staff</b>		1		1
<b>TOTAL</b>	<b>6</b>	<b>9</b>	<b>7</b>	<b>6</b>

Overall, across clients and family members, the experimental group contained a total of 23 participants (10 clients, and 13 family members) and the wait-list control group contained a total of 27 participants (12 clients, and 15 family members). The expressed emotion rating for a household, as earlier described was determined by the key family member as is conventional practice (Weardon et al., 2000). However, the present study also measured clients' assessment of their perception of family members' EE levels, as is possible with the self-report EE instrument used in the current study and described in the next section.

## ASSESSMENT

After receiving training on the assessments from the researcher, independent assessors (Schizophrenia Fellowship fieldworkers or Richmond Fellowship key-workers) carried out a multi-method assessment at each of the assessment intervals, prior to treatment, immediately following the intervention or control period and again at 9 month follow-up. In addition to multi-method measurement of the main dependent variables at 9 month follow-up, relapse rates during that interval were also assessed. For the initial assessment, family members were interviewed shortly after clients in either their own homes or at the local branch of S.F. or R.F. based on their wishes.

The dependent variables in the present study were the knowledge about schizophrenia held by the family members, as measured by the Knowledge About Schizophrenia Interview (KASI; Barrowclough et al., 1987), the level of Expressed Emotion, as measured by the Level of Expressed Emotion Scale (LEE; Cole & Kazarian, 1988) and burden of care, distress and coping as measured by the Family Questionnaire (FQ; Barrowclough & Tarrier, 1992). The independent variable was the psychoeducational programme. Demographic information as well



as information about type and frequency of support accessed from S.F. or R.F. and other relevant factors was also collected.

Relapse as defined by the re-emergence of major symptoms resulting in a psychiatric hospital admission was also assessed at the 9-month follow-up. The researcher stayed in regular phone and email contact with each of the key-workers and field-workers who were working with the participants to ascertain if this occurred.

### **Patient and Family History Interview**

This structured intake form was designed by the researcher to collect demographic information as reported in the previous section, information about the predominant type of support family members receive (such as face-to-face support or phone contact) as well as the frequency of support accessed from S.F. or R.F and other relevant factors, including the length of involvement with the agency (Refer to Appendix 3).

### **The Knowledge about Schizophrenia Interview (KASI)**

The KASI (Barrowclough et al., 1987) was designed to assess and evaluate knowledge, beliefs and attitudes about six broad aspects of schizophrenia (Diagnosis, Symptomology, Aetiology, Medication, Course and Prognosis and Management), and the effects of that information on family member's behaviour. It takes up to 30 minutes to complete, depending on the length of response and the structuring of the interview. Most questions require a single word answer or a "Yes/No/Don't know" choice, but the final section on Management additionally contains two open-ended sections.

Each section is scored on a 4-point scale (1-4; Barrowclough & Tarrier, 1992). A score of 1 equals a negative value in that the family member gives information which if acted upon may be detrimental to the client. A score of 2 equals a neutral value in that the family member knows little relevant information but gives no information that if acted upon may be detrimental to the client. A score of 3 equals positive value in that the family member gives information which if acted upon may be beneficial to the client. A score of 4 equals positive value in that in addition to information provided for a score of 3, the family member has shown a wider knowledge and understanding of the assessed aspect of schizophrenia. This allows family

members' responses to be assessed in terms of how helpful, neutral or possibly detrimental, their beliefs and attitudes about schizophrenia are likely to be to the management of the illness and support of the client (Barrowclough et al., 1987). The KASI has acceptable psychometric properties including reliability, validity and treatment sensitivity (e.g., Barrowclough & Tarrier, 1992; Moxon & Ronan, 2008).

Interviews were audio taped for reliability purposes. The researcher scored all interviews and five interviews were randomly selected and scored by an independent rater not affiliated with this study (a trained psychologist) for reliability calculations. In all instances, this measure was administered before the LEE and FQ to avoid contamination by later questions and responses to the other measures.

### ***The Level of Expressed Emotion (LEE): Patient and Relative Versions***

Although the Camberwell Family Interview (CFI) has been consistently shown to be the superior instrument for assessing EE (Gerlsma & Hale, 1997; Van Humbeeck, Van Audenhove, De Hert, Pieters, & Storms, 2002), the administration and scoring process is lengthy and requires in-depth training and administration (Startup, 1999). A particular disadvantage of the CFI, pertinent to this study, is that while it is used in research settings, it is not easily used in routine clinical practice or in community settings (Cole & Kazarian, 1992).

The LEE was developed to measure the “perceived emotional climate of social environments” (Cole & Kazarian, 1992, p216) and was specifically designed as a measure for the 1) client to assess the level of EE in an identified family member, and 2) a self-report measure for family members to reflect their levels of EE. These two versions of the LEE are intended to provide a more comprehensive, multi-informant measurement of the affective environment in the family. In the case of the non-biological family members, instructions are altered to measure the environment in which the client spends 20 or more hours a week of face-to-face contact with an identified person.

The LEE contains 60 true/false items, which are broken into four subscales, reflecting the components of the EE construct (Vaughn & Leff, 1981). These are: Intrusiveness, Emotional

Response, Attitude toward Illness and, Tolerance/Expectations. In addition to the four subscale scores, a total score is also rendered, with a higher score denoting higher levels of EE.

Kazarian and colleagues (Kazarian, Cole, Malla, & Baker, 1990) investigated the comparison of the LEE scores with the CFI ratings and found that for total scores, the relationship between the two measures was encouraging, that the 4 scales have high internal consistency, and good temporal stability (Cole & Kazarian, 1988). It has been further found that total LEE score and the Intrusiveness scale do predict re-hospitalisation (Cole & Kazarian, 1988). As a consequence, given the setting, the aims of the study, and the multi-informant versions of the measure, the LEE was chosen for the present study as a preferable, everyday alternative to the CFI.

In terms of more specific psychometric qualities, the sub-scales have been shown to possess internal consistency (KR-20 = .84-.95) and temporal stability (Pearson  $r = .67-.82$ ) over a six-week time frame (Cole & Kazarian, 1988). Three separate studies have demonstrated predictive validity of the LEE. It has also been demonstrated to have construct validity, independent from effects due to sex, age, or face-to-face contact hours (Cole & Kazarian, 1988). In the current study, the Cronbach alpha coefficient for the client LEE total score was .92 demonstrating good internal consistency with the following coefficients found for subscales: Intrusiveness .85; Emotional Response .80; Attitude toward Illness .81; Tolerance/Expectations .76.

The Cronbach alpha coefficient for the family members LEE total score was .81 demonstrating good internal consistency with the following coefficients found for subscales: Intrusiveness .74; Emotional Response .66; Attitude toward Illness .63; Tolerance/Expectations .51.

The scores of the two different versions have also been demonstrated to correlate well with the corresponding ratings of the CFI (Kazarian et al., 1990). Finally, the LEE has been found to be sensitive to psychoeducational intervention, particularly the Attitude toward Illness subscale (Moxon & Ronan, 2008).

### **The Family Questionnaire (FQ)**

The Family Questionnaire (Appendix 6; Barrowclough & Tarrier, 1992) is a checklist of client-focused problems specifically targeted to those associated with clients diagnosed with schizophrenia. It was designed for use in cognitive behavioural interventions with families of those diagnosed with schizophrenia (Barrowclough et al., 1987).

The FQ is used clinically to identify specific areas of symptomology or behaviour that the family members may be having difficulty coping with. The checklist is also useful for validating information covered in the KASI interview and in assessing what the family member perceives to be the main problems. It can also be used as a follow-up measure to evaluate progress and outcomes in the three areas of burden of care, distress and coping (Barrowclough & Tarrier, 1992).

The present research utilized the early version (Barrowclough & Tarrier, 1992); where forty-nine problems are described with one open 'other' category to allow for identification of any idiosyncratic difficulties. The family member is requested to indicate on three 5-point scales the frequency with which the behaviours occur (1= never – 5= always); the amount of distress the behaviours cause them (1= not at all – 5= considerably); and how well they feel able to cope with the behaviour (1= not at all – 5= as well as possible).

A later version was developed (Quinn et al., 2003) which narrowed the list of symptoms down to 45 and the likert scales from 5-point scales down to 3-point scales of never/rarely, sometimes and often. This version has demonstrated good psychometric properties (2003) but the present study began before the psychometric properties were published. Hence, the current study used the original 49 question scale and 5-point likert response format. Scoring in the original (1992) version is accomplished simply by adding up the points for each of the three dimensions to obtain three individual scores of between 1-49. By computing each of these scores, it can be seen how often the family member believes problems occur, how much the family member feels bothered or distressed by the problems and to what extent the family member feels able to cope with the problems. In the current study, the Cronbach alpha coefficient was found to be .92 for the Frequency scale, .95 for the Bother scale, and .95 for the Control scale.

## **PROCEDURE**

This research was approved by the Massey University Regional Human Ethics Committee, and was found to be consistent with the principles outlined in an internationally recognized standard for the ethical conduct of human research (citation number 02/10). Following this approval, the National offices of Schizophrenia Fellowship (S.F.) and Richmond Fellowship (R.F.) were approached by the author to discuss the present research. Both agencies gave permission for the author to approach individual branches of their organisations in New Zealand to ascertain whether they were interested in being involved in the study. Once a branch agreed, key-workers employed in each agency branch then approached members of the organization and invited them to voluntarily participate if they met the criteria outlined in the participants section.

Key-workers at Richmond Fellowship<sup>6</sup> branches around New Zealand who were trained by the author on the contact and assessment protocol contacted clients (those diagnosed with schizophrenia) who met the predetermined inclusion criteria and who were living or in close contact (20 hours or more a week) with a key family member for at least 3 months prior to the study. They discussed the study, explained what commitments would be involved in participating and what possible benefits they might obtain from participating. Once clients confirmed a willingness to participate in the study, permission was then obtained to contact the nominated key family member of each client. Key-workers then discussed the study with the family members, explained what would be involved in participating, and they were also invited to participate. Information sheets (Appendix 1) were disseminated to clients and family members as well as consent forms (Appendix 2) to enable the family to take time to consider and discuss their potential involvement. The key-worker later followed up with the participants to confirm continuing interest and obtain informed consent of both a client and corresponding key family member were committed. Contact details for the researcher were provided for any further questions participants may have had.

Richmond Fellowship and Schizophrenia Fellowship have a different focus in that Richmond Fellowship predominantly supports clients in a residential setting and Schizophrenia Fellowship as an agency of support and advocacy, predominantly supports family members. For

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<sup>6</sup> Rehabilitative residential accommodation for adults diagnosed with mental illness.

this reason, a slightly different procedure was utilised for Schizophrenia Fellowship in recruiting participants.

Fieldworkers at Schizophrenia Fellowship<sup>7</sup> branches around New Zealand contacted family members who met the predetermined inclusion criteria and who were living or in close contact (20 hours or more a week) with a client for at least 3 months prior to the study. They discussed the study, explained what commitments would be involved in participating and what possible benefits they might obtain from participating. Once family members confirmed a willingness to participate in the study, permission was obtained to contact the client. Field workers then discussed the study with the client, explained what would be involved in participating, and invited them to participate. Information sheets (Appendix 1) were then disseminated to clients and family members as well as consent forms (Appendix2) to enable the family to take time to consider and discuss their potential involvement. The fieldworker then followed up with the participants to confirm continuing interest and obtain informed consent. Contact details for the researcher were provided for any further questions participants may have had.

After obtaining informed consent from clients and family members, an appointment was made for the family member and client separately to complete the pre-test measures and further appointments were made separately to attend the education session. This separate completion and attendance was done as a result of client concerns voiced in a previous study (Moxon & Ronan, 2008) and confirmed here that they would feel “too self-conscious” or “on guard” to be able to actively participate in the education sessions if their key family member was present (discussed in more depth further in this section). Concern was also expressed by clients that the family members may judge them during the session or become embarrassed themselves which would inhibit the ability to participate freely in the session.

Based on this idea then, the actual education programme itself has two subtly but distinct versions for clients and family members (refer to the Education Programme section). For the purpose of the education session, participants were treated as either families of those with schizophrenia (family members) or as family members diagnosed with schizophrenia (clients) and were provided the appropriately corresponding education. The summary hand-out remained identical for both family members and clients.

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<sup>7</sup> During the completion of this thesis, Schizophrenia Fellowship was renamed Supporting Families as supporting the families of those diagnosed is their primary focus.

The amount of time between pre-assessment, the education session, a follow-up phone call and post-assessment for the experimental and control group was equivalent at 7-10 days between each session. In this way, the present study was based on Barrowclough et al. (1987) and Moxon and Ronan (2008) who had a one week and 7-10 day interval between assessments, respectively. The reasons for the approximately one week interval between each session were as follows:

- Family members sometimes became anxious or misunderstood the information they were exposed to either during the informed consent process or pre-test assessment. An early second appointment for assessment allowed an opportunity to discuss any confusion that had occurred.
- KASI assessment was thought to be more likely to assess longer term information assimilation and retention than if it were administered immediately after the education session.
- This interval after the intervention allowed family members and clients' time to discuss the information, whether separately or together and to read the booklet.
- The interval wasn't so long that it minimised the possibility of various confounds impacting on assessment responding, including maturation, history and so forth: "The possibility of the outcome evaluation (KASI post-test) being affected by factors other than the education programme was minimised" (Barrowclough et al., 1987, p3).

The education programme itself (Moxon & Ronan, 2002) was administered by the researcher<sup>8</sup> for the experimental group and following the control period for the wait-list control group, providing information on:

- Diagnosis, Symptomology, Aetiology, Medication, and Course and Prognosis of schizophrenia;
- Practical and easy to utilize management and communication strategies designed to assist both the client and family members.

The intervention itself (Moxon & Ronan, 2008) was developed following personal correspondence with researchers Christine Vaughn, Nicholas Tarrier and Ian Falloon, and incorporated aspects of programmes by Barrowclough and Tarrier (1992), and Falloon and colleagues (Falloon, Falloon, & Lusetti, 1997; Falloon, Graham-Hole, & Fadden, 1997).

Additional limited information drawn from the literature about expressed emotion was included, with three features incorporated: (i) an overview and definition in lay terms, (ii) information about the vulnerability a person, particularly those diagnosed with schizophrenia might possess; (iii) practical advice on how to help maintain a low stress and stimulus environment in the home for the entire family unit's benefit. The programme was also individualised for family members based on their pre-test KASI responses.

Participants' sense of safety and comfort during the intervention was of prime importance. Each participant had the choice of whether they attended this session within their own homes (n = 49), or in a nominated venue that was familiar to them (the Schizophrenia Fellowship; n = 1). The initial session lasted approximately 1 hour and 15 minutes for clients and 2 hours for family members depending on the amount of questions asked. If more than one family member attended the session (n = 6 families), the education was conducted with them together, as it was for the one family with two clients participating, although each participant completed the measures separately. The family member with two clients participating completed two sets of measures – one for each client participating. The reasoning for this was that the two clients (who were sisters) each had a different history, different symptomology and different medications. The same process was followed for the families where two family members were participating with the one client, in that each family member completed a separate set of measures regarding their knowledge, EE status and burden of care.

Based on feedback from a previous study (Moxon & Ronan, 2008), clients were given the choice of whether they had a support person present and whether they attended the session before or after their key family member. In all instances, clients wanted to receive the information separately from their family member and no clients brought a support person with them. All clients also chose to receive the information before their key family member did and subsequently received the education earlier on the same day as their family member. No family member chose to have a support person present, but three family requests were granted to have another family member present for the education session only and not participate in the actual study (i.e., a sister and two fathers of the diagnosed) who was not participating in the education programme but who wanted to learn more about the disorder. Before this occurred, permission was sought and obtained from all participants in the family unit.

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<sup>8</sup> Training on delivering this manualised intervention was provided for the previous study (Moxon, 1998; Moxon & Ronan, 2008) by a senior clinical psychologist with many years experience delivering manualised interventions as well as services to clients with schizophrenia and family members.



All participants took the education booklet away with them and two clients requested and were given extra copies that they wanted to send to other family members who had not participated in the study.

Knowing that active involvement has been shown to predict benefits in psychoeducational intervention programmes (Bergin & Garfield, 1994; Falloon et al., 1993; Lambert, 2004), questions from all participants were encouraged with the belief that the more interested and involved participants were in the education, the more knowledge would be retained by them. Information was presented in 4-5 minute segments followed by a brief and time-limited opportunity for participants to discuss the information relayed and how it may or may not relate to their own experiences, as well as ask any questions they may have as related to the information. Social reinforcement such as encouragement, supportive body language and positive attention to points raised by participants was provided to encourage continued involvement. Participants were encouraged to summarize their understanding of the key points at the end of each segment. In the event of misunderstanding of key points, clarification was provided. It was kept in mind throughout the sessions that the purpose of this study was not to conduct an intervention or family therapy per se. Rather, the manual and its application were designed to provide psychoeducation-based information (Moxon & Ronan, 2002).

### *Assessments*

The first testing session conducted by the trained assessor consisted of three assessments for family members, and one for clients:

- (i) Patient and Family History Interview (family members only)
- (ii) Knowledge about Schizophrenia Interview (family members only)
- (iii) Level of Expressed Emotion scale (client and family members separate versions)
- (iv) Family Questionnaire (family members only)

Both the experimental and control groups attended the pre-assessment session

### **Family Members' Initial Assessment**

At the beginning of the session, the assessor gave relevant background information from the information sheet, reiterated the procedure for the present study to clarify the amount of time involved and answered any questions related to participating.

The family member was then interviewed with the Patient and Family History Interview by a trained, independent assessor, blind to condition, who was familiar to the family unit as a key-worker through the relevant agency (i.e., R.F. or S.F.). This took approximately 6-10 minutes to complete. The interview was designed to collect details about the client and family members participating as well as information on prevalent symptoms, the nature of the current treatment and the agency, length and type of support.

The assessor then administered the Knowledge about Schizophrenia Interview. If during the interview insufficient or unclear information was given by the family member, the examiner repeated the question or gave up to three prompts of “can you tell me more”, or “is there anything you would like to add?”. Responses were written by the examiner verbatim, and audio-taped, allowing for later confirmation of the responses.

The interview took 10-30 minutes to administer and was conducted, as recommended (Barrowclough, et al., 1987) in a conversational manner, and not as a test with correct and incorrect answers. For families participating in the research with more than one family member participating, each family member was interviewed separately. Owing to the KASI being knowledge based, it was conducted before the LEE scale in an attempt to avoid contamination by later responses. Following the KASI interview, the LEE scale was given to family members to complete, and took approximately 10-25 minutes to complete. Lastly, the FQ was given to family members to complete and took between 10 and 25 minutes to do so.

### **Clients Initial Assessment**

At the beginning of the session, the assessor gave relevant background information from the information sheet, reiterated the procedure for the present study to clarify the amount of time involved, and answered any questions raised related to participating.

Clients attended this session singularly and the LEE scale was administered by assessors to clients to complete, taking between 10-25 minutes with the key-worker available to clarify any of the questions. This was the only measure administered to clients.

### **Education Programme**

Session Two was the education programme (Moxon & Ronan, 2002), administered by the author for both clients and family members.

At the beginning of the education session, an outline of what information was going to be provided as well as how long it was expected to take was provided under the premise that if participants had knowledge of the agenda, they might be more comfortable. Research indicates that agenda setting has some relationship with treatment outcome (Lambert, 2004). With this in mind, the first part of the session was designed to be relatively informal and friendly and conveyed:

- “First we’ll discuss what schizophrenia is, the different symptoms that are involved, what is thought to cause it, how it can be treated and what the possible long-term outcomes are for those diagnosed with it.
- This will take about  $\frac{3}{4}$  of an hour, and after that you might like a short break, so if you want we can stop for 10 minutes.
- The second part of this session will discuss some coping skills that research has shown can sometimes help. And that will take about 50 minutes.
- Finally, we’ll make a date for me to phone you in about seven days to briefly discuss any further questions or concerns either of you have, and you’ll make an appointment with the fieldworker to come back in about 14 days to fill out the questionnaires again.
- Please, ask questions whenever you want or jump-in at any time” (Moxon & Ronan, 2002, p.1).

No participants took the opportunity for a break, but it was noted that clients often made a hot drink or had a cigarette whilst listening. All participants asked to continue without a break in order to use the extra time for questions on the information provided.

After the outline was provided, an information booklet written by Christine Barrowclough and Nicholas Tarrier (1992) was given to each person attending the session so that they could follow it as the education session progressed as well as take home to use as a resource.

The booklet also helped to overcome the potential problem of retention of information and allowed participants to look further at the material in their own time. Most participants in the current study read parts of the booklet as the session progressed. The booklet was written in simple language, was directly related to the topic and according to the Flesch reading scale (1948) is able to be understood by at least 75% of the population.

Although the format of the first half of the session did follow that of the booklet, additional and updated information from our own protocol (Moxon & Ronan, 2002) was provided in the first half of the session and presented in a flexible manner to enable:

- (i) Subjects or areas that family members indicated that they wanted to know more about in the Patient and Family History Interview to be discussed in more depth,
- (ii) Areas of information not known or seen as incorrect in the pre-test KASI to be paid particular attention,
- (iii) Relevant information was incorporated into the session from Falloon et al. (1997) Integrated Mental Health Care and Falloon et al. (1997) Integrated Mental Health Care (a guidebook for consumers; both from the Optimal Treatment Project) as well as information about expressed emotion and ways to help lower it in the home.

As described previously, if more than one family member attended the session, the education was conducted with the family members together, but the client was seen separately (apart from the two client family where the two sisters chose to participate in the education session together) and were provided with the same information on the same day.

In the second half of the session, the family members were provided information on what they could do to help their diagnosed family member. These words were added prior to imparting the information to both family members and clients, "We believe that there are some specific things that research supports which you can do to make things easier on yourself and better for your family member. While we will provide some coping techniques, some will not be appropriate or possible to use in your particular situation, and you most probably use some

of these anyway. You of course will be the final judges of which ones suit you”(Moxon & Ronan, 2002, p.11). Then, coping strategies from our protocol (Moxon & Ronan, 2002), including an array of relaxation strategies that participants from Moxon and Ronan (2008) found to be helpful were described and discussed (such as taking time out for oneself to garden, exercise, read a book, go out with a friend, deep breathing and so forth).

Anecdotally, most participants appeared to visibly relax once they realised they were not being asked about in-depth historical or personal information. Most were open and volunteered information which indicated that they had been listening to the information being presented, but also may have begun to assimilate at least some of it.

Questions in the treatment manual were also flexible in that for each participant relevant information was taken into account from the pre-test KASI. In that way, more appropriate questions could be asked such as “You said earlier you thought that taking drugs caused Meg’s illness, how do you feel about this now?”, or, “You said earlier that a lot of stimulation seems to make Meg’s symptoms worse, does that make more sense now?” Again, the aim of these questions was to encourage the participant to become more involved, personalise the information and thus retain more information.

At the end of the education session, participants made appointments for the post-measures assessment session and were reminded that they could take the information booklets with them. All participants did in fact take the information booklets with them.

As part of the education intervention, approximately 7-10 days after the education session, a phone call was made by the researcher to all participants to ask them a structured series of questions as follows: how had they found the education, if they had a chance to talk to their family about what they had learned yet and lastly, if they had any further questions. At this stage, all participants reported that they had spoken with their corresponding family member in the study about the educational session and no-one had any further questions to ask during this phone call.

Alongside the intervention, information was also provided to the community support centres (S.F. and R.F. branches) to provide ongoing support for clients and families if the participants requested it. It is important to note that although all participants were members of S.F. or R.F.

branches, there was a broad range of support accessed from daily to none at all. All participants had equal opportunity to access information or support before and after the intervention as well as during the approximately one week intervals between the intervention sessions.

Session Three was the post-test assessment session which consisted of three measures for Family members and one for clients:

- (i) KASI (post-test; Family members only)
- (ii) LEE scale (post-test; Family members and clients separately)
- (iii) FQ (post-test – Family members only)

As with the pre-treatment assessment, clients and family members completed the measures independently from each other.

This session for the family member involved completing the KASI post-test (which again was audio-taped and administered individually), the LEE and FQ. The clients filled out the LEE scale.

At the end of this session, participants were informed that in nine months time they would be contacted to complete the measures again as a follow-up. They were also told that once the results had been analysed, they could receive feedback on study findings if they would like. Table 4 illustrates the numbers of participants involved in assessments and intervention by condition.

**Table 6: Flowchart of the Education Programme**

Groups		Session 1 (pre- test)	Session 2 (Ed. 1) <sup>910</sup>	Session 3 (post- meas1)	Session 4 (Ed. 2)	Session 5 (post- meas2)	9-month Follow- up
Experimental	Clients	10	10	10			<b>10</b>
	Family members	13	13	13			<b>13</b>
Wait-list control	Clients	12		12	12	12	<b>12</b>
	Family members	15		15	15	15	<b>15</b>

Ed.1 – Education provided to experimental group; post-meas1 = post-test measures; Ed.2 = education provided to wait-list group following the control period; post-meas2 = post-test measures following Ed2.

### **Follow-up Assessment**

Nine months following treatment, the independent assessors again administered the KASI, LEE scales and FQ with family members and the LEE with clients. In addition, clients and family members were asked whether there were any psychiatric hospitalisations during that nine month interval. As a means of confirmation, this information on relapse was then double-checked with S.F and R.F. personnel

### **Data Analysis**

All analyses were carried out using SPSS for Windows version 12. Descriptive analyses were followed by inferential analyses that used a combination of non-parametric (Mann Whitney test, Wilcoxon Signed Ranks Test) and parametric analyses (t-test, analyses of variance) to compare mean scores within and across groups.

<sup>9</sup> Part of the education component of the intervention included the follow-up phone call one week after participation in the education session.

<sup>10</sup> Education session 1 was provided to the experimental group and Education session 2 to the wait-list control group. Similarly, post-measures 1 was delivered to the experimental group and post-measures 2 to the wait-list control group.

# Chapter 3

## Results

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## **RELIABILITY**

The degree of inter-rater agreement for the KASI was 80%. This data is based on the two raters<sup>11</sup> individually scoring five randomly selected audio-taped interviews (30 separate subscales). It was concluded that the scores obtained were of acceptable reliability, and that this finding might be generalised from the random sample to the total population of audiotapes scored by the author.

## **GROUP COMPARABILITY**

Pre-treatment differences across conditions were examined by means of one-way analysis of variance (ANOVA) tests. Variables compared across groups included age, gender, ethnicity, city of residence and client's place of residence, education level and employment status, family member's relationship with the client, whether the participants had previous education on schizophrenia, the agency of support, length of time of support with the agency and the amount of support accessed and type of support accessed. For these variables, analyses in which subjects in the treatment condition were compared with those in the wait-list condition resulted in non-significant differences ( $p's >.05$ ), indicating that the subjects were demographically similar across the experimental and wait-list control conditions.

Similar analyses were conducted on the pre-treatment dependent variables of family members' knowledge and family members' and clients' (separate) levels of expressed emotion, as well as on burden of care, levels of distress and coping. None of the analyses indicated significant differences ( $p's >.05$ ).

## **TREATMENT INTEGRITY**

The specified strategies outlined in the manual for the education sessions were used in all sessions. There were no instances where other forms of therapeutic intervention were used in place of the treatment manual. The treatment manual was not implemented in a rigid fashion,

but in a semi-flexible manner that maintained programmatic strategies while permitting limited individualisation on the basis of each participant's needs as identified in the KASI pre-test, or as raised by participants during the session. A checklist was completed by a senior clinical psychologist who sat in on selected sessions in the initial research and confirmed the fidelity of the education programme.

All participants took the education booklet away with them and two clients requested and were given extra copies that they wanted to send to other family members who had not participated in the study.

### **PRELIMINARY ANALYSES**

Based on a median split of family members' EE scores (median = 10), participants were identified as high or low in EE.<sup>12</sup> This divided the sample in terms of EE status at 10 clients rated as low-EE (four in the experimental group, six in the control group) and 12 as high-EE (six in the experimental group, six in the control group), with 13 family members rated as low-EE (seven in the experimental group, six in the control group) and 15 as high-EE (six in the experimental group, nine in the control group).

There were no significant pre-treatment differences on study variables between those who came from high EE households and those from low EE households (all  $p$ 's  $>.05$ ).

The Mann Whitney test was used to test whether previous education on schizophrenia made a difference to how much knowledge was gained from pre- to post-test. All results were non-significant ( $p$ 's  $>.05$ ).

Analysis of the outcome scores between those who accessed support during this interval and those who did not also showed no significant differences ( $p$ 's  $>.05$ ).

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<sup>11</sup> The second rater was a trained psychologist familiar with such measures.

<sup>12</sup> Median splits are recommended by the authors Cole and Kazarian (1992) due to a lack of empirical evidence to determine cut-off points for the scale.

The Spearman's Rank Order Correlation was used to test whether the length of involvement (time) with the support agency (S.F., or R.F.) affected the amount of knowledge gained from pre- to post-test. All results were non-significant ( $p's >.05$ ).

## **TREATMENT OUTCOME**

All of the analyses conducted within the present study were selected specifically to address the three hypotheses of the study. Namely, as a result of attending a brief educational programme, 1) participants' knowledge would increase, 2) as a result of this, participants' reported level of expressed emotion would decrease compared to the control condition, and 3) family members' perceived levels of distress and burden of care would decrease, whilst perceived coping would increase as a result of the intervention.

The means and standard deviations of the Knowledge about Schizophrenia Interview (KASI; for family members only) are presented in Table 7 and the means and standard deviations of the Level of Expressed Emotion Scale (LEE; for family members and clients separately) are presented in Tables 9-10. The means and standard deviations of the Family Questionnaire (FQ; for family members only) are presented in Table 14. The analyses addressing changes over time for the LEE Scale total score and subscales, those addressing changes over time for the KASI total score and subscales as well as analyses addressing changes over time for the FQ subscales can be found in the summaries of each section. Tables 8 (KASI), 11 and 12 (LEE) and 15 (FQ) reflect scores for dependent variables by EE status (high versus low).

### **Knowledge about Schizophrenia Interview (KASI) Analyses**

A Wilcoxon matched pairs signed ranks test was performed on the data for all 28 family members comparing pre-test and post-test scores for both the treatment and wait-list group. This non-parametric test was used for the KASI data instead of the corresponding parametric test because of the way in which the KASI data is measured. KASI subscales are ordinal with participants rank-ordered on a single variable (negative value, neutral value, positive value, and positive value with additional correct information) and each value has meaning in relation to the

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next (least to most). There is not an equal distance between each of these values. Thus, parametric tests which require interval or ratio data were not applicable (see also Barrowclough et al., 1987; Moxon & Ronan, 2008).

### **Control Period**

As expected, there were no significant differences between the pre-test1 and pre-test2 measures for the control group on the KASI, showing no change in knowledge as a function of the control period ( $p$ 's  $> .05$ ). By contrast, knowledge was gained by family members following treatment. For ease of distinguishing between the groups, the waitlist control group between pre2 and post-test following intervention will now be referred to as Treatment Group II and the experimental group will be referred to as Treatment Group I.

**Table 7 – Means and Standard Deviations for the KASI**

	Treatment		Wait-list Control			All Family members
Measures	Pre-test	Post-test	Pre-test 1	Pre-test 2	Post-test	Follow-up
<b>Diagnosis</b>						
M	2.77	3.08	3.07	3.13	3.20	3.14
SD	0.44	0.28	0.59	0.52	0.68	0.45
Range	2-3	3-4	2-4	2-4	2-4	2-4
<b>Symptomology</b>						
M	3.00	3.62	2.93	3.07	3.47	3.57
SD	0.82	0.65	0.88	0.80	0.74	0.69
Range	1-4	2-4	2-4	2-4	2-4	2-4
<b>Aetiology</b>						
M	2.31	3.23	2.27	2.27	3.40	3.18
SD	0.63	0.73	0.46	0.46	0.74	0.77
Range	1-3	2-4	2-3	2-3	2-4	2-4
<b>Medication</b>						
M	2.62	3.62	3.13	3.20	3.73	3.71
SD	1.33	0.87	1.13	0.94	0.60	0.60
Range	1-4	1-4	1-4	1-4	2-4	2-4
<b>Course &amp; Prognosis</b>						
M	2.38	3.31	2.47	2.40	3.07	3.07
SD	0.96	0.75	1.36	1.30	0.80	0.72
Range	1-4	2-4	1-4	1-4	1-4	1-4
<b>Management</b>						
M	2.69	3.38	2.67	2.60	3.27	3.39
SD	0.63	0.51	0.82	0.74	0.70	0.69
Range	2-4	3-4	1-4	1-4	2-4	2-4
<b>Total Score</b>						
M	15.77	20.23	16.53	16.67	20.13	20.07
SD	2.71	1.88	3.91	3.58	2.72	2.18
Range	11-20	17-23	10-21	11-21	14-23	15-24

### Pre-test-Post-test Change for Treatment Groups

Analysis of the KASI total score for the treatment group between pre- and post-test revealed a significant gain in knowledge for Treatment Group I ( $z = -3.192$ ,  $p = 0.001$ ). Analysis of the KASI total score for the Treatment Group II between pre- and post- revealed an equally significant gain in knowledge ( $z = -3.306$ ,  $p = .001$ ) following the intervention.

For the subscale of Diagnosis, analyses of Treatment Group I showed a slight significant effect at ( $z = -2.000$ ,  $p = .046$ ), whereas for Treatment Group II there was no significance at ( $z = -.816$ ,  $p = .414$ ), showing no gain in knowledge for Treatment Group II following the intervention.

For the subscale of Symptomology, analyses revealed a significant gain for Treatment Group I ( $z = -2.309$ ,  $p = .021$ ) and an identical gain for Treatment Group II ( $z = -2.309$ ,  $p = .021$ ) following the intervention.

For the Aetiology subscale, analyses revealed a significant gain for both Treatment Group I ( $z = -2.585$ ,  $p = .010$ ) and Treatment Group II ( $z = -3.017$ ,  $p = .003$ ) following the intervention.

For the Medication subscale, analyses revealed a significant gain in Treatment Group I ( $z = -2.392$ ,  $p = .017$ ) and a result closely approaching significance in Treatment Group II ( $z = -1.933$ ,  $p = .053$ ) following the intervention.

For the subscale of Course and Prognosis, analyses revealed a significant gain in Treatment Group I ( $z = -2.360$ ,  $p = .018$ ) and Treatment Group II ( $z = -2.081$ ,  $p = .037$ ) following the intervention.

For the final subscale of Management, analyses revealed a significant gain in Treatment Group I ( $z = -2.714$ ,  $p = .007$ ) and Treatment Group II ( $z = -2.496$ ,  $p = .013$ ) following the intervention.

### **Information Acquired as Affected by Initial EE Rating**

Further analyses collapsing across both Treatment Group I and Treatment Group II were conducted to determine whether an initial rating of high-EE or low-EE would affect how much knowledge family members gained between pre-test and post-test. The means and standard deviations of those sub-groups are displayed in Table 8.

**Table 8: Low and High-EE Means and Standard Deviations of the KASI**

Measures	Pre Treatment		Post Treatment	
	Low EE	High EE	Low EE	High EE
<b>Diagnosis</b>				
M	2.92	2.93	3.15	3.13
SD	0.49	0.59	0.38	0.64
Range	2-4	2-4	3-4	2-4
<b>Symptomology</b>				
M	3.15	2.80	3.69	3.40
SD	0.90	0.78	0.63	0.74
Range	1-4	2-4	2-4	2-4
<b>Aetiology</b>				
M	2.38	2.20	3.62	3.07
SD	0.51	0.56	0.51	0.80
Range	2-3	1-3	3-4	2-4
<b>Medication</b>				
M	3.00	2.80	3.69	3.67
SD	1.41	1.08	0.86	0.62
Range	1-4	1-4	1-4	2-4
<b>Course &amp; Prognosis</b>				
M	2.38	2.47	3.23	3.13
SD	1.12	1.25	0.83	0.62
Range	1-4	1-4	1-4	2-4
<b>Management</b>				
M	3.08	2.33	3.31	3.33
SD	0.64	0.62	0.63	0.62
Range	2-4	1-3	2-4	2-4
<b>Total Score</b>				
M	16.92	15.53	20.69	19.73
SD	2.9	3.70	1.97	2.58
Range	12-21	10-21	17-23	14-22

The analyses conducted revealed that there was a difference between how much knowledge low-EE family members gained and how much knowledge high-EE family members gained.

Low-EE family members gained in knowledge on the subscales of Symptomology ( $z = -2.111$ ,  $p = .035$ ), Aetiology ( $z = -3.176$ ,  $p = .001$ ), Course and Prognosis ( $z = -2.121$ ,  $p = .034$ ), as well as on the total score ( $z = -3.069$ ,  $p = .002$ ).

High-EE family members gained in knowledge on all of the subscales, bar Diagnosis. The gains were as follows; Symptomology ( $z = -2.496$ ,  $p = .013$ ), Aetiology ( $z = -2.530$ ,  $p = .011$ ), Medication ( $z = -2.489$ ,  $p = .013$ ), Course and Prognosis ( $z = -2.223$ ,  $p = .026$ ), Management ( $z = -3.419$ ,  $p = .001$ ) and total score ( $z = -3.417$ ,  $p = .001$ ).

Neither low-EE nor high-EE family members gained in knowledge on the Diagnosis subscale ( $p$ 's  $>.05$ ). Of note, the Diagnosis subscale continues the trend of being the least treatment sensitive (see Moxon & Ronan, 2008). Further, low-EE family members did not significantly gain in knowledge on the sections of Medication and Management ( $p$ 's  $>.05$ ).

### **Summary of KASI Analyses**

- Treatment Group I showed a significant increase in knowledge in the subscales of Diagnosis, Symptomology, Aetiology, Medication, Course and Prognosis, and Management, as well as in the total score from pre- to post-test.
- The control group showed no changes in any subscale or the total score from Pre1 – Pre2 as a function of the control period.
- Treatment Group II showed a significant increase in knowledge in the subscales of Symptomology, Aetiology, Course and Prognosis, and Management with the subscale of Medication approaching significance, as well as in the total score.
- Low-EE family members showed a significant increase in knowledge in the subscales of Symptomology, Aetiology, Course and Prognosis, as well as in the total score.
- High-EE family members showed a significant increase in knowledge in the subscales of Symptomology, Aetiology, Medication, Course and Prognosis and Management, as well as in the total score. There were significant increases in all subscales bar the Diagnosis subscale.

### **The Level of Expressed Emotion Scale (LEE) Analyses**

The effects of the educational intervention versus the control period were analysed by means of a 2 (assessment periods of pre- and post-treatment) by 2 (treatment vs. wait-list) mixed factorial ANOVA. Because dependent variables were not viewed as multiple measures of a single variable (not interested in the linear combination of dependent measures), MANOVA was not used. The means and standard deviations of the Relative and Client versions of the LEE scale can be seen in Tables 9 and 10, respectively. Separate ANOVAs were completed for family members and clients for reasons outlined in the Method section.



**Table 9: Means and Standard Deviations for the LEE Scale - Relatives Version**

Measures	Treatment		Wait-list Control			All Family members
	Pre-test	Post-test	Pre-test 1	Pre-test 2	Post-test	Follow-up
<b>Intrusiveness</b>						
M	2.38	.92	3.60	3.27	2.40	1.18
SD	1.895	1.115	3.135	2.604	2.874	1.679
Range	1-7	0-3	0-10	0-9	0-11	0-8
<b>Emotional Response</b>						
M	4.08	3.08	3.93	3.27	2.40	2.32
SD	2.465	2.431	2.685	2.344	1.404	1.887
Range	1-9	1-10	1-9	1-9	1-6	0-8
<b>Attitude toward Illness</b>						
M	.92	.31	1.60	1.47	.60	.54
SD	1.188	.630	1.993	1.922	.986	.744
Range	0-3	0-2	0-7	0-7	0-3	0-2
<b>Tolerance/Expectations</b>						
M	2.15	1.31	2.13	1.53	1.07	.82
SD	1.994	1.437	1.642	1.407	1.163	1.219
Range	0-6	0-4	0-6	0-4	0-4	0-4
<b>Total Score</b>						
M	9.54	5.62	11.27	9.53	6.47	4.86
SD	5.364	3.927	6.713	6.232	5.263	4.034
Range	3-10	1-13	2-23	2-19	1-21	0-15

**Table 10: Means and Standard Deviations for the LEE Scale - Clients Version**

Measures	Treatment		Wait-list Control			All Family members
	Pre-test	Post-test	Pre-test 1	Pre-test 2	Post-test	Follow-up
<b>Intrusiveness</b>						
M	4.20	3.40	3.75	3.42	3.17	2.27
SD	4.237	3.062	3.306	2.610	3.243	2.394
Range	0-11	0-8	0-10	0-8	0-9	0-9
<b>Emotional Response</b>						
M	5.20	3.50	2.92	2.75	1.75	2.68
SD	3.259	3.504	3.315	2.768	1.960	2.950
Range	0-9	0-9	0-9	0-9	0-6	0-9
<b>Attitude toward Illness</b>						
M	2.30	1.90	2.67	2.42	1.17	1.55
SD	2.751	1.729	3.20	2.712	1.528	2.154
Range	0-8	0-5	0-10	0-8	0-5	0-7
<b>Tolerance/Expectations</b>						
M	4.70	2.30	4.08	3.67	2.75	2.45
SD	3.592	2.214	3.059	2.774	2.958	2.668
Range	0-10	0-7	0-10	0-9	0-10	0-10
<b>Total Score</b>						
M	16.40	11.10	13.42	12.25	8.83	8.95
SD	11.578	7.852	10.193	8.292	7.907	8.249
Range	2.33	2-23	1-31	3-26	1-22	0-27

### Pre-test – Post-test Change for Treatment Groups

A mixed factorial ANOVA was conducted to compare participant's scores on the Level of Expressed Emotion statistic test at pre-test (prior to the intervention) and post-test (following intervention). Analysis of the LEE scale Total score for family members' revealed a significant trials effect for time [Wilks' Lambda = .48 ( $F(1,26)=28.157$ ,  $p=.0005$ , multivariate partial eta squared=.52] indicating a large effect size, and a non-significant interaction effect ( $p >.05$ ). Analysis of the LEE scale Total score for clients' revealed a significant trials effect for time [Wilks' Lambda = .63,  $F(1,20)=11.774$ ,  $p=.003$ , multivariate partial eta squared=.37] also indicating a large effect size, and a non-significant interaction effect ( $p >.05$ ). The lack of interaction effects suggest that the effects over time were unrelated to whether the participant was in the experimental or control group.

For the Intrusiveness subscale of the family members' version of the LEE, analyses revealed a significant trials effect [Wilks' Lambda = .75,  $F(1,26)=8.459$ ,  $p=.007$ , multivariate partial eta squared=.25] indicating a large effect size and a non-significant interaction ( $p >.05$ ). Analyses of the client version showed a non-significant interaction effect ( $p's >.05$ ).

For the Emotional Response subscale of the family members' version of the LEE, analyses revealed a significant trials effect [Wilks' Lambda = .66,  $F(1,26)=13.246$ ,  $p=.001$ , multivariate partial eta squared=.34] indicating a large effect size, and a non-significant interaction ( $p >.05$ ). Analyses of the client version showed a significant trials effect [Wilks' Lambda = .69,  $F(1,20)=9.17$ ,  $p=.007$ , multivariate partial eta squared=.31] indicating a large effect size, with a non-significant interaction effect ( $p >.05$ ).

For the Attitude toward Illness subscale the family members' version of the LEE, analyses revealed a significant trials effect [Wilks' Lambda = .66,  $F(1,26)=13.47$ ,  $p=.001$ , multivariate partial eta squared=.34] indicating a large effect size, and a non-significant interaction effect ( $p >.05$ ). Analyses of the client version showed a non-significant trials effect with a non-significant interaction effect ( $p$ 's  $>.05$ ).

For the Tolerance/Expectations subscale of the family members' version of the LEE, analyses revealed a significant trials effect [Wilks' Lambda = .66,  $F(1,26)=13.087$ ,  $p=.001$ , multivariate partial eta squared=.34] indicating a large effect size, and a non-significant interaction ( $p >.05$ ). Analyses of the client version also showed a significant trials effect [Wilks' Lambda = .70,  $F(1,20)=8.786$ ,  $p=.008$ , multivariate partial eta squared=.31] indicating a large effect size, and a non-significant interaction effect ( $p >.05$ ).

### **LEE Subgroup Analyses Across Treatment Groups**

One-way repeated measures ANOVAS were conducted to compare participants Total LEE scores at pre-test and post-test on the subgroups of clients Treatment Group I, clients Treatment Group II, family members Treatment Group I, family members Treatment Group II and to assess the magnitude of that change.

It was found that in the clients Treatment Group I subgroup there was a significant effect over time [Wilks' Lambda = .52,  $F(1,9)=8.31$ ,  $p=.018$ , multivariate partial eta squared=.48] with a large effect size, whilst the client Treatment Group II LEE total score change reflected a trend towards significance over time [Wilks' Lambda = .70,  $F(1,11)=4.61$ ,  $p=.055$ , multivariate partial eta squared=.30].

Analyses of the family members Treatment Group I subgroup found a significant effect over time [Wilks' Lambda = .42,  $F(1,12)=18.80$ ,  $p=.001$ , multivariate partial eta squared=.58] with a large effect size and the subgroup of family members Treatment Group II was also found to have a significant effect over time [Wilks' Lambda = .50,  $F(1,14)=13.97$ ,  $p=.002$ , multivariate partial eta squared=.50] with a large effect size. It is of note that the magnitude of change for family member LEE total scores was relatively equal across these two subgroups.

### Expressed Emotion as affected by initial EE rating

The effects of treatment were analysed by means of another set of 2 (assessment periods of pre- and post-treatment) by 2 (high-EE vs. low-EE) mixed factorial ANOVAS collapsing across both treatment groups to see the differences between high-EE and low-EE participants in EE across time. Tables 11 and 12 show the Means and Standard Deviations for this sample.

**Table 11: Low and High-EE Means and Standard Deviations of the LEE Scale – Family Members**

Measures	Pre-test		Post-test		Follow-up	
	Low EE	High EE	Low EE	High EE	Low EE	High EE
<b>Intrusiveness</b>						
M	1.62	4.27	.92	2.40	.77	1.53
SD	1.325	2.939	1.441	2.746	1.013	2.066
Range	0-4	0-10	0-4	0-11	0-3	0-8
<b>Emotional Response</b>						
M	2.23	5.53	1.62	3.67	1.62	2.93
SD	1.235	2.386	.768	2.160	1.660	1.907
Range	1-4	2-9	1-3	2.10	0-6	0-8
<b>Attitude toward Illness</b>						
M	.46	2.00	.08	.80	.31	.73
SD	.776	1.927	.227	1.014	.480	.884
Range	0-2	0-7	0-1	0-3	0-1	0-2
<b>Tolerance/Expectations</b>						
M	.92	3.20	.38	1.87	.31	1.27
SD	.954	1.656	.870	1.187	.630	1.438
Range	0-3	1-6	0-3	0-4	0-2	0-4
<b>Total Score</b>						
M	5.23	15.00	3.00	8.73	3.00	6.47
SD	2.587	4.243	2.041	4.621	3.000	4.207
Range	2-11	10-23	1-8	3-21	0-11	0-15

**Table 12: Low and High-EE Means and Standard Deviations of the LEE Scale - Clients**

Measures	Pre-test		Post-test		Follow-up	
	Low EE	High EE	Low EE	High EE	Low EE	High EE
<b>Intrusiveness</b>						
M	2.00	5.58	1.80	4.50	1.50	2.92
SD	2.211	3.191	2.044	3.344	1.354	2.906
Range	0-7	0-11	0-6	0-9	0-4	0-9
<b>Emotional Response</b>						
M	1.20	6.25	.60	4.17	1.60	3.58
SD	1.317	2.864	1.075	2.855	3.026	2.678
Range	0-3	1-9	0-3	0-9	0-9	0-8
<b>Attitude toward Illness</b>						
M	.70	4.00	.50	2.33	.50	2.42
SD	1.059	3.191	.527	1.775	1.269	2.392
Range	0-3	1-10	0-1	0-5	0-4	0-7
<b>Tolerance/Expectations</b>						
M	1.40	6.83	1.40	3.50	1.00	3.67
SD	1.265	2.038	3.062	1.732	1.826	2.708
Range	0-3	3-10	0-10	1-7	0-6	0-10
<b>Total Score</b>						
M	5.30	22.67	4.30	14.50	4.60	12.58
SD	2.312	8.004	4.296	6.987	5.948	8.328
Range	1-8	12-33	1-15	6-23	0-19	3-27

Analysis of the LEE scale Total score for family members revealed a significant trials effect [Wilks' Lambda = .43,  $F(1,26)=34.295$ ,  $p=.0005$ , multivariate partial eta squared=.57] indicating a large effect over time, and a significant interaction effect [Wilks' Lambda = .77,  $F(1,26)=7.74$ ,  $p=.010$ , multivariate partial eta squared=.23] between time and EE status.

Analysis of the LEE scale Total score for clients revealed a significant trials effect [Wilks' Lambda = .58,  $F(1,20)=14.604$ ,  $p=.001$ , multivariate partial eta squared=.42] and a significant interaction effect [Wilks' Lambda = .69,  $F(1,20)=8.93$ ,  $p=.007$ , multivariate partial eta squared=.31] between time and EE status.

For the Intrusiveness subscale of the family members version of the LEE, analyses revealed a significant trials effect [Wilks' Lambda = .76,  $F(1,26)=8.321$ ,  $p=.008$ , multivariate partial eta squared=.24] and a non-significant interaction ( $p > .05$ ). Analyses of the client version showed a non-significant interaction effect ( $p > .05$ ).

For the Emotional Response subscale of the family members version of the LEE, analyses revealed a significant trials effects [Wilks' Lambda = .65,  $F(1,26)=14.154$ ,  $p=.001$ , multivariate partial eta squared=.35] and no interaction effect ( $p >.05$ ). Analyses of the client version revealed a significant trials effect [Wilks' Lambda = .69,  $F(1,20)=8.996$ ,  $p=.007$ , multivariate partial eta squared=.31], with a non-significant interaction effect ( $p >.05$ ).

For the Attitude toward Illness subscale of the family members version of the LEE, analyses revealed a significant trials effect [Wilks' Lambda = .64,  $F(1,26)=14.445$ ,  $p=.001$ , multivariate partial eta squared=.36] with a non-significant interaction effect ( $p>.05$ ). Analyses of the client version showed a trend towards a significant trials effect ( $p=.058$ ) with a non-significant interaction effect ( $p >.05$ ).

For the Tolerance/Expectations subscale of the family members version of the LEE, analyses also revealed a significant trials effect [Wilks' Lambda = .66,  $F(1,26)=13.624$ ,  $p=.001$ , multivariate partial eta squared=.34] with a non-significant interaction effect ( $p>.05$ ). Analyses of the client version showed a significant trials effect [Wilks' Lambda = .66,  $F(1,20)=10.215$ ,  $p=.005$ , multivariate partial eta squared=.34] with a non-significant interaction effect ( $p >.05$ ).

### Summary of LEE Analyses

- Analyses showed that family members EE ratings significantly decreased from pre- to post-test on all four subscales of the LEE (Intrusiveness, Emotional Response, Attitude toward Illness, and Tolerance/Expectations) as well as on the Total score. All were large effects as shown from the eta scores which ranged from .25 to .52, including the Total score which had a very large effect with an eta of 0.52.
- Analyses showed that clients EE ratings significantly decreased from pre- to post-test on the subscales of Emotional Response, Tolerance/Expectations on the LEE as well as on the Total score. These decreases had large effects as shown from the eta statistic which ranged from .31 to .37.
- There were no interaction effects for family members or clients in the Total score or in any of the subscales, suggesting the reduction in EE over time was unrelated to the condition to which they were assigned (experimental or wait-list control group). However, it can be seen that the majority of variance contributing to the significant trials effect in all instances was as a function of the change in the treatment group, pre-

post scores (e.g., change in LEE Total score of 3.92 for the family members treatment group versus 1.74 for the wait-list control group and 5.3 for the client treatment group versus 1.17 for the wait-list control group).

- Subgroup analyses showed that both family members and clients EE ratings in Treatment Group I significantly decreased from pre- to post-test on the LEE Total score. These were large effects as shown from the eta score (.48 and .58 respectively). By contrast, for Treatment Group II, only the family members had a significant change over time (eta = .50) with the client subgroup not quite reaching significance at ( $p = 0.55$ ).
- When analysed by initial EE rating, it was found that there was an interaction effect for both family members and clients in the Total score only. This suggests that the reduction in EE over time was impacted by whether they entered the study as high-EE or low-EE (i.e., high EE participants realised more gains) but not to the degree of being reflected in individual subscale ratings.

### Changes in EE Status

Table 13 shows that 40/50 people (25 family members, 15 clients) lowered their EE score from pre- to post-test. Those who increased their EE score following intervention ( $n=3$ )<sup>13</sup> did so by up to five points each. At follow-up, 38/50 people (22 family members, 16 clients) were either still on their lowered score or had lowered further.

**Table 13: Change in EE Status Following Treatment**

EE Changes Pre-test to Post-test		Family members	Clients
Decrease	High → Low	8	4
Decrease	High → High	6	6
Decrease	Low → Low	11	5
No change	Low EE	2	4
No change	High EE	1	-
Increase	Low → High	-	1
Increase	High → High	-	2

<sup>13</sup> Further identifying information was gathered and analysed but is not included here due to potential confidentiality breaches.

### **Family Questionnaire (FQ) Analyses**

The effects of the educational intervention versus the control period were analysed by means of a 2 (assessment periods of pre- and post-treatment) by 2 (treatment vs. wait-list) mixed factorial ANOVA. Because dependent variables were not viewed as multiple measures of a single variable (not interested in the linear combination of dependent measures), MANOVAs were not used. The means and standard deviations of the FQ can be seen in Table 14.

**Table 14 – Means and Standard Deviations of the FQ**

Measures	Treatment		Wait-list Control			All Family Members
	Pre-test	Post-test	Pre-test 1	Pre-test 2	Post-test	Follow-up
<b>Frequency</b>						
M	125.23	103.85	113.13	115.07	104.73	106.29
SD	28.30	28.95	21.00	25.47	14.46	22.80
Range	64-165	57-151	87-151	77-162	81-138	61-151
<b>Bother</b>						
M	112.08	98.62	106.67	106.33	86.07	90.21
SD	41.55	39.79	25.47	28.32	29.35	34.19
Range	48-174	48-159	75-152	65-151	49-153	48-163
<b>Control</b>						
M	183.85	207.54	194.53	193.13	220.47	211.25
SD	40.74	32.36	27.61	26.41	18.68	27.74
Range	115-240	155-240	147-239	148-240	170-240	143-240

#### **Pre-test – Post-test Change for Treatment Groups**

A mixed factorial ANOVA was conducted to compare participant's scores on the FQ statistic test at pre-test (prior to the intervention) and post-test (following intervention). Analyses of the Frequency subscale of the FQ, analyses revealed a significant trials effect [Wilks' Lambda = .54,  $F(1,26)=21.81$ ,  $p=.0005$ , multivariate partial eta squared=.46] with a large effect over time and a non-significant interaction effect ( $p > .05$ ).

For the Bother subscale of the FQ, analyses revealed a significant trials effect [Wilks' Lambda = .65,  $F(1,26)=13.77$ ,  $p=.001$ , multivariate partial eta squared=.35] with a large effect over time and a non-significant interaction effect ( $p > .05$ ).



For the Control subscale of the FQ, analyses revealed a significant trials effect [Wilks' Lambda = .44,  $F(1,26)=32.94$ ,  $p=.0005$ , multivariate partial eta squared=.56] with a large effect for time and a non-significant interaction effect ( $p > .05$ ).

### **FQ Subgroup Analyses**

One-way repeated measures ANOVAS were conducted to compare participants scores at pre-test and post-test on the three FQ scales on the subgroups of family members Treatment Group I, family members Treatment Group II to assess the magnitude of change.

It was found that in the family members Treatment Group I subgroup on the Frequency scale, there was a significant effect over time with a large effect size [Wilks' Lambda = .31,  $F(1,12)=26.97$ ,  $p=.0005$ , multivariate partial eta squared=.69], whilst the subgroup family members Treatment Group II subgroup on the Frequency scale was not found to have a significant effect over time ( $p > .05$ ).

It was found that in the family members Treatment Group I subgroup on the Bother scale, there was not a significant effect over time ( $p > .05$ ), whilst the subgroup family members Treatment Group II subgroup on the Bother scale was found to have a significant effect over time with a large effect size [Wilks' Lambda = .54,  $F(1,14)=12.16$ ,  $p=.004$ , multivariate partial eta squared=.47].

It was found that in the family members Treatment Group I subgroup on the Control scale, there was a significant effect over time with a large effect size [Wilks' Lambda = .50,  $F(1,12)=12.22$ ,  $p=.004$ , multivariate partial eta squared=.51]. The subgroup family members Treatment Group II subgroup on the Control scale was also found to have a significant effect over time with a large effect size [Wilks' Lambda = .39,  $F(1,14)=22.18$ ,  $p=.0005$ , multivariate partial eta squared=.61].

### **FQ Indicators as Affected by Initial EE Rating**

The effects of treatment were analysed by means of a further set of 2 (assessment periods of pre- and post-treatment) by 2 (high-EE vs. low-EE) mixed factorial ANOVA collapsing across both treatment groups to examine the differences between high-EE and low-EE participants in

the FQ dimensions across time. Because dependent variables were not viewed as multiple measures of a single variable (not interested in the linear combination of dependent measures), MANOVAs were not used. Table 15 shows the Means and Standard Deviations for this sample.

**Table 15 - Low and High EE Means and Standard Deviations of the FQ**

Measures	Pre Treatment		Post Treatment	
	Low EE	High EE	Low EE	High EE
<b>Frequency</b>				
M	109.92	126.40	98.15	109.67
SD	26.87	21.12	22.45	20.73
Range	64-151	90-165	57-140	81-151
<b>Bother</b>				
M	100.00	117.13	87.38	95.80
SD	37.14	28.54	31.46	37.59
Range	48-174	69-157	48-147	49-159
<b>Control</b>				
M	206.62	174.80	221.46	208.40
SD	35.29	25.91	23.94	27.45
Range	115-240	147-214	158-240	155-240

For the Frequency subscale of the FQ, analyses revealed a significant trials effect [Wilks' Lambda = .60,  $F(1,26)=17.58$ ,  $p=.0005$ , multivariate partial eta squared=.40] indicating a large effect for time and a non-significant interaction effect ( $p > .05$ ) between time and EE status.

For the Bother subscale of the FQ, analyses revealed a significant trials effect [Wilks' Lambda = .65,  $F(1,26)=13.84$ ,  $p=.001$ , multivariate partial eta squared=.35] indicating a large effect for time and a non-significant interaction effect ( $p > .05$ ).

For the Control subscale of the FQ, analyses revealed a significant trials effect for time [Wilks' Lambda = .41,  $F(1,26)=38.21$ ,  $p=.0005$ , multivariate partial eta squared=.60] indicating a large effect for time and an interaction effect [Wilks' Lambda = .82,  $F(1,26)=5.73$ ,  $p=.02$ , multivariate partial eta squared=.18].

### Summary of FQ Analyses

- Analyses showed that across treatment groups family members' ratings of the frequency of behaviour and the distress it causes them significantly decreased from pre-

to post-test, each with large effects as shown from the eta scores which were .46 and .35, respectively. For the FQ subscale measuring control, there was a significant increase from pre- to post-test with a large effect and an eta score of 0.56.

- There were no intervention group X time interaction effects for in any of the subscales, suggesting the reduction in EE over time was unrelated to the condition to which they were assigned (intervention or wait-list control group). However, it can be seen that the majority of variance contributing to the significant trials effect in all instances was as a function of the change in the treatment group, pre- post scores (e.g., change in Frequency score of 21.38 for the treatment group, versus -1.94 for the wait-list control group, change in Bother score of 13.46 for the treatment group versus 0.34 for the wait-list control group, and change in Control score of -23.69 for the treatment group versus 1.4 for the wait-list control group).
- Subgroup analyses showed that Treatment Group I significantly improved from pre- to post-test on the Frequency and Control scales. These were large effects as shown from the eta score (.69 and .51 respectively). By contrast, for Treatment Group II, there was a significant improvement pre-post test on the Bother and Control scale with large eta scores at .47 and .61 respectively.
- When analysed by initial EE rating, it was found that there was an interaction effect for family members in the Control scale. This suggests that the increase in coping over time was impacted by whether they entered the study as high-EE or low-EE. The interaction effect reflected greater significant change after treatment for high-EE family members. However, the other two FQ variables (Frequency, Bother) showed significant change across time that was not a function of treatment condition (i.e., reflected in non-significant interactions and significant trials effects). Thus, participants across both high and low EE groups reflected beneficial changes on the FQ scale.

## **FOLLOW-UP**

### **KASI**

To assess maintenance of change or potential additional change, the nine month follow-up scores were compared initially with post-treatment scores collapsing across treatment groups.

As expected, gains in knowledge scores were maintained at follow-up with most people scoring the same exact Total score as their post-test score, or moving only one point in either direction. As confirmation, a Wilcoxon matched-pairs signed-ranks test showed no significance for post- to follow-up for the Total score and all subscales ( $p$ 's  $>.05$ ), refer also to Table 1 for follow-up scores.

A further separate set of analyses were conducted to assess overall change from pre-treatment (i.e., pre-test1 scores) to follow-up on Total scores. A Wilcoxon test for KASI total scores was highly significant and demonstrated that family member's gained in knowledge during the study from pre-test1 to follow-up ( $z = -4.389$ ,  $p = .0005$ ).

### **LEE**

To assess maintenance of change or potential additional change, the nine month follow-up scores were compared initially with post-treatment scores collapsing across treatment groups.

As expected, reductions in EE levels were maintained at follow-up. As confirmation, paired-samples t-tests showed no significance between post- and follow-up for family members or clients on both the Total scores and three of the four subscales ( $p$ 's  $>.05$ ). The exception was the Intrusiveness subscale where both family members ( $t(27) = 2.25$ ,  $p = 0.033$ ) and clients ( $t(21) = 2.13$ ,  $p = 0.045$ ) showed a further significant effect. That is, these findings reflected a further decrease in EE on the Intrusiveness dimension across both family members and client groups. Refer also to Tables 3 and 4 for follow-up scores.

A further separate set of analyses were conducted to assess overall change from pre-treatment (i.e., pre-test1 scores) to follow-up on Total scores. Paired t-tests analyses showed significant decreases in EE for the LEE Total score for family members between pre-test1 and follow-up revealed a significant decrease in EE ( $t(27) = 5.36, p = 0.0005$ ) as did the analysis of the LEE Total score for clients ( $t(21) = 2.88, p = 0.009$ ).

### **FQ**

To assess maintenance of change or potential additional change, the nine month follow-up scores were compared initially with post-treatment scores collapsing across treatment groups.

As expected, changes in FQ indicators were maintained at follow-up. As confirmation, paired-samples t-tests showed no significance between post- and follow-up on the Frequency. Bother and Control sub-scales ( $p's > .05$ ). Refer also to Table 8 for follow-up scores.

A further separate set of analyses were conducted to assess overall change from pre-treatment (i.e., pre-test1 scores) to follow-up on Total scores. Analysis of the Frequency score between pre-test and follow-up revealed a significant decrease ( $t(28) = 3.48, p = 0.002$ ). Analysis of the Bother score between pre-test and follow-up revealed a significant decrease ( $t(27) = 4.42, p = 0.0005$ ). Analysis of the Control score between pre-test and follow-up revealed a significant increase ( $t(27) = -4.994, p = 0.0005$ ).

### **RELAPSE**

At the 9-month follow-up, it was found that no clients had relapsed according to the criteria outlined in the Method section (i.e., no psychiatric hospitalisation during the post-test to 9-month follow-up interval as reported by clients and family members and confirmed by agency personnel).

# **Chapter 4**

## **Discussion**

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## **MAIN AIMS AND MAJOR FINDINGS**

The present study examined the effectiveness of a brief community based psychoeducational intervention for family members and clients which aimed to improve family members' knowledge about schizophrenia and expressed emotion in addition to ways of coping with it on a daily basis. It was hypothesised that the brief intervention would lead to increased knowledge, awareness, and use of coping strategies, as well as reductions in expressed emotion, burden of care and distress.

Taken together, the findings of the current study demonstrated that family members' knowledge improved significantly after intervention and that this improvement was maintained at a nine month follow-up whereas no change was reflected as a function of the control period. In addition, most EE and FQ indicators were also seen to improve. However, in these instances, while greater magnitude of change occurred across treatment relative to the control condition, the lack of significant statistical interactions tempers enthusiasm. With that said, EE indicators significantly decreased over the course of the study with the most beneficial and direct impact seen on ratings reflecting family members' intrusive behaviour towards the client. In the case of FQ indicators, burden of care and distress reported by family members decreased significantly over the course of the study and perceived coping increased. In addition, across treatment, combined with significant trials effects, the fact that the FQ indicators improved more following treatment compared to the control period is encouraging. That a similar pattern was observed for EE ratings (i.e., significant trials effects and greater magnitude change following treatment versus control periods) suggests that greater power (larger sample size) would have seen the differences between intervention and control reach statistical significance.

A main aim of the present study was concerned with what was seen to be the achievable goal of increasing family members' knowledge and understanding leading to a more relaxed attitude about the illness, more realistic expectations, a reduction in intrusiveness as well as increased tolerance, perceived ability to cope and lowered levels of EE, burden of care and distress. To this end, despite a number of limitations, the results from this study are encouraging and provide some evidence supporting the ability of this programme to achieve this goal. It also provides support for the idea that these programmes can be transported from traditional research settings to community-based support organisations.

Like the current study, the majority of intervention studies in this field also have focused on the role of intervention, EE and relapse. However, as reviewed earlier, the majority of these studies (Dyck, Hendryx, Short, Voss, & McFarlane, 2002; Falloon et al., 1993; Hogarty et al., 1991; Leff, Sharpley, Chisholm, Bell, & Gamble, 2001; McFarlane, Dushay, Stastny, Deakins, & Link, 1996; TARRIER et al., 1988a; 1989) were large multi-faceted and longer-term intervention studies of which education was only one component. By contrast, this study is part of a smaller group of studies that have looked at brief educationally-based interventions (Abramowitz & Coursey, 1989; Cassidy et al., 2001; Gleeson et al., 1999; Linszen et al., 1996; McGill et al., 1983; Moxon & Ronan, 2008; Pollio et al., 2006; Posner, Wilson, Kral, Lander et al., 1992; Reilly et al., 1988; Silverstein et al., 2006; TARRIER & Barrowclough, 1986; Vaughn et al., 1989). Thus, it is quite encouraging that during the 9-month follow-up period, no clients experienced a relapse. While education alone has been found not to impact on relapse rates (TARRIER et al., 1988a), it is worth noting that this study represents a study that was carried out not in a research setting but through community support settings. It may be that such settings have an increased capacity to assist clients and families to generalise gains over a longer term (Moxon & Ronan, 2008). Thus, in addition to increases in knowledge, coping and the emotional climate, this additional assistance might have the cumulative effect of reducing relapse. At the same time, it has to be acknowledged that relapse rates might also have to do with other factors not directly related to the intervention or the context. One factor might include increased motivation of this study sample. That is, in light of the fact that this select sample agreed to participate in the study whereas many more who were approached declined. This agreement to participate might in fact reflect an increased motivation to do something to improve family and client situations that in itself was sufficient to prevent relapse. Nevertheless, the fact that relapse was nil does provide encouragement, including encouraging future research into relapse rates and the factors underpinning those relapse rates.

### **Family Members' Knowledge**

The first aim of the present study was to increase family members' knowledge. This was assessed through a comparison of treatment and control group scores before and after the education. The results were largely positive with significant change found in most areas of knowledge as a function of intervention and no change as a function of the control condition.

Family members' knowledge did increase significantly in Treatment Group I after education on every subscale and total score. Significant increases were also achieved by those in



Treatment Group II after their education session on four of the six subscales (with significance not achieved in the Diagnosis and Medication subscales) and total score. That is, the initial effect was partially replicated. By contrast, no change on any subscale or total score was reflected following the control period.

It can be seen that for Treatment Group I and Treatment Group II, there were similar magnitude gains in knowledge between pre- and post-test in the subscale of Symptomology, Aetiology, Management and Course and Prognosis as well as in the Total score. There were disparate results on the subscales of Diagnosis and Medication. The most treatment sensitive subscales appeared to be Management and Aetiology as well as the Total score, whilst the least treatment sensitive sections were Diagnosis and Medication, particularly for Treatment Group II.

A closer examination of the questions in the Diagnosis section, and family members' individual responses to them, may explain the lack of significance for Treatment Group II. Of the 28 family members, only one demonstrated a gain in knowledge on this section after the treatment session. All other family members demonstrated the same exact knowledge and in doing so retained their original pre-test scores. Further, 25 out of 28 family members initially received a positive-value score of 3, for which all they needed to know was that the name of the disorder was schizophrenia and that it is "a severe mental illness which can affect all aspects of a person's life". Given most family members already held this knowledge at pre-test, any improvement was likely limited by their initial scores. The Diagnosis subscale continues the trend of being the least treatment sensitive (see also Moxon & Ronan, 2008).

Further analyses of the KASI showed that the initial EE status of family members did not affect the acquisition of knowledge to a great extent. That is, both high-EE and low-EE groups demonstrated significant gains in functional knowledge after the education session on a number of KASI subscales and total score, including Symptomology, Aetiology, Course and Prognosis subscales and the total score. High-EE family members additionally gained significant knowledge as reflected on the Medication and Management subscales.

Previous research (Berkowitz et al., 1984; Moxon & Ronan, 2008) has found that family members were especially lacking in knowledge about the aetiology of schizophrenia, often tending to retain their own interpretations of the causes of schizophrenia even following

intervention. However, findings here reflected significant change on this indicator for Treatment Group I that was then replicated for Treatment Group II. The Aetiology section of the KASI has an open question about the causes of the illness, followed by a number of forced-choice questions about possible causes, and enquiries which aim to investigate family members' behaviour. The present study found a significant change at post-test for family members, with 19 out of 28 family members improving their score by at least 1 point, to a positive rating of 3 or 4, demonstrating functional improvement on knowledge about the causes of schizophrenia. Why this study found significant improvements when others have not is not immediately clear. However, one speculation is that previous experience in the delivery of this programme (Moxon & Ronan, 2008), combined with awareness of the lack of change on this subscale, may have assisted with more effective delivery of the intervention sufficient to produce some useful changes. It also could be a function of the fact that deficits in knowledge identified from pre-test were also focused on in the intervention. Of course, it could simply also reflect a more engaged sample (i.e., sampling bias).

A closer examination of family members' responses in the two sections of Medication and Management is needed to explain why the improvement there did not reach significance in the low-EE group. In the low-EE group, eight out of 13 participants retained their original rating at post-test in the Medication section with half of this group retaining their positive and knowledgeable pre-test rating of 4. By contrast, in the high-EE group, only five out of 15 participants retained their original rating at post-test with over half the group (nine) improving their pre-test rating. This suggests that the low-EE group was more informed about the clients' medications and their importance at the outset of the study, leaving little room for improvement in comparison to the high-EE group.

In the Management section, eight out of 13 low-EE participants retained their original score at post-test, but in the high-EE group, only two participants retained their original score, with 13 out of 15 participants improving their score after the educational intervention. Remembering that in the KASI a score of 2 equals a neutral value in that the family member knows little relevant information but gives no information that if acted upon may be detrimental to the client, it was observed that only two low-EE participants began on a score of 2 and improved but eight high-EE family members began on a score of 2 and improved.

These data suggest that that low-EE family members had more knowledge on the diagnosis of the client, as well as more knowledge on practical information about the symptoms their

family member displays and the medications which they are prescribed. It could be theorised that low-EE family members have already established a low-stimulus environment in their homes, at least in part as a function of increased knowledge about how to support their loved one. In this regard, they might not be in a position to gain significantly in knowledge on the Management section after education because they are already aware of, and practising, many of the strategies suggested. Conversely, high-EE family members may have a fundamental knowledge of the diagnosis of their family member but have not learnt (or perhaps retained) more comprehensive knowledge on how to help manage it.

As might be expected, there were no further gains in knowledge in the 9 month follow-up interval post-education, but all gains were maintained suggesting an assimilation and consolidation of knowledge. This is in line with most other brief psychoeducational programmes (as defined by less than 8 sessions) in which most have found significant gains in knowledge retained at 3-9 month follow-up (Birchwood et al., 1992; McGill et al., 1983; Moxon & Ronan, 2008; Posner et al., 1992; Smith & Birchwood, 1990). However, Canive and colleagues (Canive, Sanz-Fuentenbro, Vasquez, Qualls, Fuentenbro, Perez, & Tuason, 1996) found in their examination of psychoeducation support groups across Spain that knowledge retention had significantly reduced by the nine month follow-up. Smith and Birchwood (1987) reported similar findings with knowledge declining six months after treatment.

These latter findings cannot be compared too closely with the present study as these studies are day-long psychoeducation workshops or multi-session programmes as opposed to the present studies brief, two hour one session with phone call follow-up format. In addition, many of these studies did not include the client as part of the study or the intervention. By contrast, the present study actively involved the client as recommended by Birchwood and Tarrrier (1998) and Kuipers et al. (2002), was additionally carried out in a setting capable of providing continued care and support. Thus, given this backdrop, findings here are particularly encouraging.

Additional analyses were conducted to examine potential variable effects of possible moderators on knowledge acquisition, such as having previously attended education sessions on schizophrenia, the length of time participants have been involved with the relevant agency, and whether participants belonged to S.F. or R.F. None of these factors predicted knowledge acquisition. It might be expected that previous education about schizophrenia would limit what and how much could be learned in the intervention. The findings here that run contrary to that

expectation might be because the intervention focused not only on imparting factual information about schizophrenia but also focused on management and coping strategies designed to help families engender a low-stimulus environment when living or in close contact with one another. Also, that gaps in knowledge identified in the pre-test KASI were able to be expanded upon in the education session itself may also have contributed here.

A similar result occurred with the variable of length of time participants had been involved with their agency, with statistically no difference on the impact of acquisition or retention of knowledge between participants with little to no involvement and those with lengthy involvement. Both groups had significant gains in knowledge post-intervention. One implication of these findings is that an intervention programme of the type evaluated in this study might be a useful addition to the resources offered to clients and families by community support agencies, perhaps offered and provided soon after clients and families become part of that agencies' "reach". If this were the case, particularly if a one off intervention is then combined with continuing support for the tenets of that programme, then future research might see a relationship between length of involvement and positive gains.

Taken together, findings support the potential of brief community education in providing family members information which might be used to assist themselves and their diagnosed family member. The results suggest that family members increased their understanding of schizophrenia and ways to manage it on a daily basis. Additionally, knowledge in areas which might lead to actions detrimental to the clients' recovery also improved.

### **Expressed Emotion**

The second aim of the present study was to see whether brief education carried out in a community setting would lead to lower participants' Expressed Emotion. It was hypothesised that the provision of information would lead to a decrease in EE. This was assessed through a comparison of treatment and control group scores before and after the education. Overall, the results were positive with significant change found in most areas of Expressed Emotion. However, unlike with knowledge, change was not observed simply as a function of the treatment condition only.

Initial analyses comparing treatment and control conditions showed that family members' EE ratings significantly decreased from pre- to post-test on all four subscales of the LEE (Intrusiveness, Emotional Response, Attitude toward Illness, and Tolerance/Expectations) as well as on the Total score. However, significant trials effect and the lack of interaction effects suggests that this decrease was independent of whether they were in treatment (i.e., Treatment Group I) or the wait-list control group.

This indicates that after pre-test1, family members began to modify their behaviour becoming less intrusive and critical, and more tolerant and relaxed around the client. They possibly began to decrease their expectations of the client resulting in a significantly lowered EE rating for both family members in Treatment Group I and the control group regardless of condition. However, it was also observed that the majority of variance accounted for in the significant trials effects was in all cases accounted for by the treatment condition. For example, treatment produced change in the Total LEE score that was over two times the magnitude of that seen in the control group, a finding similar to that reported in the 2008 study (Moxon & Ronan). In addition, given some modest change following the control period, it was encouraging that further change then occurred after the wait-list group participated in treatment. In fact, for Treatment Group II, change following treatment was twice the magnitude seen following the preceding control period. Thus, confidence in the programme is increased through magnitude of change differences seen both between and within groups. It also provides some support for nonspecific factors helping to produce changes prior to intervention. While the effects of retesting cannot be ruled out, it is also the case that positive change across the control condition might also reflect setting effects and the value of carrying out such programmes in supportive community settings as well as sampling factors (e.g., increased motivation).

Analyses of client EE scores showed significant decreases in the subscales of Emotional Response, Tolerance/Expectations and on the Total score (see also Moxon & Ronan, 2008), but not on the subscales, Intrusiveness or Attitude toward Illness. The core of the Emotional Response dimension reflects a supportive, calm and patient individual who listens and "is able to stay in control in stressful situations" (LEE Scale, Appendix 5). A reduction in this subscale following pre-test1 suggests that clients perceived that their family members were less frustrated, anxious, or dismissive around or of the client. That is, from the client's viewpoint, the family member was perceived to have become more patient and supportive of them. The core of the Tolerance/Expectations dimension reflects a tolerant, understanding and realistic individual who understands the client's limitations and "is realistic about what I can and cannot

do” (LEE Scale, Appendix 5) A reduction in this subscale following pre-test1 suggests that clients perceived that their family members were less demanding, less rigid with expectations of the client and from the clients’ viewpoint, had become more tolerant and understanding of mistakes and limitations and were also able to use empathy in viewing situations and issues from the clients’ point of view.

By contrast to these two subscales, the subscales of Intrusiveness and Attitude toward Illness did not significantly reduce for clients from pre1 to post-test. The Intrusiveness dimension reflects a calm and respectful individual who does not interfere, is not overprotective (“Isn’t overprotective of me”; LEE Scale, Appendix 5) and respects the clients right for privacy, or desire to be left alone. This scale reflects the emotional over-involvement (EOI) scale on the CFI, which is described (Leff and Vaughn, 1985) as a dimension reflecting emotional displays, excessive praise, and evidence of self-sacrifice or over-protectiveness amongst other traits and behaviours. The Attitude toward Illness dimension reflects a considerate, reassuring and sympathetic individual who encourages the client to seek help and “Is willing to gain more information to understand my condition when I’m not feeling well” (LEE Scale, Appendix 5). It is not clear why these subscales did not see significant change pre-post-test.

It is of interest that on the subscale of Intrusiveness, there was a significant decrease from post-test to follow-up on both client and family member versions, indicating that over the follow-up period family members had become less intrusive or overinvolved in the client’s life. That change, in particular was reflected in the clients’ ratings of their family member’s behaviour suggests that they felt their family members were allowing them to have more independence and control over their own lives.

As to why this change occurred, it is possible that the second half of the intervention which focuses on recognition and validation of the experiences and strategies shown to promote improved coping in similar situations – helped clients’ and family members’ to provide the foundation for this additional decrease. However if this is the case, it is unknown why the subscales of Tolerance/Expectations and Emotional Response did not also further decrease over the follow-up period.

A large portion of the family members sample group (24 out of 28) were parents. It could be that these are particularly well established behaviours for parents who are trying to care for their

child and minimise the effects of the disorder in the best way they know how. If these behaviours are entrenched then it follows that it would take longer to absorb the information and strategies presented in the education programme, and that it would also take time for the client to recognise that their parents instinct and desire to protect their loved ones had become more boundary appropriate. Hence, this may be one reason for the significant effect found from post-follow-up instead of from pre-post- intervention.

Overall findings suggest that the decreases in EE appear to have had something to do with education as such, perhaps combined with an “expectation” effect following initial assessment that perhaps combined with anticipation of receiving the education. However, here again, the magnitude of change following treatment was greater than that following the control period (e.g., Total score change twice as great following treatment) suggesting that this may only have been a minor contributing factor.

This finding is further supported by the follow-up data which show maintenance of change in EE from post-test to follow-up (apart from the family members’ and clients’ versions of the Intrusiveness subscale where further improvements were found). It was hypothesised that there would be minimal change in EE from pre- to post-test, as two weeks is scant time to absorb and assimilate new information, relate it to ones’ own experiences and behaviours and to begin to act and respond differently, whereas nine months seemed an appropriate amount of time for this process to have developed. The reverse occurred in this study; significant change was noted initially on the total score and some subscales and then maintained over the nine month follow-up period with one exception of continuing improvement. This is in line with the previous study which had a three month follow up interval (Moxon & Ronan, 2008). However, it is not consistent with other brief studies (Abramowitz & Coursey, 1989; Cozolino et al., 1988; Pakenham & Dadds, 1987; Smith & Birchwood, 1990) which found no significant changes in Expressed Emotion following brief educational interventions (less than 10 sessions; Maj & Satorius, 2002).

### **Expressed Emotion Sub-findings**

Further analyses were conducted in relation to EE to establish if the treatment produced decreases in EE were dependent upon whether the person was initially rated as high-EE or low-EE. It was found that the family members’ and clients’ Total scores on the LEE were dependent to a degree on whether the participant was initially rated as high-EE or low-EE. While both

changed significantly, the interaction effect reflected greater significant change, after treatment for high-EE family members. This is not surprising as overall, high-EE participants had more room to alter their scores than low-EE participants who had limited change potential given they were already low-EE at the outset of the study.

On the other hand, a lack of interaction effects indicates that low-EE family members can also obtain benefit from education designed to promote understanding and coping strategies. A rating of EE does not denote a problem- or stress-free household. Tarrier et al., (1988a) caution that it would be misleading to assume that any family member of someone diagnosed with schizophrenia is without stress or difficulties. It can be suggested that if low-EE families do not receive any support, they might be more prone to develop high-EE behaviours such as critical and intrusive attitudes. It has also been theorised that some low-EE behaviours such as a lack of criticism, overinvolvement or the adoption of an 'ignore/accept' style of coping may sometimes be due to exhaustion and a function of burnout (Barrowclough & Tarrier, 1992). The fact that no family members changed from low- to high-EE status over the course of the study indicates that a brief education programme may also be useful as a preventive measure.

Barrowclough and Tarrier (1992) concluded that brief education has value in engaging the family in treatment, helping them to assimilate schizophrenia and its problems from a stress vulnerability framework. Pakenham and Dadds (1987) found that brief interventions have value as they can lead to increased understanding and short-term reduction of family burden, distress, and anxiety, but not to a reduction in EE. Cozolino et al. found no increase in knowledge in their 1988 study, yet family members did report an increased sense of support and decreased feelings of personal guilt. In their 1989 study, Abramowitz and Coursey found results including a more effective management of home life and reductions in self-reported distress and anxiety. However, none of these effects lasted to six month follow-up intervals.

It is important to note that no brief intervention other than Moxon and Ronan (2008) and the current study to date has found immediate or longer term reductions in EE. Given EE literature and its impact on increased frequency and duration of client relapse (Marom, Munitz, Jones, Weizman, & Hermesh, 2005), this finding is encouraging. If replicated and particularly given the significant impact on family members' intrusiveness toward the client, combined with increased knowledge, implementing brief education programmes within supportive community organisations appears to have potential.



## **FQ**

The third aim of the present study was to see whether brief education carried out in a community setting would lead to decreases in family members' perceived burden of care and distress and increases in family members' perceived ability to cope. It was hypothesised that the provision of information would lead to change in these three variables. This was assessed in two ways: firstly, through a comparison of treatment and control group scores before and after the education, and secondly by examining whether family members' initial EE status affected these variables. The results were positive with significant change found across treatment groups.

As seen in the Results section, analyses comparing treatment and control conditions showed that there was a significant decrease from pre-test to post-test in burden of care and distress as well as a significant increase in perceived ability to cope. However, significant trials effects and the lack of interaction effects suggests, as with the EE result, that these changes were independent to a degree of whether family members were in Treatment Group I or the wait-list control group. Similar results have been found in longer psychoeducational interventions such as in the Magliano et al. (2006) study which found in their six month intervention that family burden was significantly reduced in both the treatment and wait-list control groups. However, it is in contrast with most other long-term interventions assessing familial burden of care and carer distress (Canive et al., 1996; McDonnell et al., 2003; Mueser, Sengupta, Bellack, Glick, & Schooler, 2001; Solomon, 1996).

A short-term improvement in burden of care and carer distress has also been found in other educational interventions that are shorter than ten sessions (Abramowitz & Coursey, 1989; Berkowitz et al., 1984; Lam, 1991; Posner, Wilson, Kral & Lander, et al., 1992; Smith & Birchwood, 1990) but in most of these studies an increase in distress reoccurred after six months (Birchwood et al., 1992; Smith & Birchwood, 1990). In addition it is difficult to compare the present study with these as in addition to the present study being very brief at only two hours duration, it also involved the client in the intervention which many of these studies did not.

With all this said, as with the EE result, the majority of variance accounted for in the significant trials effects was in all cases accounted for by the treatment condition, with the

magnitude of change following treatment being much greater than that following the control period. Thus, the pattern overall indicates that following the intervention family members felt less burdened by client behaviour previously rated as problematic, felt less distressed by it and felt more in control and able to cope with these behaviours. If one was to combine this finding with the significant post-follow up finding for clients and family members in the Intrusiveness subscale of the LEE, a speculation is offered. This finding of family members becoming less intrusive and overinvolved over the follow-up period, allowing clients to have more control over their own lives, could be linked to an adoption of an “ignore/accept” style of coping indicative of low-EE families following treatment. Future research could more definitively focus on this issue with a larger sample size. Finally, combined with EE findings and with previous research findings (Moxon & Ronan, 2008), this overall pattern of findings implicates various issues include statistical power, expectancy and setting effects and sampling bias. As a consequence, future studies might pay attention to these factors.

### **FQ Sub-findings In Relation to EE Status**

Further analyses were conducted in relation to EE to establish if the treatment produced changes in burden of care, distress and perceived coping were dependent upon whether the person was initially rated as high-EE or low-EE. The lack of interaction effects in the decreases between the high-EE and low-EE groups on burden of care and distress suggests that these decreases were independent of whether they were initially rated as high-EE or low-EE. This set of findings indicates that there is still benefit to be found in such interventions for low-EE family members.

On the other hand, it was found that the family members’ decreases in the coping subscale were dependent to a degree on whether the participant was initially rated as high-EE or low-EE. While both changed significantly, the interaction effect reflected greater significant change after treatment for high-EE family members. This specific finding is in keeping with the expressed emotion analyses which also found greater significant change after treatment for high-EE family members. It could be theorised that this result is also unsurprising as it is in line with previous research findings that low-EE family members already utilise a range of positive and effective coping strategies, such as an ‘ignore/accept style’ (Kuipers et al., 2002; Magliano et al., 1998; Sartorius et al., 2005) and although they still felt burden of care they appeared not to use avoidance strategies. High-EE families tend to use more avoidance coping strategies (Barrowclough & Parle, 1997; Raune et al., 2004; Scazufca & Kuipers, 1999) and perceive

themselves less able to cope as compared to low-EE family members (Smith et al., 1992; Wykes, Tarrier & Lewis, 1998).

It has also been found that low-EE family members are associated with, in general, a higher degree of coping than their high-EE counterparts (e.g., Harrison & Dadds, 1992) indicating that there was potentially more for high-EE participants to gain from the educational intervention to promote and reinforce effective coping strategies.

### **LIMITATIONS OF THE STUDY**

Despite the overall positive results of this study, it is important to acknowledge its limitations. The results are qualified by methodological limitations that included a relatively small sample size of 50 and smaller subgroups yet. This reduced the power of statistical tests. This study used samples drawn from national branches of Schizophrenia Fellowship and Richmond Fellowship, with approximately one fourth of those initially contacted participating in the study. While there were many reasons for this, the main reason was that both a key family member and client needed to be involved. In many cases, clients were eager to participate but a family member was ill or not willing, or a family member was willing but the client was not on regular psychiatric medications. Many other families who also expressed interest could not participate because of overseas holidays, family deaths, illnesses, hospitalisations and shifting cities. It was also found that in the larger cities of Auckland, Wellington and Christchurch, family members were less interested in participating in an education programme than those from smaller cities such as Timaru, Palmerston North and Blenheim who often appeared to be eager for more information and support.

Family member reticence in participating in the intervention is in line with previous studies with community samples where it has been found that only up to 50% of family members take the opportunity of community support or family intervention (Barrowclough et al., 1999; Mueser & Jeste, 2008). The author relied upon the field-workers and key-workers of the different branches of S.F. and R.F to promote the intervention, the possible benefits that may be obtained from participating, and to recruit participants. The differing levels of motivation of staff from branch to branch may also have affected the number of participants.

All participants voluntarily participated in the study which suggests a commitment to learning more about the illness, and likely reflected increased levels of intrinsic motivation by virtue of their willingness to participate. All factors which could have led to a biased sample group and likely had an impact on the outcomes, limiting the ability to generalise the findings to all family members with a relative with schizophrenia. It is possible that a different outcome would have resulted from family members who were less enthusiastic about the process (Cassidy et al., 2001; Leff et al., 1989; Mullen et al., 2002). While use of the randomized controlled design was used for these reasons to increase confidence that the findings were not simply due to increased motivation, the ethical imperative of voluntary participation doesn't erase concerns here. Thus, it is possible that the clients and family members who were contacted but did not participate in the programme would not have gained in knowledge about schizophrenia and coping or decreased in EE, burden of care and distress. Future research can help shed light on this issue.

As to why EE decreased in this brief intervention and a previous brief intervention (Moxon & Ronan, 2008) but not others, it is worth highlighting some possibilities. Firstly, the self-report measure used to assess EE should be discussed. Most previous studies (Cole & Kazarian, 1992; Gerlsma & Hale, 1997; Tarrier et al., 1988; Van Humbeeck et al., 2002) have used the CFI as the current optimal EE assessment measure and while the LEE Scale has been found to correlate well with the CFI, findings based on methodological differences cannot be excluded. In the present study, the LEE scale was preferred to the CFI in part because it is a quick, non-intrusive and easy to administer and measure with documented reliability and validity. Conversely, the CFI is a lengthy and involved interview in which the scoring process is difficult and extensive, something which would not easily integrate with the nature of community setting the intervention was conducted through.

However, it is possible to respond in a socially desirable manner on the LEE and create an illusion of low-EE by responding 'False' to items such as "I don't blame him/her when he/she is not well", and 'True' to "I am tolerant with him/her even when he/she doesn't meet my expectations". It is possible that the EE score that some people received did not accurately reflect their EE status. Most participants reported struggling with having to respond with a definitive True/False on some questions and recommended that improvements could be made by introducing a scale with a Likert type rating scale instead of using mere True/False responses.

It is possible though that family members and clients were accurate in their self-report ratings, but the accuracy of these self-report ratings cannot be verified from the data in the present study. Additionally, while there are difficulties with reliance on the singular use of a self-report measure to assess EE, the present study utilised using both the client and family member versions of the LEE to obtain a more robust rating. Additionally, while there are problems with the use of a self-report measure, confidence in findings is increased through the use of a multi-method, multiple informant approach, the use of independent assessors, and the randomized design. Nevertheless, other possibilities accounting for change include repeated testing and regression to the mean cannot be completely ruled out. However, other studies have not found such effects (Tarrier et al., 1988).

Two final methodological limitations which might have influenced the outcome of this study are that no chart diagnosis was obtained to confirm the diagnosis and the absence of stringently applied treatment fidelity measures makes it difficult to judge quality control within the present study. Fidelity could have been assessed more comprehensively through taping all education sessions and/or having participants complete a checklist post intervention. Having said that, selected sessions of this intervention were checked by a senior clinical psychologist to ensure that the education was delivered as intended. In addition, an outline that included some flexibly scripted elements (see Method) were carried out in every application of the educational intervention. Additionally, the addition of structured materials, notably, the take home booklet, guaranteed additional standardisation. Nevertheless, future research would benefit from increased attention to the direct measurement of fidelity.

In summary, this study has a number of limitations that restrict the interpretation of its findings. There were methodological shortcomings and the sample was small and not representative of all families affected by schizophrenia. The results may reflect a sampling bias. However as Pollio et al. reported in their 2006 study, “biases associated with self-selection to participate in educational workshops are inherent to these programmes as these programmes are not for everyone” (p.36).

## **FURTHER INVESTIGATIONS AND IMPLICATIONS**

Previous brief education programmes such as the one used in the Tarrier and Barrowclough research (Barrowclough et al., 1987; Tarrier et al., 1988a), and many reviews (Pitschel-Waltz et al., 2001) have concluded that education alone does not reduce EE or affect relapse, but it has been found that brief interventions can produce immediate increases in family members' knowledge (Birchwood et al., 1992; Cassidy et al., 2001; Linszen et al., 1996; Moxon & Ronan, 2008; Mullen et al., 2002), increases in general coping, and to an extent alleviate family members' burden and distress (Abramowitz & Coursey, 1989; Lam, 1991; Merinder, 2000; Posner, Wilson, Kral, Lander et al., 1992). This study found that education perhaps combined with some other non-specific factors can reduce EE, burden of care and distress to a degree which can be maintained at a 9-month follow-up. Over the course of the current study, there were significant reductions in EE, which were either maintained or, in the case of family members' intrusiveness, continued to improve over a nine-month follow-up interval. Here, reductions in EE appeared to be due largely to education.

One question here is why did EE decrease in this study when it has not in other studies with the sole exception of the Moxon and Ronan (2008) study that this replicated. As discussed earlier, it is quite possible that as a function of being connected to a community support agency as well as based on voluntary participation, participants entered the study with a certain mindset, level of motivation, and expectations. For those in the control condition, there was quite possibly anticipation that someone within a familiar setting who seemed to understand their situation was going to put aside time to listen, and discuss on a knowledgeable, empathic and one-to-one basis. Positive expectancies, and perhaps the effect of retesting, may have been sufficient to produce some non-significant changes in various indicators during the control period.

It is possible that the anticipation of participating in the intervention led to a reduction of EE, burden of care and distress as well as an increase in coping. All participants at the outset of the study discussed it with the author. Each participant was told that they would receive information about schizophrenia, expressed emotion, and techniques that other families have found helpful in not only coping with the client on a daily basis, but to aid them as well. Perhaps the idea that this study could help was part of the reason for the decrease. Some clients stated that it might be beneficial for their family member to participate as it may help lower their feelings of guilt and responsibility about the illness, stop them from 'nagging' and help

them to see more from their point of view. Some family members stated that it would be beneficial for clients to participate as the helpful techniques given may help if heard from a non-medical type person or authority figure. Perhaps the initial information coupled with expectancy effects that were further magnified by the self-assessment and reflection required for the pre-test measures – in a sample of motivated participants - may have combined to promote some cumulative effect. Such factors might then have been sufficient to begin to lower EE, burden of care and distress while increasing perceived coping during the control interval.

It is also possible that the beneficial changes achieved during the course of the intervention itself were due in part to the design of this particular protocol and to the additional focus of the second part of the education programme. The second half of the education programme focused on providing validation to participants in how they may be feeling in response to the illness, in addition to reassurance that they are not alone in learning to cope with and manage it. Information was also provided on the value of a low-stimulus environment, as well as coping techniques and self-care strategies, all proven to have had a modicum of success with people in similar situations. Encouragement of participants to become actively involved was particularly provided for this component of the intervention, as was the exposition on particular areas identified as weaker in the pre-test measures. This additional focus may have contributed to a mutual reduction in EE levels (of both client and family member) as well as a reduction in family members' subjective burden of care.

This study also differs from other brief interventions in that it was conducted in New Zealand and it was not conducted in a research-based setting. The positive results achieved here likely were influenced by this study being conducted through community organizations who believe in, support and practice the principles advocated in the intervention. All participants were members of, or affiliated with the organizations, although not all participants were actively involved with the agencies. It is highly likely that the community setting helped produce an atmosphere conducive to both increased expectancies as well as actual change. More research is needed to examine whether there is more direct data-based support for the potential of community organizations to influence the way clients and families perceive, react to and manage this disorder on a daily basis.

The professionals administering the measures were agency field or key-workers, and the author (a PhD student in psychology) conducted the education. These people were not clinicians and all saw the participants in their nominated venue where they felt most

comfortable. They did not appear to be threatening or intimidating, and all made themselves available for queries, concerns, or support. It was also suggested during the intervention that it would be of benefit to utilise the appropriate fellowship for additional resources, knowledge and support. Perhaps this was a more laid-back (though still experimentally rigorous) approach than previous clinical trials resulting in a more relaxed atmosphere for participants.

When considering reasons for the success of this intervention, in addition to the intervention itself, the delivery also should be considered. That is, the author of the study is another possible factor in the results of the intervention. The author/educator had gathered by the close of the intervention 13 years practical experience working in the mental health field and 12 years research experience over the course of the two research projects (Masters and PhD). It is likely that this influenced the ability to be flexible and for the intervention to be tailored according to each participants pre-test information. This may have been due to the amount of comprehensive and up-to-date knowledge about schizophrenia coupled with clinical experience gained from working in the field. Any future research would need to ensure that educators had a similar wealth of knowledge and experience to be able to effectively implement a flexible education programme. Additionally, in studies that have multiple therapists, including the therapist as a variable in future research would also be desirable to start addressing questions that revolve around the level of experience and skills required for useful delivery of this and related programmes.

The difference of results between previous studies and the Moxon and Ronan (2008) and present study could also have been influenced by a cultural difference. Future research would benefit from conducting the same study in different environments (e.g., inpatient settings, outpatient settings, community support settings) in different cities and regions throughout N.Z. (i.e., Auckland, Hamilton, Dunedin, and Christchurch) as compared to different countries.

In summary, in terms of an overall direction for future research, with support now from two RCT evaluations that have produced a similar pattern of findings, a next step may be to begin identifying and isolating more precisely what the therapeutic elements are in this intervention.



## **CONCLUSIONS**

This thesis has described the development, implementation and results of a brief community education programme which aimed to 1) inform family members and clients about schizophrenia with a particular focus on strategies found to be helpful in coping with schizophrenia symptoms on a daily basis, 2) to lower Expressed Emotion, and 3) to decrease burden of care and distress whilst increasing perceived coping for family members.

Many family members brought to the education programme well-developed and long-standing belief systems about schizophrenia. Nevertheless, it was found against established research that a brief intervention carried out under the auspices of community support settings helped to foster useful change. Despite study limitations, findings largely point to the ability of this brief psychoeducational intervention to achieve intended goals.

Though the present study demonstrated positive findings, it is important to note that brief education is obviously not suitable or enough for all and nor is it designed per se to facilitate long-term change. Many clients and family members need more in the way of problem solving skills, communication skills, and regular one-to-one support and assistance. A comprehensive intervention is often the most appropriate treatment for long-term management of the disorder, especially for those who have lived with the diagnosis for longer and have developed a crystallised mindset about schizophrenia. However, brief education as conducted here, appears to have clear merit within a community-based intervention approach, and perhaps as one way to connect families to more intensive mental-health services where necessary.

The effects and usefulness of brief interventions can be summarised by Pollio et al. (2006) in their argument that expecting durable effects from brief interventions may be unrealistic and that it may be “more appropriate to conceptualise such brief interventions as portals to more intensive services, providing hope and support, and offering ideas for coping with family concerns and problems related to the illness” (p.32). Following this line of reasoning, the current findings support the role for brief education programmes in community settings which provide information to family members and clients about schizophrenia. The present study attempted to address this need by providing information about schizophrenia, expressed emotion and practical ways of coping with both on a daily basis. It was expected that providing information about schizophrenia and its management would alter the attributions that family

members make about the client's symptomatic behaviour – which would be reflected in increased knowledge in family members, lowered expressed emotion in all participants and decreased burden of care and distress in conjunction with increased coping in family members compared to a randomly assigned wait-list control condition.

The effectiveness of this brief programme was demonstrated, particularly in terms of knowledge and various other indicators including family members' intrusive attitudes over time. This is encouraging and supports the value of these programmes in recovery and community support settings. The brief community education intervention not only appeared to address the needs of the family units in a non-threatening manner, but anecdotally may have also established, in some cases, a similarly non-threatening link to more intensive and long-term services. Further research is needed to address more complex issues such as intervention active ingredients, the relationship between burden of care and specific types of EE and the comparison of samples in community support settings as opposed to more traditional settings (e.g., intensive hospital treatment settings).

# **Appendix 1**

## **Information Sheets**

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## **Appendix 2**

# **Consent Forms**

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