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PROVIDING INFORMATION TO RELATIVES ABOUT EXPRESSED
EMOTION AND SCHIZOPHRENIA

A thesis presented in partial fulfilment
of the requirements for the degree of
Master of Arts in Psychology
at Massey University

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1999

Abstract

Studies have shown that long term psychoeducational programmes aimed at lowering the Expressed Emotion (EE) in family environments can improve communications between the family members and the client, reduce EE, and lower expectations. The present study aimed to enhance family members knowledge about schizophrenia and expressed emotion, as well as awareness of their current coping strategies by conducting a brief educational intervention designed to overcome methodological shortcomings of similar studies. It was hypothesised that providing information to families (excluding clients) about schizophrenia, expressed emotion and ways in which each member can help, would alter the views and attributions that relatives make about the causality of the client's behaviour compared to a randomly assigned wait-list control condition. These changes would then be reflected in reduced criticism, hostility, and emotional overinvolvement and increases in the amount of accurate information concerning schizophrenia. People with schizophrenia were recruited into a controlled trial of a brief educational intervention with family members. Relatives and clients were randomly allocated to one of two groups: a treatment group or a wait-list control group. They received a brief educational intervention designed to give clients and relatives individualised information about schizophrenia, expressed emotion, and how to manage individually in the home and in their relationships. Analyses of the results showed that relatives knowledge increased significantly after the education, and was maintained at the three month follow-up. The control condition reflected no changes in knowledge. Other results showed that relatives' and clients' EE ratings significantly decreased from pre- to post-test. All gains were maintained at the three month follow-up. At nine months after education only 1/19 clients had relapsed. The analyses suggested that although knowledge increased as a result of education, the decreases in EE were not due to education alone. The discussion considers these findings in some detail.

Acknowledgements

I would like to take this opportunity to thank the following people who have helped make the completion of this thesis possible.

Ian Falloon , Nicholas Tarrier and Christine Vaughn for their kind encouragement and generosity with the use of their research.

My supportive friend Erina, whose sympathetic ear helped to lighten the load.

Duncan Hedderley for his statistical assistance and for being kind, patient and understanding at the time when I most needed it.

The Ladies at Manawatu SF - Christine, Elizabeth and Pauline - whose support, encouragement and guidance was so steadfast that I truly do not have the words to express my gratitude.

My parents who put up with me and my thesis, I believe they came to know it as well as I did. Without their support, tolerance, love and ability to make me laugh at myself in times of great stress, this thesis would never have been completed.

The participants who made this research possible.

Kathryn Platz who despite difficulties gave her valuable assistance and time.

June Read who believed in me and in doing so gave me the courage to believe in myself.

Finally, I wish to thank my supervisor Kevin Ronan for his knowledge, understanding and genuine desire to help others which helped turn a vague but enthusiastic idea into a workable reality, and for his constant faith in my ability to 'fight the good fight'.

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Chapter 1

“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, p679).

Most people are reared as children on fairy-tales laced with evil, madness, witches, and hallucinations. This can be seen in ‘Peter Pan’ where the villain ‘Captain Hook’ frequently a) experienced auditory hallucinations (the tick-tock of a clock), and b) committed irrational acts. As adolescents, people are educated on madness and schizophrenia with the Shakespearean works “King Lear, Hamlet, Othello, and Macbeth”. For example in “Macbeth”, both the title character and his wife have visions of witches, slain friends, and bloodied hands which cannot be cleaned. The main characters both commit irrational acts whilst Lady Macbeth lapses into incoherence and is diagnosed with an “infected mind” (Shakespeare, 1975, Act V, Scene I, pg 1066).

On television, people with schizophrenia are generally to be pitied, jailed, seen as a source of amusement, the source of violence, an irritation, or are portrayed as mass murderers. It is rare indeed when a person diagnosed with schizophrenia is shown as someone with an illness who is functioning in some way adaptively.

Motion pictures also seem to compound the confusions and fear about schizophrenia and mental illness. In fact, in the movie industry there exists something called the schizophrenic drama (Halliwell, 1997), seen in the films *The Three Faces of Eve*, *Lizzie* and *Vertigo*. Yet the current trend in films is to present a) “case histories (of schizophrenia) in which no solution is offered” (Halliwell, 1997, p334), b) psychological (or schizophrenic) horror, and c) homicidal sociopath films (Fleming & Manvell, 1985). These interpretations of the schizophrenic drama can be seen respectively in a) *Repulsion*, and *Morgan*, b) *Psycho*, *The Shining* and *Misery*, and c) *Silence of the Lambs*, *Kalifornia*, and *Natural Born Killers*.

It has been suggested by advocacy groups for the mentally ill (Noll, 1992) that these trends in both television and feature films have unfairly accentuated the “homicidal

maniac” stereotype of individuals suffering from schizophrenia. Also, it has been further suggested that these are unrealistic portrayals which contribute to maintaining a negative stereotype about schizophrenia for the general public (Prawer, 1980).

Is it any wonder then that schizophrenia is so misunderstood and that when any mass shootings, or attempted assassinations take place, the media in some cases start proclaiming that the alleged is a “paranoid schizophrenic”.

This is unfortunately compounded when the rare person with schizophrenia does commit an act of violence upon another person, such as the attempted assassination of US President Ronald Reagan by John Hinckley. Such media attention can be extensive and helps preserve, again, the negative stereotype that people with schizophrenia are violent. What is not usually broadcast by the media is that persons like John Hinckley are not representative of the 1% of the population suffering from schizophrenia.

The point of this is that from childhood onwards people are conditioned through various mediums, from folk-lore to the popular media, to stereotypes of schizophrenia.

It is not then surprising that families and friends of the diagnosed may also share the beliefs of the general population. If they do have these beliefs, then how do they reconcile these general stereotypical attitudes to their loved one who has just been diagnosed with schizophrenia? “Do they reject their previous opinions of mental illness, or do they develop an attitudinal dichotomy, continuing to care for their ill relative and coping with their behaviour, whilst still incorporating general (negative) stereotyped beliefs regarding the mentally ill?” (Atkinson & Coia, 1995, pp27-28).

When someone develops and suffers from schizophrenia, it has a varying degree of impact on everyone in the family. Relatives may see their loved family member develop odd, or bizarre ideas and perceptions, enhanced anxiousness and restlessness, inexplicable rituals or belief systems, a disregard to personal hygiene, an indifference to other people and erratic, sometimes disruptive behaviour. The despair and anxiety

relatives can feel at these times is often worsened by guilt and worry about their contribution to the development of schizophrenia in the individual.

Most families struggle to come to terms with the differences in the personality of their family member and have difficulty reconciling their stereotypical beliefs about schizophrenia with their diagnosed family member. The attempts to reconcile these two things can often lead to guilt and compensatory over-involvement in some family members. However, in some other families, attempts to help can deteriorate and be replaced by criticism, 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).

Family education programs provide information about schizophrenia to assist clients and relatives and to overcome stereotypes. They endeavor to teach family members what they can do to help their diagnosed relative and themselves in order to create and maintain a more relaxed and benign family environment. This thesis is focused on such a programme.

Literature Review

The History of Schizophrenia

The disorder known as schizophrenia appears to have existed for a very long time. Accounts of people with the symptoms of modern-day schizophrenia go as far back as Ancient Greece (Rosen, 1968).

One example is Dionysius (I) the Elder from ancient Greece 430-367 BC. He was famed as the Tyrant of Syracuse and known to be brutal, merciless and suspicious about plots to kill him. As a side-line to war, he wrote plays and often submitted them to local drama contests. Unfortunately, he apparently made a better warrior than he did playwright. As after one particularly humiliating judgement on one of his plays, he began to accuse all he knew (including friends) of plotting against him because they were envious. Many people were executed on false charges after this incident. Such behaviour is exemplary of paranoid psychopathological symptoms found in schizophrenia.

One only needs to read the Bible (e.g. Ezekiel the Prophet; Smith, 1982) or study works on the British Royal family (King Henry VI, Charles VI of France and King George III) to note that disorderly behaviour with features of what we know as schizophrenia has existed throughout recorded history. Yet, it was not till the late 1800s, that it began to be clearly described and identified as a diagnostic entity with characteristic features.

Emil Kraepelin, a German psychiatrist, first presented his concept of dementia praecox in 1898. He emphasised the progressive intellectual deterioration (dementia) and the early onset (praecox) was the core of the illness that is now called schizophrenia. However, a Swiss psychiatrist of the same time, Eugene Bleuler, emphasised the “breaking of associative threads” (which in normal people would link thoughts, emotions, and behaviours resulting in rational, intentional behaviour) as the core of the disorder. This focus differed from Kraepelin’s focus on classification by prognosis and the onset and course as the essence of the disorder. Because of these opposing emphases, different

definitions of the disorder developed. Kraepelin's view led to a relatively narrow definition of schizophrenia, whilst Bleuler's led to a broad one with a much greater emphasis on 'core symptoms' (Bleuler, 1950; Kraepelin, 1981).

Yet both psychiatrists contributed to defining schizophrenia, outlining characteristics for the disorder which are still largely held to be true. For example, Kraepelin stated that the disease begins in early adulthood or late adolescence, generally more women than men develop it, and that the illness seems to be largely hereditary. These premises are today still true (Noll, 1992).

Bleuler's influence can be seen in two developments. First, he proposed the shift from the label "dementia praecox" to schizophrenia. He developed the term schizophrenia from the Greek words schizein (to split) and phren (mind). Bleuler believed this term to better capture the essence of the illness, as to him it referred to the fragmentation of thought processes seen in schizophrenia (Bleuler, 1950).

Second, Bleuler's influence is also seen in the increased use of his version of the diagnosis. In direct contrast to Kraepelin's narrow definition of schizophrenia and emphasis on description and classification, Bleuler had a more theoretical emphasis and included in his definition of schizophrenia those with "many atypical melancholias and manias of other schools, especially hysterical melancholias and manias, most hallucinatory confusions, some 'nervous' people and compulsive and impulsive patients" (Bleuler, 1923, p436). This led to a broader definition and an increased use of the diagnosis.

Adolf Meyer (an American psychiatrist in the first half of the 20th century) was another who contributed to the increase in the frequency of diagnosis of schizophrenia. Following Bleuler, Meyer proposed that schizophrenia had much to do with "intrapsychic processes" (Birchwood, Hallett, Preston, 1989, p16) as with behaviour and experiences (Meyer, 1917). This led to the concept of schizophrenia becoming applied based on non-observable, theoretical descriptors which did not rely on "specific symptoms or progressive deterioration for a definition of the disorder" (Davison & Neale, 1996, p395). Again, the concept was broadened.

Recently though, as reflected in the DSM-IV (APA, 1994), the concept of schizophrenia has been narrowed in many ways. First, specific diagnostic criteria are required; second, those with the symptoms of a mood disorder are excluded; third, some symptoms of the disturbance must be present for at least six months prior to a diagnosis, and may include a prodromal or residual phase. It now excludes those patients with acute psychotic reactions to stress. Finally, what used to be considered mild forms of schizophrenia are now seen as personality disorders.

The Symptoms and Characteristics of Schizophrenia

Owing to the complexity of the disorder, the focus here will be on major distinguishing features: namely those which are needed in order to qualify for a diagnosis of schizophrenia. The symptoms reviewed derive largely from DSM criteria and from information collected on the International Pilot Study of Schizophrenia (IPSS), conducted by the World Health Organization (Sartorius, Shapiro & Jablonsky, 1974).

Schizophrenic disorders are a class of psychological disorders also referred to as psychotic disorders, that are marked by major disturbances in perception, thinking, emotion, and behaviour. Their effects can range from mild deterioration of personality to total withdrawal from human contact. Acute sufferers often lose touch with reality and can suffer from hallucinations and paranoia which can cut them off from the world and trigger intense anxiety and depression. Some have asserted that "schizophrenia means that a person finds it difficult to decide what is real and what is not real. It is a bit like having dreams when you are wide awake" (Barrowclough and Tarrier, 1992, Appendix 6).

There are many problems which are commonly found in schizophrenia, yet those diagnosed with schizophrenia can differ widely in the symptoms which they exhibit (Strauss & Carpenter, 1981). The range of potential problems is so extensive that it is extremely unlikely that an individual will exhibit all of the symptoms of schizophrenia at one time. It is more likely that each individual will exhibit a cluster of possible symptoms varying in number and severity (Barrowclough & Tarrier, 1992; Weiton, 1992).

Positive, Negative, and Other Symptoms

Most symptoms of schizophrenia can be characterised as either positive or negative (Andreasen, Flaum, Swayze, Tyrrell & Arndt, 1990). Positive symptoms are not “good” or benign symptoms per se, rather they refer to an excess related to changes and distortions apparent in behavioural, perceptual, and thought processes. These include disorganised speech (which can also be accompanied by disorganisation of behaviour), delusions (including thought disturbances), and hallucinations (Andreasen & Olsen, 1982).

Disorganised speech (also referred to as formal thought disorder) thinking which manifests as incoherent, fragmented or irrelevant speech. It is a problem in which the organisation of thoughts and subsequent voicing of them are characterised by loose associations, “derailment”, or lack of logical continuity. The individual may have difficulty sticking to one topic, drift off on irrelevant tangents, or produce meaningless associations. Disorganised speech can also be manifested in its more extreme form as incoherence, where the ideas and fragments of thought are not intelligible.

Delusions are seen as a deviance in the content of thought. They are beliefs that are not in touch with reality, are at times not coherent, and do not derive from an everyday experience. They can also be bizarre, persistent and unshakeable. Delusions are usually held to be true despite (a) other people not sharing the belief and (b) evidence to the contrary, as in the patient’s “ ‘heart of hearts’ they believe that others are wrong” (Keefe & Harvey, 1994, p25).

Delusions common to schizophrenia (Schneider, 1959; Mellor, 1970) are:

- a belief that you are being experimented upon, poisoned, followed, or will be harmed by others (paranoid and/or persecutory delusions). Unfortunately, in these instances, it may be that everyday occurrences (such as hearing a song on the radio or hearing a car horn toot) will hold special significance and be taken as further proof of their persecution.
- a belief that you are a famous or historical figure (e.g. Napoleon, Jesus Christ;

delusions of grandeur).

- a belief that you have no control of your thoughts or actions as someone else is operating and manipulating your body, thoughts and so forth (made feelings, made volitional acts, made impulses, somatic passivity).
- beliefs that your thoughts can be heard by others as if they are being spoken out loud (thought broadcast); the belief that thoughts that are not your own are being inserted into your mind by an outside agency (thought insertion); or a belief that thoughts are being stolen from you (thought withdrawal).

Some people also experience symptoms called 'hallucinations'. These are sensory experiences in the absence of any corresponding stimuli (false sensations). This means that the person hears, sees, smells, and sometimes tastes or feels things that are not heard, seen, smelt, tasted or felt by other people (Barrowclough & Tarrier, 1992). Particularly prominent hallucinations in schizophrenia include auditory hallucinations, such as hearing voices (Sartorius, Shapiro & Jablonsky, 1974). These are rare though as it is difficult to prove whether they are true or not.

These positive symptoms are often accompanied by significant difficulty in managing daily activities and social interactions (or grossly disorganised behaviour). This is most obvious in self-initiated, goal-directed activities, where the individual may be so absorbed in their positive symptoms that they lack the ability to follow a task through to its logical conclusion.

Negative symptoms are those symptoms which indicate an absence or decrease in behaviour. Included in this category are - lack of motivation and apathy, which usually involves a greatly reduced activity level (avolition); an inability to show emotion which at times may involve an unchanging, or 'frozen' facial expression, monotonous tone of voice, or lack of body language when speaking (blunted or flat affect); a disinterest in conversation, poverty of speech (e.g., single-word answers) or poverty in content of speech (alogia); an inability or decreased capacity to enjoy some activities that used to give pleasure (anhedonia).

At times, as a result of the negative symptoms, the client may forget to take care of their most basic needs, and thus become not only inattentive to other people, but to themselves. This may result in the client not sleeping, eating or attending to personal hygiene (i.e. not brushing teeth or hair).

Each of these symptoms separately or together with positive symptoms may lead to social withdrawal. There may be many reasons for this: they may have a delusional belief that people want to harm them, find holding a conversation too difficult due to distracting internal stimuli, find themselves socially anxious, have no interest, or simply prefer to be alone. Whatever the reason, this isolation is unfortunately a particularly difficult symptom for both the clients and family.

Other symptoms that individuals may exhibit do not fit into the positive or negative symptom categories. These can include strange facial expressions, odd gestures or a maintenance of unusual postures for long periods of time. Some catatonic clients, may move into and maintain strange positions that their limbs have been placed into by another person. Some clients with schizophrenia may also display emotional responses which are out of context with the situation (inappropriate affect).

Typology

“The DSM determines for the diagnostician how many problems must be present, and in what degree, to justify the diagnosis” (Davison & Neale, 1996, p389). There is no one key symptom necessary for a diagnosis of schizophrenia, and as mentioned earlier, the range of potential problems is so extensive that it is possible for those diagnosed to differ widely in the symptoms which they exhibit (Strauss & Carpenter, 1981).

This heterogeneity has led to schizophrenia being subdivided into types, according to the clusters of symptoms manifested by the client. Three types of schizophrenia initially proposed by Kraepelin are included in the DSM-IV. These are disorganised schizophrenia, catatonic schizophrenia and paranoid schizophrenia. Other types include undifferentiated schizophrenia, and residual schizophrenia.

Disorganised schizophrenia is characterised by profuse and poorly organised delusions and hallucinations, incoherent speech, disorganised behaviour, and neglect of self-care. Catatonic schizophrenia is characterised by motor disturbance and negativism. It is rare in the present day. Paranoid schizophrenia is the most common form of schizophrenia, and is characterised by auditory hallucinations or prominent delusions which are usually persecutory but may be grandiose. These symptoms may also be accompanied by other delusions.

Undifferentiated schizophrenia, put most simply, is when the individual does not meet the criteria conclusively for any of the above types, but still demonstrates signs and symptoms typical of schizophrenia. Residual schizophrenia is diagnosed when the individual no longer meets the full criteria for schizophrenia but still demonstrates some symptoms of the illness.

The subtypes of schizophrenia, including the undifferentiated and residual types, exhibit low diagnostic reliability, considerable overlap between types, and limited predictive validity. While the distinction between positive and negative symptoms is most often used, most people with schizophrenia demonstrate a mixed symptom picture and do not always fit neatly into one of the categories of schizophrenia (Davison & Neale, 1996).

Those wishing to add further depth to their knowledge of schizophrenia are advised to consult the World Health Organization's (WHO) International Classification of Diseases (ICD-10, 1992) and the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994).

Aetiology

It should be noted before discussing the various proposed causes of schizophrenia that there are some prominent researchers and psychiatrists who believe that schizophrenia does not exist, that a) it is not an illness but a lifestyle choice or b) the only rational way to cope or deal with a pathological family environment or an insane world. For example research by British psychiatrist R.D.Laing (Laing, 1960) suggested that schizophrenia may be a reasonable and indeed rational response to a family problem, and that those diagnosed with schizophrenia were only ‘marching to the beat of a different drum’. He further suggested that at least some sufferers wanted to experience delusions and hallucinations, and had actively chosen to do so. To dispel this theory, one only needs to talk with a sufferer of schizophrenia to discover that hallucinations are often seen to be intrusive, frightening and very unwelcome.

Another proponent of the non-existence of schizophrenia is Thomas Szasz (1979) who has argued vigorously over time that schizophrenia is merely a convenient label used by society to cope with people seen as bothersome and aberrant, that an individual is not ill, merely ‘defined’ as ill. He proposes that schizophrenia is

“fatally flawed by a single logical error: namely all of the contributions to it treat ‘schizophrenia’ as if it were the shorthand *prescription of a disposition*; in other words, they use the term schizophrenia as if it were a *preposition* asserting something about psychotics when in fact it is a *justification legitimising* something that *psychiatrists* do to them” (Szasz, 1979, p89).

On the other hand, the more mainstream view is that schizophrenia is an identifiable disorder (Davison & Neale, 1996). However, despite much research, scientists have not been able to find the exact cause or causes of schizophrenia and no specific neuropathology has yet been found.

The genetic component

However, research has been able to demonstrate in a convincing body of evidence that a predisposition for at least some forms of schizophrenia is transmitted genetically (Gottesman, 1991).

Many studies (Gottesman, McGuffin & Farmer, 1987; Kendler & Gruenberg, 1984) have shown not only that the illness runs in families and that the concordance rates for identical twins is consistently much greater than for fraternal twins, However, they have shown that biological children of schizophrenic parents have a high risk of developing the illness, even when separated from them at birth and reared in relatively healthy adoptive homes (Wender, Rosenthal, Kety, Schulsinger, & Welner, 1974).

Biochemical

The theory that schizophrenia is brought on by an increased number of dopamine receptors in parts of the basal ganglia of the brain (in chronic schizophrenia). This theory is based mainly on the mode of action of the drugs phenothiazines, which have been shown in many controlled studies to alleviate or eliminate psychotic symptoms, and to halve the rate of relapse (Hogarty, Goldberg & Schooler, 1974; Klein & Davis, 1969). If given in larger amounts phenothiazines also produce side-effects similar to Parkinson's disease which is known to be caused by low levels of dopamine. To date, the excess dopamine hypothesis has not been proven conclusively as there is uncertainty over whether the excess is a fundamental abnormality that precedes the development of the disorder (Kornetsky, 1976; Haracz, 1982; VanKammen, Hommer & Malas, 1987).

The Brain and Schizophrenia

A percentage of schizophrenics, particularly those with chronic, negative symptoms, have been found to have observable brain pathology, but it is as yet unknown whether these abnormalities are concentrated in a small number of brain areas or are more widespread.

Autopsy studies indicate structural problems in the limbic areas, the diencephalon, and the prefrontal cortex, and Computerised Axial Tomography (CAT) scans and Magnetic Resonance Imaging (MRI) studies reveal modestly enlarged ventricles (Golden, Moses, Zelazowski, Gruber, Zataz, Horvath & Berger, 1980; Zipursky, Lim, Sullivan, Brown & Pfefferbaum, 1992), suggesting a deterioration or atrophy of brain tissue. However, it is still unclear whether this is actually a direct cause of schizophrenia, an indirect

predisposing factor, or a consequence of the condition (Andreasen, 1985; Suddath, Christisan, Torrey, Casanova & Weinberger, 1990).

Some evidence supports the hypothesis that a viral infection occurring during the sixth month of foetal development may cause brain damage. It has been hypothesised that this early brain injury remains dormant until the prefrontal cortex matures, usually in adolescence (Mednick, Machun, Hottunen & Bonett, 1988; Barr, Mednick & Munk-Johnson, 1990).

The Family and Schizophrenia

There is little doubt that environmental factors are an important influence in schizophrenia. Identical twins (developing from a single fertilised ovum) are genetically identical, but if one of the twins develops schizophrenia, there is still only a 50% chance or less that the other twin will develop it also (Kendler & Robinette, 1983). This alone is sufficient to suggest that environmental factors are important. Unfortunately, we still know little about exactly what these environmental factors are and whether they influence the onset or alternatively, the course of schizophrenia (Loving, Mirsky, & Pereira, 1983).

In the 1950s and 60s, it was largely believed that (mainly) one environmental factor induced schizophrenia -- the mother of the diagnosed. It could perhaps be suggested that this was due to the emphasis on schizophrenia and its causes being more to do with "intrapsychic processes", due to the leaning away from biological causes for schizophrenia, or due to the prominence of Freudian psychoanalysis (from the 1920s to the 1960s; Noll, 1992). Whatever the reason, the theory of the schizophrenogenic mother (Fromm-Reichmann, 1948) came to the fore.

The theory of the schizophrenogenic mother or the refrigerator mother fully blamed mothers for causing schizophrenia in their offspring. The theory was that the mother was cold, distant, dominant, conflict inducing, and lacking in warmth and affection to the extent that she induced schizophrenia in her child. The feelings of rejection that the child

experienced, coupled with the loss of parental encouragement and reassurance, ultimately resulted in the development of schizophrenia.

Thankfully, this view has largely been refuted. However, other environmental factors have some support as detailed in the next few sections.

The Current Stance

Although there is no evidence that having an unhappy childhood or a neglectful mother may cause schizophrenia, there is evidence (Zubin, 1986) that the onset of the disorder may often be triggered or preceded by stressful experiences or events (such as a death of a loved one, starting university, or breaking up with a partner).

According to the underlying theory (the vulnerability model; Zubin & Spring, 1977; Nuechterlein & Dawson, 1984), an individual's vulnerability to schizophrenia (or an episode of schizophrenia) is influenced by 'ordinary' stressful environmental occurrences. Thus, high levels of stress may prompt an episode of schizophrenia in someone who is already vulnerable to developing it.

It is proposed that the "threshold at which an episode occurs is modelled as an inverse relationship between intrinsic vulnerability and the level of stress (i.e., the higher the vulnerability, the lower the level of stress required and vice versa") (Birchwood, Hallett & Preston, 1989, p339).

In more recent years, this theory has been expanded (Kavanagh, 1992; Zubin, Steinhauer & Condray, 1992) and incorporated into what is known as the diathesis-stress theory. This model holds that it is the interaction between a genetic predisposition (the 'diathesis' or 'biological vulnerability' which may place the individual at a high risk of developing the illness) and stressors in the environment (social and life events) that causes the disorder.

This theory is currently perhaps the most widely accepted theory among researchers and mental health professionals (Noll, 1992; Tarrier & Barrowclough, 1986). The generally held view is that schizophrenia basically results as a combination of two conditions: 1) a neuro-chemical disturbance (or imbalance) in the working of the brain which is inherited, and 2) stressful situations.

This model also holds that stress may not only induce the initial onset of schizophrenia, but may also induce episodes or worsen symptoms of schizophrenia once developed. This is possible because 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, p22). Keeping in mind the inverse relationship between intrinsic vulnerability and level of stress, this means that the level of stress required to induce episodes varies and at times for some individuals may result from ‘ordinary’ life experiences involving interpersonal, work-related, social and family interactions. Thus, “it appears that living in a stressful environment results in an increasing and accumulating level of physiological arousal, and a propensity to react in such a way to further stressors” (Barrowclough & Tarrier, 1992, p21).

People with schizophrenia (because of their symptoms) often have a lower stress tolerance, and this includes a lower tolerance for the normal family stresses that occur in the home. It can be said that they have a sensitivity or vulnerability to stress (Falloon, Graham-Hole & Fadden, 1997).

Expressed Emotion

Family stress or tension in living with a relative with schizophrenia can manifest itself in a variety of ways: as either denial of the illness, bewilderment, criticism of the diagnosed relative’s behaviour. Another way that families may handle stress is to compensate for the family member’s inadequacies and problems by becoming emotionally overinvolved and overprotective of the relative with schizophrenia (Anderson, Reiss & Hogarty, 1987; Barrowclough, Tarrier, Watts, Vaughn, Bamrah, & Freeman, 1987).

This is a potentially vicious cycle as a relative's concern for or reactions to the individual can be (intentionally or unintentionally) critical and hostile, and as earlier discussed, this may be stressful for the client. This may then result in a deterioration of behaviour or exacerbation of symptoms, which may then influence further overinvolvement.

This type of behaviour or communication problem in the family environment may not necessarily be an actual cause of schizophrenia. However, many researchers (Randolph, Eth, Glyn, Paz, Leong, Shaner, Strachan, VanVort, Escobar & Liberman 1994; McFarlane, 1994; Falloon, 1988) have found that this behaviour exhibited by families is a stressor that can either exacerbate or lessen the risk of episodes of schizophrenia. Families may influence this risk by alternatively placating or intensifying the symptoms of the illness with their response patterns or coping styles.

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. p899), and is an "index of environmental stress" (Barrowclough & Tarrier, 1992, p21). It refers to three areas of family relationships seen in the home environment: hostility, emotional overinvolvement, and criticism. More specifically, it is the amount of hostility and criticism, and the level of emotional overinvolvement directed from family members to the individual with schizophrenia.

The construct of Expressed Emotion was first developed in the early 1950s when Brown and colleagues (Brown, Carstairs & Topping, 1958) conducted a series of studies observing the outcome of releasing chronic schizophrenic patients in London (Brown, 1986). The initial finding was that those who returned home to live with working mothers were notably less likely to relapse than those who went home to mothers who stayed in the home (Brooker, 1990a). Brown et al. (1958) hypothesised that the emotional atmosphere at home was directly related to relapse

Brown spent the next fourteen years working with colleagues further investigating and refining the construct of expressed emotion (Leff et al., 1985). Thus, it was not until 1972 that everything “came together” (Brown, 1986, p32) and the construct of expressed emotion was introduced.

“It was initially formulated as an index of the emotional climate within the home environment, an attempt to assess the quality of the relationship between patient and relative” (Tarrier, 1996, p272). The make-up of this emotional climate was seen as potentially important in the course and prognosis of schizophrenia. Further, if this were true, then a measure assessing EE could possibly predict the outcome of schizophrenia.

While what EE truly represents is still under debate by researchers (see Kavanah, 1992), it is generally viewed as something which does not directly cause relapse per se, but “rather is a barometer of family distress in response to disturbing symptoms, behaviours, or life styles of their ill relatives” (Lefley, 1992, p592).

It has been found that High EE families tend to be either hostile, highly critical, overinvolved or controlling, and their response pattern is marked by “intolerance to patient problems, intrusiveness, and inappropriate and inflexible methods of solving problems” (Barrowclough, Johnston & Tarrier, 1994, p68). On the other hand, families lower on EE tend (or appear) to be more tolerant, warm and understanding, and their characteristic response pattern is to generally be broad-minded, nonintrusive, open to their family members needs, and flexible in coping with problems (Barrowclough, et al., 1994).

It has also been demonstrated that “high-EE relatives tend to be locked into a series of negative interactions” (Barrowclough & Tarrier, 1992, p22) with the client, whilst low-EE family members appear to be more able to ‘go with the flow’ (Hahlweg, et al., 1989).

Research has clearly authenticated the predictions that the Expressed Emotion in the family environment that the client returns home to or resides in, plays a role in the

likelihood of the client experiencing relapse (Kuipers & Bebbington, 1994; Falloon, Boyde & McGill, 1982; Vaughn & Leff, 1976b).

Early research by both Brown, Birley, and Wing (1972) and Vaughn and Leff (1976a) indicated that approximately 92% of clients with schizophrenia (not on regular medication) who resided with high EE families and had more than 35 hours of face-to-face contact with their families a week relapsed over a nine month period. This was in direct contrast with clients who lived with low EE families (with the same amount of contact) -- only 15% relapsed. This makes the ratio of clients from high EE families experiencing relapse to those of low EE families roughly 6:1. These statistics have been replicated by other researchers including Falloon, Boyde & McGill (1985) and Kuipers and Bebbington (1994). Tarrier and Barrowclough (1990, cited in McFarlane, Lukens, Dushay, Deakins, Newmark, Dunne, Horen and Toren 1995), found that a total of 53% of patients living with a relative who had high EE relapsed, in comparison to 23% living with a low EE relative.

An in-depth aggregate analysis was conducted by Bebbington and Kuipers in 1994 using 25 studies (with 17 providing original data) from different parts of the world linking expressed emotion and schizophrenia. Their results demonstrated that 50.1% of those residing in high EE households relapsed within a nine month period compared with 21.2% from the low EE households, and that the amount of face-to-face contact time with high EE relatives was a risk factor for relapse, yet interestingly a protective factor for patients residing in low EE families.

The Attributional Model

To add further depth to the construct of expressed emotion, it is useful to look at the attributional model of expressed emotion. Instead of examining how relatives differ in response to the client, the attributional model explores why they differ in their responses and attitudes to sufferers of schizophrenia. This model suggests that the attributions family members make about the causes of symptoms in the client may be important in

understanding the family members attitudes and reactions to the client, and their subsequent ability to cope effectively (Harrison & Dadds, 1992).

Many have theorised that high EE in relatives is related to attributing symptoms to the client rather than to the disorder (Brewin, MacCarthy, Duda, & Vaughn, 1991; Greenly, 1986; Hooley, 1985). Vaughn and Leff (1981) have suggested that high EE relatives have unrealistic expectations --possibly because of their lack of knowledge about schizophrenia-- that cause them to feel that if the client wanted to, they could control their symptomatic behaviour. So the idea here is that when not controlled, it then proves annoying and makes them less sympathetic toward both the illness and the client. Alternatively, low EE relatives are thought to believe that the patient suffers from a 'real' illness and cannot control some symptomatic behaviours, prompting them to be more tolerant and understanding, both to the illness and the individual.

It has been further proposed (Hooley, 1985) that Expressed Emotion is also affected by the attributions that family members make about the discretionary control the client has over specific symptoms or symptom clusters. Hooley (1985) suggests that clients with positive symptoms (e.g. hallucinations or delusions) are more likely to be perceived as involuntary and unintentional, and are thus more likely to be attributed to a legitimate illness. Negative symptoms (behavioural deficits particularly self-neglect and apathy) are more likely to be attributed as controllable, and the patient seen as merely unwilling to behave in an appropriate manner (see also Vaughn & Leff, 1981). Hooley and colleagues have provided empirical support for these suggestions (Hooley, Richters, Weintraub, & Neale, 1987).

A broader theory relating emotions to different attributional dimensions has been proposed by Weiner (1986). Weiner proposes that emotions such as anger, guilt, pity, and shame occur because of prior attributional beliefs about the causes of behaviour exhibited by clients. In relation to Expressed Emotion, his theories about anger have particular relevance. The theory in relation to anger is 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). A client's symptoms and negative behaviours may thus elicit anger and subsequent hostility and critical comments in relatives who perceive the patient as being able to control their symptoms and behaviours. If this pattern continues, one result can be what we know as high EE.

Research has supported 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 would attribute negative symptoms to the personality rather than the illness of the client, the results have supported the predictions (Brewin, 1994; Brewin, MacCarthy, Duda & Vaughn, 1991; Harrison & Dadds, 1992; Barrowclough, Johnston, & Tarrier, 1994).

Thus, while there is empirical support for the theory that particular emotional attitudes in relatives (and in particular anger) have an attributional origin, more research needs to be done to get a more comprehensive idea of this view of the attributional theory of expressed emotion.

The research cited here has demonstrated that high EE relatives make different attributions about client's symptoms and behaviour than do low EE relatives and that low EE and emotionally overinvolved relatives are similar in their attributions because they attribute the cause of negative symptoms and behaviour to factors more outside of the patients control. On the other hand, family members high in critical comments and/or hostility attributed more causes to factors inside of the patient's control.

Treatment

Historical Overview

Over time there have been a plethora of treatments for schizophrenia which have all differed widely in both their administration and success. However, all past and present treatments have one thing in common - none has shown to cure the condition outright.

Previous centuries have witnessed such treatments as incarceration in private and public madhouses and workhouses, the use of sedative drugs and purgatives and new-age approaches such as astrology, phrenology, physiognomy, palmistry and graphology (Hunter & Macalpine, 1964). Such treatments may have been inventive and usually had good intentions, but they seldom worked in any useful way.

Currently, research based approaches are much more commonplace. However, the fears, uncertainties and frustrations that are brought about by the illness continue to be a “fertile breeding-ground for worthless treatments and fanciful theories of causation” (Gregory, 1987, p698). In the last 30 years, there have been numerous claims that schizophrenia can be completely cured by: some forms of psychotherapy, ingesting large amounts of vitamin B, strength of will and special diets.

Fortunately, although some people may grasp hopefully at such “cures”, most people seek help from mental health professionals who specialise in those interventions that have some established empirical support.

Current Treatment Models

In the past, most schizophrenics spent much of their lives in hospital and were subjected to radical treatments such as insulin coma therapy (Sakel, 1938), fever therapies, prefrontal lobotomies (Moniz, 1936) and electroconvulsive therapy (Corletti & Bini, 1938). While each of these therapies had proponents which claimed high levels of

success, none demonstrated any scientific support and have largely been abandoned since the 1950s until the discovery of the effects of the phenothiazines (neuroleptics).

It was discovered that chlorpromazine (trade name Thorazine) could, in some people, reduce or eliminate some symptoms of schizophrenia (Kalat, 1995) to the extent that it “prompted the huge exodus of patients from state hospitals in the 1950s” (Keefe & Harvey, 1994, p145). Since then, researchers have developed many antipsychotic drugs, most belonging to the two chemical families - the phenothiazines and the butyrophenones.

These drugs affect neurophysiological systems in different ways, but they all have two things in common. When taken regularly, they have been shown to reduce positive symptoms and to prevent or lessen the chance of further psychotic relapses. At the neuronal level, they all inhibit transmission in dopaminergic neuron systems in the brain by blocking the postsynaptic dopamine receptors (Snyder, Banerjee, Yamamura & Greenberg, 1974; van Praag, 1977).

Unfortunately, for most people, phenothiazines also produce side-effects. These may include dry mouth, drowsiness, sedation, dizziness, blurred vision, constipation, weight gain, restlessness (akathisia), muscle rigidity, Parkinsonian Syndrome and sometimes a disorder involving involuntary movements (tardive dyskinesia).

In the decades since the 1950s, there have also been important social changes which along with the advent of neuroleptics, have contributed to an improved future for those diagnosed with schizophrenia. Perhaps the most important change is that those with schizophrenia are now rarely consigned to the neglected (Wing & Brown, 1970) ‘long-stay’ wards of the type of mental health hospital that can lead to “an impoverished life in grossly abnormal surroundings that probably increased the intrinsic handicaps of the illness and certainly (have) little curative effect” (Smith, 1982, p149).

Thus, instead of staying (by choice or otherwise) in hospital for long periods, clients now tend to be released as soon as possible. In this way, those “who in the past would have spent 40 or 50 years in an asylum are now able to live useful and even happy lives”

(Gregory, 1987, p699). The flip-side is that this may also create a 'revolving-door' pattern of admission, discharge, readmission, and once their acute symptoms are controlled, another discharge. Research shows rehospitalization rates of 40-50% after one year (since onset) and 75% upwards after two years (Anthony et al, 1986; Paul & Menditto, 1992).

Such a state of affairs can also create an increasing burden of care for the families of those with schizophrenia. Studies have found that between 46% (Bland & Harrison, 1995) and 65% (Intagliata, Willer, & Egri, 1986) of hospitalised schizophrenic patients return on discharge to live with their families.

The return of the family member can cause a major upheaval in both his or her life and those of their families. Those with schizophrenia may feel hurt, angry and resentful for not being understood or helped and for being admitted to the hospital. Relatives may feel 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 (in some cases sacrificing time or even a full-time job) than is normally required for a person of the client's age (Schene, vanWijingaarden & Koeter, 1998).

Relatives also may then feel guilty for any ill feelings, or may have thoughts that their parenting style has been too domineering, uninvolved, disciplined, lax, punishing or over-protective (Bernheim & Lewine, 1979; McFarlane, 1983). "When something goes wrong, most people look to themselves to see what they could have done differently, and most people find something that they can worry about. These concerns tend to be reinforced by the messages of the popular media that emphasise the connection between good parenting and a child's success" (Anderson, Reiss & Hogarty, 1987, p109-110). Additionally, clients and families may feel stigmatised or ashamed and socially isolate themselves (Wahl & Harmon, 1989).

When someone in a family is diagnosed with schizophrenia, it is difficult for family members to try and do all they can to help that person, on top of their normal parental duties while also trying to keep their family lives stable for the rest of the family. At times, family members may find this struggle and the extra burdens tiring and stressful (Clark, 1994; Schene, Tessler & Gamache, 1996) and even though they may be aware that their family member is ill, “it is impossible to avoid feeling angry at behaviours that seem thoughtless, inconvenient or irritating” (Anderson et al., 1986, p110).

Underneath all of these emotions, a sense of grief can usually be found for the “loss of health, personality and vitality in the person they love” (Miller, 1996, p51).

The current plight of families with a relative diagnosed with schizophrenia has been encapsulated by Smith (1982):

“The families feel burdened, ill-understood by the professional services, and bewildered by the patients’ 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 patients 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).

Findings related to EE suggest that removing the patient from the home, providing them with some form of therapy and then returning them to the same environment most likely is not the optimal treatment for some clients and families (Anderson et al., 1986).

To summarise, the client with schizophrenia generally has an intrinsic vulnerability or lower tolerance for stress. Returning to the same environment where their symptoms may adversely effect the family in terms of how they will cope and respond to them, particularly in those families with high EE, is quite likely detrimental to both the client and the family. Hostility, criticism and emotional over-involvement will tend to exacerbate symptoms, and potentially contribute to the client’s relapse (Vaughn & Leff, 1976). Thus, interventions aimed at reducing stress and EE have been developed.

Family Interventions

Family-based interventions, differ widely in their components and methods. The reason for this is that family interventions are basically packages of interventions with different elements involved. The most frequently used elements of family interventions are psychoeducation, behavioural problem solving, family support, and crisis management. Additional interventions (e.g., social and vocational skills for clients) may be included as supplementary individually-based components.

They also differ in whether they are conducted: with multi-family groups or with individual families; with the patient included and seen with the family, included but seen separately, or excluded; in the home or not in the home.

Most family-based interventions, however, do follow some general assumptions (Lam, 1991): 1) schizophrenia is seen as an illness, 2) the family is not blamed for the development of the illness, and such fears are allayed, 3) support, information, and specific coping mechanisms are provided, 4) families are conscripted as therapeutic agents, and 5) the interventions are part of a treatment package which includes, regular medication and the outpatient services (e.g., support, skills-training).

There have been a large number of these type of interventions over the past 20 years (see Brooker, 1990; Dixon & Leham, 1995 for reviews) that have aimed to reduce the risk of relapse. Most programmes also (Hogarty et al, 1986, 1991; Anderson, Reiss & Hogarty, 1986) follow four general phases, although they may differ somewhat in what they do within each phase, and each treatment programme gradually unfolds over a 1-2 year period.

For this review, the intervention package outlined is the one developed by Anderson, Reiss and Hogarty (1986) which has been described as possibly the most comprehensive (Atkinson & Coia, 1995).

The first of the four phases is usually called “connecting with the family” and involves the following: Establishing a relationship with the family, finding out how each person in the family is reacting to the illness, and what personal stressors each individual is under. In this way, the clinician can map out a family history and establish the immediate needs. It also involves the client, therapist, and family members drawing up a contract which specifies goals, rules, and methods of the after-care programme which are designed for after discharge. The main goal of this contract is for the client to stay out of hospital.

Phase two is the Survival Skills Workshop. This is usually a day-long multi-family educative session which aims to give families information about schizophrenia and its management. Techniques are taught to enable the families to communicate and problem solve effectively. These generally include suggestions such as: temporarily revising expectations, creating barriers to overstimulation, learning to set limits, selective ignoring, keeping communication simple, supporting the medication regime, normalising the family routine, and learning to recognise signals for help.

Families are helped to see the need for decreased stimulation and a more benign, tranquil family environment. It is suggested that this can be done through the setting of reasonable limits and the decreasing of the families’ expectations of the relative with schizophrenia. Thus, even if not explicit, re-attribution training is carried out in this phase.

One of the the most important parts of the phase two workshop is that families can share experiences with others who know what they are going through. Families are encouraged to establish support networks with these other families.

The third phase is re-entry of the client into the family or community environment, and this is the lengthy part. Individual family sessions are held every 2-3 weeks for at least one year, two years in some cases. Sessions involve addressing problems such as the idea of discontinuing medication, ongoing frustrations, and any family tendency to become overinvolved and controlling. Another focus of this phase is to gradually encourage the patient to assume more responsibility for their own lives and daily functioning by initially

doing small activities such as brushing their teeth regularly. They then progressively take on additional responsibilities (such as showering daily, managing medication, taking public transportation, finding and holding down a job).

The final phase involves gradual continued treatment, or disengagement. Once the 1-2 years is up, and the original goals for effective functioning have been achieved, the family makes a choice to either: a) attend periodic supportive maintenance sessions that will gradually decrease, or b) attend more traditional family oriented sessions to resolve any remaining long term family conflicts.

It has repeatedly been demonstrated that such psychosocial programmes aimed at lowering the EE in family environments can also reduce the rate of client relapse (Gamble & Midence, 1994; Dixon & Lehman, 1995). As well as obtaining statistically significant results, McFarlane, Lukens, Dushay, Deakins, Newmark, Dunne, Horen and Toren (1995) found that after participating in a family education programme, relatives' mental health and global functional knowledge about schizophrenia increased considerably, as did communications between the family members and the client, high EE was reduced and expectations were lowered. There were also improvements seen in clients' personal functioning and social adjustment.

As mentioned earlier, this format has been found to be successful, but it tends to be successfully applied in research settings in psychiatric hospitals. 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, p505).

Unfortunately, this treatment approach is still under-utilised. Its availability is scanty, and there are few accounts of it being used successfully in a standard clinical setting. On the rare occasions where this has been accomplished, it has usually been by those "authors with a strong research interest in the field (Smith & Birchwood, 1990; Leff, 1994)" (Anderson & Adams, 1996, p505).

There could be many reasons for this state of affairs. The programmes, although comprehensive, can be extremely lengthy, and may not be applicable to the clinical setting where time is often at a premium, and resources are often over-booked. One might imagine the problems in trying to get the whole family together at the same time every two weeks for two years, and the problems involved in keeping the whole family, including the client, committed to treatment. The issue of finding providers of such a service, particularly those who have the resources and are at low cost, may also be problematic.

Family Education Programmes

An integral part of psychoeducational programmes is the knowledge or information component, where patients & relatives are given information on the diagnosis, symptomology, aetiology, treatment, and course of schizophrenia (Falloon, Liberman, Lillie, Vaughn, 1981; Anderson, Hogarty, & Reiss, 1981). It has been suggested by Tarrier and Barrowclough (1986) that such a component might be quite easily integrated as a short-term programmes in community settings. These are now known as family education programmes.

As with psychosocial interventions, there are a variety of different approaches: lecture-based (Leff, Kuipers, Berkowitz, Eberlein-Vries, & Sturgeon, 1982), video presentations (Smith, 1984), written pamphlets, or a combination of individual presentations combined with pamphlets. Information has been presented in a work-shop format (Anderson *et al*, 1981), to multi-family groups (Smith, 1984), to individual families (Leff *et al*, 1982; Falloon *et al*, 1982), in the home, and out of the home.

Apart from these differences, education packages have much in common. To begin with they are brief. They generally involve 2-4 sessions (Berkowitz *et al*, 1984; Barrowclough *et al*, 1987) which are about two hours in duration (Falloon *et al*, 1985).

The information given is usually concise, and only the items of information which "are hypothesized to be most useful in assisting patients and relatives to cope with the

problems caused by the illness and to comply with medication treatments” are included (Tarrier and Barrowclough, 1986, p462). This form of information giving has been suggested as the best form to follow, as research (Ley, 1979) has shown in doctor-patient type communications, only a small number of items of information are remembered by recipients. To this end, many education programmes also provide easy-to-read pamphlets which summarise the verbal information given (Barrowclough *et al*, 1987; Smith & Birchwood, 1985).

The information given is also very similar amongst programmes. Although there may be minor variations, most approaches (Falloon, 1985; Barrowclough *et al*, 1987; Berkowitz *et al*, 1984) have these common themes in their information given: 1) nature of schizophrenia, including symptoms, diagnosis, aetiology, and course of illness, 2) treatment, including medication and family management, 3) prognosis and management, including the interaction between relatives and the ill family member, and 4) other things that can help, including available services.

Family education focuses on giving facts about schizophrenia to the family, and most programmes generally have the following goals:

- “1. The passing on of information with the goals of giving a rationale for treatment, including medication.
2. Reducing relatives’ guilt and/or blame, particularly about aetiology.
3. Encouraging realistic expectations regarding prognosis.
4. Giving practical advice about management including ways of reducing expressed emotion” (Atkinson & Coia, 1995, p69).

Common to all of the successful interventions is the emphasis on educating the family about schizophrenia. Education itself does not appear to reduce relapse, but it probably is important in engaging the family in treatment and helping them to conceptualise the illness and its problems from a stress-vulnerability framework. Other studies have found that such information has the effect of decreasing the relatives’ reported levels of burden, distress, and anxiety, although there was no effect on the patients’ disturbed behaviour (e.g. Smith and Birchwood, 1987).

In the Smith and Birchwood (1987) programme, a four session course resulted in a significant retention of information in families. They found that the course resulted in reductions the manifested symptoms of stress, and an improvement in relatives' feelings of having some control over the situation. They therefore theorised that one important aim of education is to improve 'cognitive mastery' and beliefs about relatives ability to influence situations.

Barrowclough and Tarrier (1992) describe a 'more collaborative approach' perhaps than other researchers. They suggest that:

'an understanding of the relatives' beliefs and attitudes about the illness in general and the symptoms of the patient 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, p76).

In the Barrowclough and Tarrier programme, information is gathered and assessed from an interview at the outset of the education using the Knowledge About Schizophrenia Interview (KASI) which reflects six areas of schizophrenia: Diagnosis, Symptomology, Aetiology, Medication, Prognosis, and Management.

Information in the programme itself is structured around relatives' knowledge, beliefs and misconceptions about the illness. Attention is paid to the assimilation of knowledge, notably where initially held beliefs are contradicted by new information. They have noted that after the programme, administration of the KASI is helpful for assessing change and "where further attitude or belief change will be important, since it is unlikely that relatives, particularly those where patients have a long history of illness, will change all their views after a brief education component" (Barrowclough & Tarrier, 1992, cited in Atkinson & Coia, 1995, p77). However, in this and other research, methodological shortcomings (e.g., lack of control group) limits conclusions.

The Present Research

This research involved conducting a brief educational intervention which aims to enhance family members' knowledge about schizophrenia and expressed emotion, as well as increasing awareness of coping strategies. It is expected that education concerning the illness and its management will alter the views and attributions that relatives make about the causality of any of the client's unusual behaviour (particularly those made by high-EE families), thereby reducing criticism, hostility, or emotional overinvolvement that might follow from misinformation, frustration, and less effective coping skills compared to a randomly assigned wait-list control condition.

The information is designed to help family members develop a sense of mastery about a sometimes chaotic and seemingly uncontrollable process. A sense of mastery has been associated with a decrease in fear, anxiety, and confusion (Keefe & Harvey, 1994). In turn, this may then free up energy that could be better used for coping with the illness and its ramifications, and for lowering EE.

It was also expected that knowledge about the illness and its course can help family members develop realistic expectations and plans for the future. Rather than clinging to unrealistic hopes that the illness will simply go away, or becoming overwhelmed with hopelessness, family members can begin to understand and accept the illness.

This Education Programme

The present research involves assessing the merits of a short, uncomplicated education programme, applicable to everyday settings. It was designed to retain the effectiveness of those programmes designed and utilised in research settings.

The brief education programme used in this study sought to make the family environment more consistent, predictable, and safe by reducing relative's guilt, feelings of responsibility and anxiety, and by increasing their awareness and tolerance through the provision and discussions of information about the nature and course of schizophrenia,

expressed emotion, and their consequences. It also sought to provide specific coping (or management) strategies found to be helpful in coping with schizophrenic symptoms on a daily basis, for both clients and relatives.

The basic content of the present education programme followed this format:

- 1) Provide information about the nature of schizophrenia.
- 2) Provide information on the positive and negative symptoms of schizophrenia.
- 3) Provide information on the currently held explanation of the aetiology of schizophrenia.
- 4) Provide information about medication and possible side-effects.
- 5) Provide information on the course, prognosis, and management of schizophrenia.
- 6) Provide information on expressed emotion, characteristic patterns of response to various behaviours and, ways in which the family and client can solve problems (including relaxation techniques).

In conclusion, there is a need for brief education programmes in community settings (e.g. Schizophrenia Fellowship) which provide information to relatives of individuals with schizophrenia. The present study attempted to meet this need in providing information about not only schizophrenia, but also expressed emotion and possible ways of coping with both on a daily basis. It was expected that providing information about the illness and its management would alter the attributions that relatives make about the client's symptomatic behaviour - and will be reflected in increased knowledge in family members, and lower expressed emotion compared to a randomly assigned control condition.

Method

Participants

All members of the Manawatu Schizophrenia Fellowship and Wellington Schizophrenia Fellowship who volunteered and met inclusion criteria were included if they:

- were aged 17-65
- had a diagnosis of schizophrenia according to DSM-III-R which could be confirmed by a chart diagnosis
- provided informed consent to be interviewed & have relatives interviewed
- were on regular medication
- had no evidence of an organic brain syndrome or a primary problem of substance abuse which would explain the psychopathology.

Relatives were accepted into the study if they met the following criteria:

- gave informed consent
- resided with, or spent more than 35 hours of face-to-face contact a week with the client

Table 1 shows the demographic and historical characteristics of the clients and relatives in the present study. There were no significant differences between those who came from high EE households and those from low EE households (all p 's $> .10$).

Table 1: Demographic Information of Participants

Characteristics of (19) schizophrenic clients, and (20) relatives with whom they resided			
Clients (19)			
Male/Female	13M/6F		
<i>Age (years):</i>			
Mean	33	S.D.= 9.82	
Median	30		
Range	22-58		
<i>Living with:</i>			
Parents or Partner at home	13		
Others in a flat or flat run by parents	6		
<i>Age of Onset:</i>			
Mean	20	S.D.= 3.92	
Median	20		
Range	12-26		
<i>Years since Onset:</i>			
Mean	13	S.D.=10.03	
Median	11		
Range	2-36		
<i>Marital Status:</i>			
never married	13		
married	6		
Relatives (n)			
<i>Relationship to patient:</i>			
Mother	11		
Father	4		
Spouse/Partner	4		
Sibling	1		
<i>Current/previous employment:</i>			
Full-time	4		
Part-time	8		
Unemployed	8		

Table 2 shows the composition of the respective households which are represented here by one relative for each household, bar one household represented by two relatives. Of those who were included in the study, no participants refused to complete any of the measures and no participants dropped out of the study.

Table 2: Composition of family households

Households	<u>High EE</u>		<u>Low EE</u>	
	Experimental	Control	Experimental	Control
Parent	3	2	7	3
Spouse/partner	1	1	1	1
Other		1		
TOTAL	4	4	8	4

In the high-EE group there were 8 relatives - 4 in the experimental group (1 male and 3 female) and 4 in the control group (4 female). In the low-EE group there were 12 relatives - 8 in the experimental group (3 male and 5 female) and 4 in the control group (4 female).

Expressed emotion in a household is determined by the key family member, but this particular study also measured clients’ assessment of relatives’ EE. Thus, henceforth any reference to clients’ EE is referring to clients’ assessment of their relatives’ EE.

In the high-EE group there were 11 clients - 5 in the experimental group (4 male and 1 female) and 6 in the control group (4 male and 2 female). In the low-EE group there were 8 clients - 6 in the experimental group (3 male and 3 female) and 2 in the control group (2 male).

These particular subjects were selected because 1) clients had the necessary diagnosis of schizophrenia, 2) clients were residing with their families, or spending more than 35 hours of face-to-face contact a week with them, 3) relatives were the people who were seen (by the client) to be the most influential and important people in their lives, and 4)

because both relatives and clients had a desire to know more about the illness of schizophrenia, how to treat it, and how to manage it in the home on a daily basis.

Design

A mixed factorial design was used in the present study.

There are two main groups included in the present study, a treatment (experimental) group and a wait-list control group. There are also two sub-groups, HEE families and LEE families. The relatives with their corresponding families were randomly allocated to either the experimental or wait-list control group. This ensures that each group contains a random mixture of families high in EE (HEE), and families low in EE (LEE) as well as random allocation on other variables (e.g. demographics).

Assessment

The independent variables in the present study were the knowledge about schizophrenia held by the relatives, as measured by the Knowledge about Schizophrenia Interview (KASI; Barrowclough, Tarrier, Watts, Vaughn, Bamrah, & Freeman, 1987), and the level of Expressed Emotion, as measured by the Level of Expressed Emotion Scale (LEE; Cole & Kazarian, 1992). The independent variable was the education programme.

Patient and Family History Interview

This was designed to collect demographic information and information about first diagnosis and other factors (see Appendix D).

The KASI

The Knowledge about Schizophrenia Interview (KASI; Barrowclough, Tarrier, Watts, Vaughn, Bamrah & Freeman, 1987) was designed to assess and evaluate in relatives their knowledge, beliefs and attitudes about six aspects of schizophrenia, and the effects of that information, beliefs and attitudes on the relatives behaviour (see Appendix E).

The six aspects of diagnosis, symptomology, aetiology, medication, prognosis and management are contained in different sections which can be scored independently. It takes 10-30 minutes to complete, depending on the length of response and the structuring of the interview. Each interview was audio-taped for reliability purposes.

Most questions require a single word answer or a "Yes/No/Don't know" choice, but the final section on management contains two open sections. Each of the sections are scored on a 4-point scale (1-4). A score of 1 equals negative value in that the relative gives information which if acted upon may be detrimental to the patient. A score of 2 equals neutral value in that the relative knows little relevant information but gives no information that if acted upon may be detrimental to the patient. A 3 equals positive value in that the relative gives information which if acted upon may be beneficial to the patient. A score of 4 equals positive value in that in addition to information provided for a score of 3, the relative has shown a wider knowledge and understanding of the assessed aspect of schizophrenia. Thus relatives' responses can be assessed in how un/helpful their beliefs and attitudes about schizophrenia are likely to be to the management of the illness (Barrowclough et al., 1987).

All interviews were scored by the author and 5 interviews were randomly selected and scored independently by an independent rater (a trained senior clinical psychologist) for reliability calculations. In all instances, this measure was given first to avoid contamination by later questions and responses to the LEE scale.

The LEE

The Level of Expressed Emotion Scale (LEE) was developed to measure the "perceived emotional climate of social environments" (Cole & Kazarian, 1993, p216) and was specifically designed to measure the construct of EE as described by Vaughn and Leff (1981). It is a self-report measure containing 60 true/false items and is a less time consuming alternative to the Camberwell Family Interview (a structured interview designed for measuring EE). There were two versions of the LEE both of which were used in the present study: the client version (see Appendix F) in which the individual with a psychiatric illness assesses EE in their key family members, and the relative version (see

Appendix G) in which a key family member assesses EE within themselves. Considering this is a pen and paper measure and not an interview, having two versions gives a more comprehensive, multi-rater measurement of the affective environment in which the person with an illness resides. Given that it is also less time consuming, it was considered more appropriate for the purposes of this study.

There are four subscales which reflect the four affective, cognitive and behavioural correlates of the EE construct (Vaughn & Leff, 1981). These are (a) intrusiveness, (b) emotional response, (c) attitude toward illness and, (d) tolerance and expectations. In addition to the four subscale scores, a total score is also rendered, with a higher score denoting higher levels of EE. Subjects were classified as Low-EE or high-EE based on the median of all pre-test scores. The median was 11 thus those who scored 0-10 on the pre-test were classified as Low-EE and those who scored 11+ were classified as high-EE.

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 research studies have demonstrated predictive validity in the LEE, and it has also been demonstrated to have construct validity, independence from effects due to sex or age (Cole & Kazarian, 1988) and the scores of the two different versions have been demonstrated to correlate well with the corresponding ratings of the CFI (Kazarian, Cole, Malla & Baker, 1990).

Procedure

All subjects voluntarily participated. Fieldworkers at the Manawatu SF and Wellington SF contacted clients (those with schizophrenia) who were living or in close contact (35 hours or more a week) with a key family member for at least 3 months prior to the study, and who met the inclusion criteria. They discussed the study, and explained what would be involved in participating. Once participants confirmed a willingness to participate in the study, permission was obtained to contact the family members of each client, and they were also invited to participate. At this stage, information sheets and consent forms were

distributed by the author to both the clients (see Appendices A and B) and family members (see Appendix C), so that the whole family could discuss it. The researcher followed up with the participants to confirm continuing interest and ensure informed consent. Appropriate phone numbers were provided for any further questions participants may have had.

After obtaining informed consent from both clients and relatives, an appointment was made for the relative and patient to separately complete the pre-tests (session 1) and further appointments were made to separately attend the education session (sessions 2).

For the purpose of the actual education programme, participants were divided into two sub-groups of either a) families of those with schizophrenia (relatives) or b) family members diagnosed with schizophrenia (clients). This was for the purpose of the first session of the education programme only.

Also, the amount of time between pre- and post- assessments for the experimental and control group was equivalent. As the present study was based on the Barrowclough et al (1987) study, their format was adopted. Thus the reasons for the one week interval between pre-test 1 and post-test were the following:

“(i) Relatives occasionally became worried, or misunderstood the information they were given. An early second appointment allowed an opportunity to discuss any problems. (ii) KASI assessment one week after the education session was thought to be more likely to assess longer term information retention than a test given immediately after the education session. (iii) The one week period allowed relatives and clients time to discuss the information and to read the booklet. (iv) 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).

Assessments and the Education Programme

Session One

Session One consists of three assessments for relatives, and one for clients:

- (i) Patient and Family History Interview (relatives only)
- (ii) Knowledge about Schizophrenia Interview (pre-test; relatives only)
- (iii) LEE scale (pre-test)

Both the experimental and control groups attended Session One at the beginning of the study.

Relatives

At the beginning of Session One, the researcher reiterated the exact procedure for the present study to clarify the amount of time and other issues related to participating in the present study.

The relative was interviewed with the Patient and Family History Interview by two trained, independent assessors. This took approximately 10 minutes to complete. The interview was designed to collect extensive details about the client regarding when diagnosed and by whom, prevalent symptoms, and the nature of the current treatment. The information collected allowed for a chart diagnosis to be obtained in between Sessions One and Two.

The trained assessor then administered the Knowledge about Schizophrenia Interview (pre-test). If during the interview insufficient or unclear information was given by the relative, 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, not as a test with correct and incorrect answers. If more than one relative attended, each were interviewed separately. The KASI was conducted before the LEE scale in an attempt to avoid contamination by later responses. Following the KASI interview, the LEE scale was administered, and took approximately 15-25 minutes to complete.

Clients

Clients attended this session singularly. This session consisted of filling out the LEE scale only.

Session Two

Session Two consisted of the education programme (Moxon & Ronan, 1998; Appendix H) for both patients and relatives initially in the experimental group only (see Table 3). This was administered by the author after training (conducted by a senior clinical psychologist):

- (i) information giving on diagnosis, symptomology, aetiology, medication, and course and prognosis of schizophrenia.
- (ii) information on management, strategies that can help both the client and relatives, and 10-15 minutes of relaxation.

At the beginning of the session, an outline was provided with the idea that if participants knew what was coming they might be put more at ease than if they were worrying about what might be said. With this in mind, the first part of this session was designed to be friendly and non-accusatory and went basically as follows:

“Well I thought to start with I could give you an idea of what is going to happen, so this is the outline:

- we'll discuss what schizophrenia is and the different symptoms that are involved with it, 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 three quarters of an hour, and I figure after that we might want a break, so if you feel like it we can take a short break for a drink or something”.

Most participants appreciated the opportunity for a break, but it was noted that although clients often liked to stop for a smoke and/or coffee, relatives often preferred to keep going and use the extra time for questions on the information just given.

“The second part of this session will provide some coping skills that research has shown can sometimes help, including relaxation. And that will take about one hour.

Finally, you'll make an appointment to come back in about five days to discuss with your family member and myself the main points of this session, and any further questions or concerns either of you have. This isn't a test, it's just an opportunity to come together

and work out queries and concerns. And that's it for this session. Please feel free to jump-in, or ask questions at any time.

After the outline was given, an information booklet written by Christine Barrowclough and Nicholas Tarrier (1992) was given to each person attending the session and it was explained that the format would generally be following that of this booklet. For example, "I'm going to give you a hand-out, it's written by two experts from England in association with the British Schizophrenia Fellowship. It's basically information for those suffering from schizophrenia and their families. This session will be based on it to some extent, so if you wish you can follow it or refer to it as we go, but basically it's for you to take home and refer to if you want to check something or have a question before our next meeting.

What I am going to talk about is based as close as possible on the average situation, and as you know every situation is different and you know better than I do about your situation. So if you do have anything you want to say just jump-in with it".

Although the format of the session did follow that of the booklet, additional information was provided and presented in a flexible manner to enable:

- (a) subjects or areas that relatives indicated that they wanted to know more about in the Patient and Family History Questionnaire to be discussed in more depth,
- (b) areas of information not known or seen as incorrect in the pre-test KASI to be paid particular attention,
- (c) relevant information to be incorporated into the session from Falloon, Graham-Hole & Fadden's (1997) *Integrated Mental Health Care* and Falloon, Falloon, & Lussetti's *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.

If more than one relative attended the session, the education was conducted with the relatives together, but the client was seen separately and given the same information either immediately before or immediately after their relative received it. In all instances,

clients were initially given the choice of whether they: (a) wanted to attend the session with their key relative, (b) have a support person present, or, (c) attend the session before or after their key relative.

In all instances, clients wanted to receive the information separately from their family member, only two people brought a support person with them, and all but four clients chose to receive the information before their key family member.

Two relatives insisted upon attending the session with the client but relented when it was explained to them that they themselves would be able to talk more freely if they attended the session separately. It was also stressed on those two occasions that they would both be receiving the same information and the same booklets and would have the opportunity to attend a summary session together. Both of these relatives were classified as being high in EE.

After the break, when it came to the second part of the session and what the family could do to help their diagnosed family member, the participant was asked if they would like this additional information. These words were added prior to imparting the information, "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".

Questions from all participants were encouraged as it was theorised that the more involved participants were, the more knowledge would be retained by them given findings that active involvement has been shown to positively predict outcome in psychoeducational programmes (Bergen & Garfield, 1994). With that in mind, this was the format followed with all participants:

- the clients and relatives were invited to actively participate and share in the presentation by describing their experiences of the disorder and its treatment.
- social reinforcement was provided to encourage continued involvement.

- each issue was presented in no more than five minute segments. Participants were then asked to describe their own experiences, concerns, or queries. Participants were encouraged to summarise the key points that they have understood at the end of each issue.

It was noted that most participants relaxed once they realised they were not being asked about in-depth historical or personal information. Most were open and volunteered much information which indicated that they may not only have been listening to the information being presented, but assimilating it to some extent also.

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 and thus retain more information.

Participants sense of safety and comfort during this session was of prime importance, so for this reason each participant had the choice of whether they attended this session within their own homes, or in a nominated venue which was familiar to them. In the high EE group, there were 4 relatives (3 clients) who chose to receive this in their homes, and 4 relatives (8 clients) who preferred it at either the Manawatu Schizophrenia Fellowship or Ahuru (the Lower Hutt Mental Health Hospital). In the low EE group there were 2 relatives (3 clients) who received it at home, and 10 relatives (5 clients) who preferred it at either the MSF or Ahuru. Exactly the same format was followed in each venue

Participants were then made appointments for Session Three and were reminded that they could take the booklets with them. The booklet (Barrowclough et al, 1992) is written in simple language, and according to the Flesch reading scale (Flesch, 1948) can be understood by 75% of the population.

Session Three

Session Three consists of three stages for relatives and two for patients:

- (i) Questions/feedback (relatives and clients together)
- (ii) KASI (post-test; relatives only)
- (iii) LEE scale (post-test; relatives and clients separately)

Clients and relatives attended this session together so that any further questions about the study or the information they have learned could be asked. It was kept in mind throughout the sessions that the purpose of this study was not to conduct an intervention, or family therapy. Rather, the manual and its application are designed to provide information (Moxon & Ronan, 1998).

Thus, the first stage of Session Three involved questions/feedback. The second stage of this session for the relative was to complete the KASI post-test (which again was audio-taped and given individually) and the LEE scale again conducted by the independent assessors. The second stage for clients involved filling out the LEE scale.

At the end, participants were informed that in three months time they would be contacted to complete the measures again (as a follow-up) and that once the results had been analysed they would receive feed-back. Table 3 presents the flowchart for assessment and intervention by condition.

Table 3: Flowchart of the Education Programme

Groups		Session 1 (measures)	Session 2 (Ed. 1)	Session 3 (post-meas)	Session 2 (Ed. 1)	Session 3 (post-meas)	Follow- up
experi- mental	clients	✓	✓	✓			✓
	relatives	✓	✓	✓			✓
control	clients	✓		✓	✓	✓	✓
	relatives	✓		✓	✓	✓	✓

Results

Reliability

The degree of inter-rater agreement for the KASI was 80%. This data is based on the two raters 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 a one-way analysis of variance (ANOVA) tests or chi-square tests. Variables compared across groups included age, gender, client's place of residence, relative's and client's (separate) marital and employment status, age of onset, length of disorder, and whether the participant had previously attended any education courses. For these variables, analysis in which subjects in the treatment condition were compared with those in the wait-list condition resulted in non-significant differences ($p's > .05$), which indicates that the subjects were demographically similar in the two conditions.

Similar analyses were conducted on the pre-treatment dependent variables of relatives' knowledge and relatives' and clients' (separate) levels of expressed emotion. None of the analyses indicated significant differences ($p's > .05$).

Treatment Integrity

The strategies called for in the education sessions were indeed used in those 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 flexible manner that maintained programmatic strategies while permitting individualisation on the basis of each participant's needs. A checklist was

completed by a senior clinical psychologist who sat in on selected initial sessions and confirmed the fidelity of the educational intervention.

A few sessions are worth mention. On one occasion, a client declined discussing the symptomology section of the programme, one patient declined discussing the medication section, and 12 relatives and 11 clients declined participating in the optional relaxation exercise at the end of the session. Analyses of the outcome scores between those who participated in the relaxation exercise, and those who did not, showed no significant differences ($p's > .05$). Four clients and one relative requested the relaxation exercise to be recorded on cassette tape by the researcher for them to use at home. This was done. All participants took the education booklet and a written copy of the relaxation exercise with them at the end of the session.

Treatment Outcome

It should be noted that all of the analyses conducted within the present study were selected specifically to address the two hypotheses of the study. Namely, as a result of attending a brief educational programme, 1) participants' knowledge would increase, and 2) as a result of this, participants' reported level of expressed emotion would decrease compared to the control condition.

The means and standard deviations of the Knowledge about Schizophrenia Interview (KASI; for relatives only) and the Level of Expressed Emotion Scale (for relatives and clients separately) are presented in Tables 4 (KASI), 6 (LEE Relative version), and 7 (LEE Client version). The analyses addressing changes over time for the LEE Scale total score and subscales, and those addressing changes over time for the KASI total score and subscales can be found in the summaries of each section. Tables 5 (KASI) and 8 (LEE) reflect scores for dependent variables by EE status (high versus low).

Table 4: Means and Standard Deviations for the KASI

Knowledge About Schizophrenia Interview						
Measures	Treatment		All Relatives	Wait-list Control		
	Pre-test	Post-test		Pre-test 1	Pre-test 2	Post-test
Diagnosis						
<i>M</i>	3.00	3.00	3.00	2.88	3.13	3.13
<i>SD</i>	0.00	0.00	0.34	0.64	0.35	0.60
<i>Range</i>	0.00	0.00	2-4	2-4	3-4	2-4
Symptomology						
<i>M</i>	3.00	3.83	3.61	2.88	3.13	3.63
<i>SD</i>	1.13	0.37	0.70	0.84	0.84	0.70
<i>Range</i>	1-4	3-4	2-4	2-4	2-4	2-4
Aetiology						
<i>M</i>	2.42	3.08	3.28	2.25	2.13	3.25
<i>SD</i>	0.67	0.76	0.75	0.46	0.35	0.66
<i>Range</i>	2-4	2-4	2-4	2-3	2-3	0.33
Medication						
<i>M</i>	2.50	3.58	3.78	2.75	2.50	3.88
<i>SD</i>	1.45	0.95	0.55	1.28	1.07	0.33
<i>Range</i>	1-4	1-4	2-4	1-4	1-4	3-4
Course & Prognosis						
<i>M</i>	2.17	2.67	3.11	2.75	2.75	3.13
<i>SD</i>	1.03	0.85	0.68	1.28	1.03	0.78
<i>Range</i>	1-4	1-4	1-4	1-4	1-4	2-4
Management						
<i>M</i>	2.92	3.25	3.22	2.50	2.50	3.25
<i>SD</i>	0.52	0.60	0.81	0.76	0.76	0.66
<i>Range</i>	2-4	2-4	2-4	1-3	1-3	2-4
Total score						
<i>M</i>	16.00	19.58	20.00	16.00	16.13	20.25
<i>SD</i>	3.10	2.22	1.91	3.74	3.04	2.39
<i>Range</i>	12-21	15-22	16-23	10-19	11-29	15-23

Knowledge About Schizophrenia Interview

A Wilcoxon matched pairs signed ranks test was performed on the data for all 20 relatives 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 in that participants are rank-ordered on a single variable (negative value,

neutral value, positive value, and positive value and additional correct information) and each value means something in relation to the next (least to most). There is not an equal distance between each of these values. Thus, parametric tests which usually require interval or ratio data are not applicable.

This particular inferential statistical test is a nonparametric procedure employed with ordinal/rank-order data in a hypothesis testing situation involving a design with two dependent samples and is used for evaluating a hypothesis about the medians of two independent populations (i.e., pre- and post-test).

Information Acquired: As expected, there were no differences between the pre-test 1 and pre-test 2 interviews for the control group, showing no change in knowledge as a function of the control period ($p's > .05$). Knowledge was gained between pre- and post-by relatives in the treatment group and following treatment (i.e., between pre2- and post-) by relatives in the wait-list control group. For the purposes of this section, this group from pre 2-post is now referred to as treatment group II.

Analysis of the KASI total score for the treatment group revealed a significant gain in knowledge ($z = 2.810, p < 0.005$). There was also a significant gain for treatment group II after their education ($z = 2.530, p < 0.005$).

For the subscale of Diagnosis, neither the treatment or treatment group II gained significantly in knowledge ($p's > .05$)(see also the means in Table 1).

For the subscale of Symptomology, analyses revealed a significant gain for the treatment group ($z = 2.428, p < 0.05$), and for treatment group II after education ($z = 1.633, p < 0.05$).

For the Aetiology subscale, analyses revealed a significant gain for both the treatment group ($z = 1.780, p < 0.05$) and treatment group II after education ($z = 2.251, p < 0.01$).

For the Medication subscale, analyses revealed a significant gain for both the treatment group ($z = 2.232, p < 0.01$), and treatment group II ($z = 2.460, p < 0.01$).

For the subscale of Course and Prognosis, only the treatment group gained significantly in knowledge ($z = 1.656, p < 0.05$). No change was found for the treatment group II though it approached significance ($z = 1.342, p < 0.10$).

For the final subscale Management, both the treatment group ($z = 1.633, p < 0.05$) and treatment group II gained significantly in knowledge ($z = 2.45, p < 0.05$).

Information Acquired and the Expressed Emotion dimension: It can be seen from Table 4 that with the exception of the Diagnosis subscale, knowledge was gained between pre- and post-test by participants in all sections of the KASI as a function of treatment. No change was seen as a function of the control period.

Further analyses collapsing across both the initial treatment group and treatment group II were conducted to determine whether an initial rating of high or low-EE would affect how much knowledge relatives gained between pre-test and post-test.

They revealed that there was a difference between how much knowledge low-EE relatives gained and how much knowledge high-EE relatives gained.

Low-EE relatives gained in knowledge on the subscales of Symptomology ($z = 2.271, p < 0.01$), Aetiology ($z = 2.261, p < 0.01$), Medication ($z = 1.857, p < 0.05$), Course and Prognosis ($z = 1.633, p < 0.05$), Management ($z = 1.667, p < 0.05$) as well as on the total score ($z = 2.673, p < 0.005$).

High-EE relatives gained in knowledge on the subscales of Symptomolgy ($z = 2.070, p < 0.05$), Medication ($z = 2.401, p < 0.01$), Management ($z = 2.236, p < 0.01$) as well as on the total score ($z = 2.68, p < 0.005$).

Neither low-EE or high-EE relatives gained in knowledge on the diagnosis subscale (p's >.10). Further high-EE relatives did not significantly gain in knowledge on the sections of (a) Aetiology and (b) Course and Prognosis (p's >.10).

Table 5: Low and High-EE Means and Standard Deviations of the KASI

Subscale	Pre-treatment			Post-treatment		
	Mean	S.D.	Range	Mean	S.D.	Range
<i>Diagnosis</i>						
Low-EE	3.00	0.00	0.00	3.00	0.00	0.00
High-EE	2.89	0.57	2-4	3.11	0.57	2-4
<i>Symptomology</i>						
Low-EE	3.09	0.90	1-4	3.91	0.29	3-4
High-EE	2.78	1.03	1-4	3.56	0.69	3-4
<i>Aetiology</i>						
Low-EE	2.27	0.44	2-3	3.27	0.62	2-4
High-EE	2.44	0.69	2-4	3.00	0.82	2-4
<i>Medication</i>						
Low-EE	3.00	1.28	1-4	3.73	0.86	1-4
High-EE	2.11	1.20	1-4	3.67	0.67	2-4
<i>Course & Prognosis</i>						
Low-EE	2.55	1.16	1-4	2.91	0.79	1-4
High-EE	2.22	1.03	1-4	2.78	0.92	1-4
<i>Management</i>						
Low-EE	2.82	0.58	2-4	3.27	0.62	2-4
High-EE	2.67	0.67	1-3	3.33	0.47	2-4
<i>Total Score</i>						
Low-EE	15.82	3.64	12-21	20.09	1.73	17-22
High-EE	15.10	3.51	10-20	19.33	2.94	15-22

Summary of KASI Analyses

- 1) The treatment group 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. The control group showed no changes in any subscale or the total score.
- 2) Treatment group II showed a significant increase in knowledge in the subscales of Symptomology, Aetiology, Medication, and Management, as well as in the total score (Course and Prognosis approached significance).
- 3) Low-EE relatives 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.
- 4) High-EE relatives showed a significant increase in knowledge in the subscales of Symptomology, Medication, and Management, as well as in the total score.

The LEE Scale

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 Relative and Client versions of the LEE scale can be seen in Tables 6 and 7, respectively. Separate ANOVAs were done for relatives and clients for reasons outlined in the Method section.

Expressed Emotion - Analysis of the LEE scale total score for relatives' revealed a significant trials effect ($F(1,18) = 21.953, p < 0.005$), and a non-significant interaction effect ($p > .10$). Analysis of the LEE scale total score for clients' revealed a significant trials effect ($F(1,17) = 24.697, p < 0.005$), the interaction was non-significant ($p > .10$).

Table 6: Means and Standard Deviations for the LEE Scale - Relatives Version

Level of Expressed Emotion Scale - Relatives Version						
Measures	Treatment		All Relatives	Wait-list Control		
	Pre-test	Post-test	Follow-up	Pre-test 1	Pre-test 2	Post-test
Intrusiveness						
<i>M</i>	3.33	2.33	1.72	4.38	4.13	3.13
<i>SD</i>	3.87	4.09	2.44	2.56	2.64	1.76
<i>Range</i>	0-14	0-15	0-8	1-8	0-7	0-6
Emotional Response						
<i>M</i>	3.83	3.08	3.06	3.88	3.75	2.75
<i>SD</i>	3.38	2.60	2.41	2.36	2.66	1.56
<i>Range</i>	1-9	1-10	1-8	1-8	1-9	1-6
Attitude Toward Illness						
<i>M</i>	0.66	0.58	1.33	2.13	2.13	0.88
<i>SD</i>	0.84	1.11	1.85	2.36	2.36	1.05
<i>Range</i>	0-3	0-4	0-7	0-7	0-7	0-3
Tolerance/Expectations						
<i>M</i>	1.92	1.50	1.39	1.50	1.25	1.00
<i>SD</i>	2.47	2.40	2.15	1.20	1.28	0.50
<i>Range</i>	0-9	0-9	0-7	0-3	0-3	0-2
Total EE score						
<i>M</i>	9.58	7.50	7.50	11.88	11.25	7.75
<i>SD</i>	9.34	8.92	7.87	4.30	6.36	3.38
<i>Range</i>	2-32	2-35	1-29	4-19	1-19	1-12

For the Intrusiveness subscale of the relatives' version of the LEE, analyses revealed a significant trials effect ($F(1,18) = 8.319, p < 0.01$) and a non-significant interaction ($p > .10$). Analyses of the client version showed no significant effects (p 's $> .10$).

For the Emotional Response subscale of the relatives' version of the LEE, analyses revealed a significant trials effect ($F(1,18) = 4.28, p < 0.05$), and a non-significant interaction ($p > .10$). Analyses of the client version showed a significant trials effect ($F(1,17) = 13.621, p < 0.05$) with no significant interaction effect ($p > .10$).

Table 7: Means and Standard Deviations for the LEE Scale - Clients Version

Level of Expressed Emotion Scale - Clients Version						
Measures	Treatment		All Clients Follow-up	Wait-list Control		
	Pre-test	Post-test		Pre-test 1	Pre-test 2	Post-test
Intrusiveness						
<i>M</i>	4.46	3.36	3.63	5.63	5.38	5.38
<i>SD</i>	4.50	4.27	3.34	3.42	3.34	3.20
<i>Range</i>	0-12	0-13	0-11	0-10	0-10	0-9
Emotional Response						
<i>M</i>	4.81	3.82	4.19	4.50	4.00	2.25
<i>SD</i>	4.85	4.15	4.29	3.59	3.46	2.17
<i>Range</i>	0-13	0-12	0-12	0-9	0-9	0-6
Attitude Toward Illness						
<i>M</i>	2.27	1.64	2.44	2.88	2.38	1.25
<i>SD</i>	2.20	1.82	2.66	3.04	2.88	1.56
<i>Range</i>	0-7	0-5	0-10	0-10	0-9	0-5
Tolerance/Expectations						
<i>M</i>	3.73	3.46	3.69	4.00	3.75	2.88
<i>SD</i>	3.90	3.85	4.08	2.27	2.32	2.20
<i>Range</i>	0-12	0-12	0-12	1-7	1-7	1-6
Total EE score						
<i>M</i>	15.27	12.18	12.59	17.00	15.50	11.75
<i>SD</i>	13.89	13.48	12.01	8.75	8.90	8.15
<i>Range</i>	1-41	1-39	1-41	6-31	6-28	1-22

For the Attitude Toward Illness subscale the relatives’ version of the LEE, analyses revealed a significant trials effect ($F(1,18) = 6.386, p < 0.05$) and a significant interaction effect ($F(1,18) = 8.34, p < 0.01$). Analyses of the client version showed a significant trials effect ($F(1,17) = 8.316, p < 0.01$) and a non-significant interaction ($p > .10$).

For the Tolerance/Expectations subscale of the relatives’ version of the LEE, analyses revealed a significant trials effect ($F(1,18) = 4.233, p < 0.05$) and a non-significant interaction ($p > .10$). Analyses of the client version also showed a significant trials effect ($F(1,17) = 4.845, p < 0.05$) and a non-significant interaction ($p > .10$).

Summary

- 1) Analyses showed that relatives EE rating 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.
- 2) There were no interaction effects, apart from the subscale of Attitude toward illness (relatives), suggesting the reduction was independent of whether they were in the treatment or control group (except for the attitude toward illness subscale). However, it is also noted that the majority of the variance contributing to the significant trials effect in all instances was as a function of the change in the treated group, pre- post-scores (e.g., change in LEE total score of 2.08 for treated group versus 0.63 for the control group).
- 3) Analyses showed that clients' EE ratings significantly showed significant decreases in the subscales of Emotional Response, and Tolerance/Expectations) as well as on the total score.
- 4) There were no interaction effects on the client LEE ratings suggesting that these reductions were independent of whether clients were in the treatment or control group. However, as with the relatives' LEE scores, the magnitude of the change of the treated, versus control group, was in every instance greater (e.g., change on LEE total score of 3.09 versus 1.50).

The effects of treatment were analysed by means of another set of 2 (assessment periods of pre- and post-treatment) \times 2 (high-EE vs. low-EE) mixed factorial ANOVA collapsing across both treated groups. 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.

Analysis of the LEE scale total score for relatives revealed a significant trials effect ($F(1,18) = 55.90, p < 0.005$), and a significant interaction effect ($F(1,18) = 11.83, p < 0.01$). Analysis of the LEE scale total score for clients revealed a significant trials effect ($F(1,19) = 24.15, p < 0.005$) and a non-significant interaction ($p > .10$).

For the Intrusiveness subscale of the relatives version of the LEE, analyses revealed a significant trials effect ($F(1,18) = 18.50, p < 0.005$) and a non-significant interaction ($p > .10$). Analyses of the client version showed no significant effects ($p > .10$).

For the Emotional Response subscale of the relatives version of the LEE, analyses revealed no significant effects (p 's $> .10$). Analyses of the client version revealed a significant trials effect ($F(1,19) = 19.03, p < 0.005$), and a non-significant interaction ($p > .10$).

For the Attitude toward illness subscale of the relatives version of the LEE, analyses revealed no significant effects ($p > .10$). Analyses of the client version showed a significant trials effect ($F(1,19) = 6.57, p < 0.05$) and a non-significant interaction ($p > .10$).

For the Tolerance/Expectations subscale of the relatives version of the LEE, analyses also revealed no significant effects ($p > .10$). Analyses of the client version showed a significant trials effect ($F(1,19) = 24.15, p < 0.005$) and a non-significant interaction ($p > .10$).

Summary

- 1) Analyses showed that treated relatives' EE rating from pre- to post-test significantly decreased on the Intrusiveness subscale and total LEE score only. The total score change was dependent on the initial rating of EE (High or Low-EE). While both changed significantly, the interaction effect reflected greater significant change after treatment for High-EE relatives. The lack of interaction effects on the Intrusiveness subscale suggest that this treatment related decrease was independent of whether they were high or low-EE.
- 2) Analyses showed that treated clients rating of relatives EE showed significant decreases in the subscales of Emotional Response, Attitude toward illness, Tolerance/Expectations, as well as in the Total Score. The lack of interaction effects suggest that the initial EE rating, whether high or low did not predict a decrease in EE. People decreased after treatment regardless of their EE ratings.

Table 8: Low and High-EE Means and Standard Deviations of the LEE Scale

Subscale	Relatives Pre-test			Relatives Post-test			Clients pre-test			Clients post-test		
	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.	Range	Mean	S.D.	Range
<i>Intrusiveness</i>												
Low-EE	2.10	1.58	0-5	0.70	1.00	0-3	3.25	2.82	0-7	1.25	1.48	0-4
High-EE	5.91	8.00	1-14	4.64	3.75	1-15	6.30	3.72	1-12	6.50	3.85	1-13
<i>Emotional Response</i>												
Low-EE	1.90	0.94	1-3	1.90	0.70	1-3	0.88	0.60	0-2	0.50	0.50	0-1
High-EE	7.00	3.79	1-10	4.27	2.70	1-10	7.30	3.47	1-13	4.90	3.70	0-12
<i>Attitude toward illness</i>												
Low-EE	0.30	0.46	0-1	0.20	0.40	0-1	1.13	1.05	0-3	0.25	0.43	0-1
High-EE	2.00	2.00	0-7	1.36	1.37	0-4	3.50	2.58	1-10	2.30	1.85	0-5
<i>Tolerance/expectations</i>												
Low-EE	0.80	0.75	0-2	0.70	0.78	0-2	1.00	1.00	0-3	0.63	0.48	0-1
High-EE	3.04	2.54	0-9	2.46	2.71	0-9	5.80	2.60	2-12	4.80	3.34	1-12
<i>Total EE</i>												
Low-EE	5.10	2.66	2-10	3.50	1.86	1-7	5.50	2.50	1-8	2.63	1.32	1-5
High-EE	17.09	7.48	11-34	12.73	8.55	3-35	23.1	9.35	14-35	18.5	11.24	6-39

Follow-up

To assess maintenance of change or any additional change, the three month follow-up scores were compared initially with post-treatment scores.

As expected, knowledge scores were maintained at follow-up with most people scoring the same exact total 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 $> .10$).

For LEE scores, paired t-tests showed no significant changes in EE between post- and follow-up ($p's > .10$) for either relatives or clients on both the total scores and each of the four subscales, except for the Attitude toward illness subscale where the relatives' version showed a significant effect ($t(17) = 2.38, p < 0.05$). That is, this finding reflected a decrease in EE on the Attitude toward dimension. Thus, initial gains were maintained and, for the relatives' Attitude toward illness subscale, additional positive change was reflected.

A further separate set of analyses were conducted to assess change from pre-treatment (i.e., pre-test 1 scores) to follow-up on total scores to assess overall change.

A Wilcoxon test for KASI total scores was highly significant and clearly showed that relatives' gained in knowledge during the study from pre-test 1 to follow-up ($z = 3.422, p < 0.0006$).

Paired t-tests showed significant decreases in EE in the total score for relatives ($t(17) = 3.50, p < 0.005$) and clients ($t(16) = 2.88, p < 0.01$) between pre-test 1 and follow-up.

Table 9: Change in EE Status Following Treatment

	EE Decreases Pre-test to Post-test					
	Decrease	Decrease	Decrease	No change	No change	Increase
	High → Low	High → High	Low → Low	Low EE	High EE	High → High
Relatives	6	3	8	3	0	0
Clients	4	4	6	2	1	2

Table shows that 31/39 people (17 relatives, 14 clients) lowered their EE score from pre- to post-test. Those who increased their score did so by only one point. At follow-up, 30/39 people (16 relatives, 14 clients) were either still on their lowered score or had lowered further.

In terms of relapse, in the nine months following intervention, 1/19 clients relapsed.

Discussion

Discussion of the Main Aims and Major Findings

The present study principally examined the effectiveness of a brief educational intervention with the aim of enhancing family members' knowledge about schizophrenia, and expressed emotion - leading to an increased awareness of coping strategies and ultimately a reduction in EE.

Taken together, the findings of the current study demonstrated that 1) relatives' knowledge improved significantly after the information session and that this improvement was maintained at the three month follow-up whereas no change was reflected as a function of the control group, and 2) EE in participants also decreased over the course of the study. However, here, while total EE decreased more in magnitude following intervention versus the control period, it is important to underscore that the time by condition interaction was non-significant. The exception here was the relatives' Attitude towards illness subscale where not only was the intervention found superior to control, but additional significant benefit was reflected between intervention and three month follow-up.

Since most of the other studies of this ilk are interested in the role of EE in relapse, it is important to emphasise that the present study was not directly concerned with clients' relapse rate though it was found that only 1/19 clients in the study relapsed in the nine months following the intervention. Previous studies (Falloon et al., 1993; Tarrier et al 1988a,1989) concerned with relapse rates have been large multi-faceted intervention studies of which education per se is only one part. It was theorised for the present study that it would be asking too much to expect a master's level brief education programme to impact relapse rates when nothing else is changing in their environment. Indeed, Tarrier et al (1988a) found that education alone did not influence relapse rates. However, this study's finding of just over 5% relapse in a nine month period is encouraging indeed.

The main purpose of the present study was concerned with the seemingly more achievable goal of increasing relatives' knowledge and understanding which would lead to a reduction of intrusiveness and emotional responses as well as a more relaxed attitude about the illness and more realistic expectations (increased tolerance = lower EE). To this end, the results from this study are clearly encouraging.

Relatives Knowledge

The first major aim of the present study was to increase relatives' knowledge. It was possible to assess this in two ways: firstly, through a comparison of treatment and control group scores before and after the education, and secondly by examining whether relatives' EE status affected knowledge acquisition.

As stated above, relatives knowledge did increase significantly in the treatment group (after education). The same increase was also achieved by those in the control group (i.e., treatment group II) after their information session. That is, the initial effect was in a sense replicated. By contrast, no change was reflected following the control period.

Further, there was also a significant change in their responses, from functionally negative or neutral (a score of 1 or 2) before the education session to positive (a score of 3 or 4) afterwards. This result applied to five of the six different aspects of schizophrenia assessed, and also to the total score of the KASI.

Also, four of the sections (symptomology, aetiology, medication, and management) reflected significant improvement in functional, positive knowledge in not only the treatment group after the information session, but in the control group after their information session also. In the case of the section here that did not reflect significant improvement (i.e., Course and Prognosis) in treatment group II, there was improvement which approached statistical significance.

Taken together, this is clearly evidence of the success of brief education in providing relatives information which might be used to assist the patients. Additionally, information which might lead to actions detrimental to the patients' recovery was significantly assimilated.

A closer examination of the questions in the Diagnosis section, and relatives' responses to them, may explain the lack of significance. Of the 20 relatives, only two actually showed a gain in knowledge after the treatment session. All other relatives demonstrated the same exact knowledge and thus retained their original score. Further, all but two relatives initially received a positive-value score (3), for which they basically needed to know 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". Since most relatives had this knowledge already at pre-test, any improvement was probably limited by their initial scores.

Further analyses of the KASI showed that the initial EE status of relatives on the whole did not generally affect the acquisition of knowledge, as those both high and low in EE demonstrated a gain in knowledge after the education session. High-EE and low-EE relatives' gained significant amounts of knowledge in the sections of Symptomology, Medication, and Management, as well as in the total score. High-EE relatives did not show significant knowledge gain in the two sections of Aetiology and Course and Prognosis, whereas Low-EE relatives did. Thus, higher EE relatives may be less receptive to information in these areas.

The finding of Berkowitz et al (1984) that relatives were especially lacking in knowledge about the aetiology of schizophrenia, and that they often tended to retain their own interpretations of the causes of schizophrenia, is partly supported by the results of the present study. 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 aimed to investigate relatives' behaviour. At pre-test, all of the relatives' responses were assessed as neutral, or positive, with the occasional positive and well-informed score. Although there was a significant change at post-test for the

treatment group, accounted for primarily low-EE relatives, a substantial number remained in the neutral category, suggesting that these relatives, particularly those high in EE had learned little about aetiology.

A closer examination of the two sections of Aetiology, and Course and Prognosis and relatives responses to them is needed to explain why the improvement there did not reach significance in the high-EE group. In this group, there were three families who were much older than most of the other families (50-85 years) in the study, and these two families scored very high in EE. It was noted in the Aetiology section that they held particular 'incorrect' beliefs about the onset of the illness (i.e., the illness was caused because of an unhappy childhood) which did not change after the education. They also held 'incorrect' beliefs reflected in the Course and Prognosis section (i.e., when asked if they thought the client may have problems again, responded no, or stated that being pushed or nagged by the family at home would not make the condition worse) which were maintained despite education.

As stated, these three families were older, and thus had lived with the diagnosis longer than the other families. This gave them more time to have been exposed to different theories about schizophrenia and to have developed their own alternative explanation to explain schizophrenia. Thus, they were more likely to have a well established lay model of schizophrenia which may be very difficult to change in a brief education programme.

Participants Expressed Emotion

The second major aim of the present study was to lower participants' EE. It was possible to analyse this in two ways: firstly, by examining whether being in the treatment or control group impacted on whether their EE rating would decrease, and secondly by examining whether relatives' initial EE status impacted on whether their EE rating would decrease.

Analyses showed that relatives' EE rating 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 the total score. However, the lack of interaction effects (apart from the subscale of Attitude toward illness relatives' version) suggest that this decrease was independent of whether they were in the treatment group or control group. This shows that after pre-test 1 all relatives began to be less intrusive, critical, and emotional, feel less responsible for the client, believe that there is a genuine illness, be more relaxed around and tolerant of the client, and to decrease their expectations of the client resulting in a significantly lowered EE rating for both relatives in the treatment and control group regardless of condition. However, it is noted 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 was over three times the magnitude of that seen in the control group.

Analyses addressing client EE scores showed significant decreases in the subscales of Emotional Response, Tolerance/Expectations and the total score. Again the decreases were independent of whether they were in the treatment or control group. This shows that immediately after pre-test 1 all clients began to feel that their relatives were not blaming themselves so much for the clients' illness, were being less angry, intrusive, or distressed around the client, were being more tolerant, their expectations were more realistic, and in general were more relaxed, showing lower EE. This suggests that the decreases in EE had less to do with the education as such, and perhaps more to do with anticipating that they were going to get 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).

This finding is further supported by the follow-up data which shows (again apart from the relatives' version of the Attitude toward subscale) no significant decreases in EE from post-test to follow-up. It was theorised that there would be little change in EE from pre- to post-, as one week is little time to assimilate new information, relate it to ones' own behaviour, become aware of ones' behaviour and to begin to acting and respond differently, whereas three months seemed an appropriate amount of time for this process to have at least partially occurred. The reverse occurred -- change was noted initially, and then maintained over the three month follow-up period.

Further analyses showed significant decreases in EE for the total score from pre-test 1 to follow-up for both client and relatives' versions of the LEE scale.

So to sum up in simple terms, 31 participants (17 relatives, 14 clients) lowered their EE rating between pre-test 1 and post-test. At follow-up, 30 participants (16 relatives, 14 clients) either lowered the rating further or maintained the new lower rating from post-test.

These reductions were to the extent that changes were made in behaviour which were apparent not only to relatives, but also to the clients. Thus the clients' LEE scores reflected the relatives' scores, as they had noticed that their family member had changed their behaviour.

Further Investigations and Implications

Previous short education programmes such as the one used in the Salford study (Barrowclough et al., 1987; Tarrier et al, 1988a) have shown that education alone does not reduce EE or relapse rates, but it does result in increases in relatives' knowledge (though not maintained at six month follow-up: Birchwood et al, 1992b). This study provides some support for those findings. However, over the course of the current study, there were reductions in EE and relatives' increases in knowledge were maintained at a three month follow-up. But the reductions, particularly in EE, appeared generally not to be due to education alone. One question here is why did EE decrease so significantly by follow-up in this study when it has not in other studies?

The analyses suggest that EE decreased not solely as a result of the education, but perhaps as a result of education combined with other factors associated with the study. There are a few possibilities. A closer look at the procedure may shed more light on some of these.

It could be assumed, for the purpose of this speculation, that the decrease in EE in the treatment group was a direct result of the education. That leaves us with the control

group. Apart from not receiving the education, they were treated no differently to the treatment group, as the procedure outlined in the method was adhered to with rigor. There were no items on schizophrenia, or on persons with schizophrenia in the news or in other major media during this time frame. No participants from the control group attended any courses which may have affected their EE rating.

It is not known conclusively, but it does seem doubtful that apart from these outside factors any other outside factor could affect the whole control group. That takes us back to the study and the procedures.

The diagnosed family member and their relative attended the pre-test 1 session together. They then separately filled out the appropriate measures and left. They were not seen again until one week later at post-test. Again this does not deviate from the procedure. It is doubtful that this had any singular effect on EE scores.

Again, what then were changes due to? A possibility here is that merely participating in the 'study' as such led to a reduction of EE. 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 an ill family member, but in helping them too.

So was the idea that this study could help part of the reason for the decrease? Some clients stated that it might be good for their key family member to participate as it may help lower their feelings of guilt and responsibility about the illness and help them to see more from their point of view. Some relatives stated that it would be good for clients to participate as the helpful techniques given may help if heard from a non-medical type person.

The point being made here is that these people entered the study with perhaps a certain mindset and expectations. Inherent in this was a certain anticipation that someone who seemed to understand their situation was going to put aside time to listen, discuss, and sympathise on a knowledgeable and one-to-one basis.

Perhaps this initial information was enough to make relatives a little more aware of their behaviours and attitudes, so that they acted a little differently. Perhaps clients noticed this behaviour and acted a little differently in response. That might have been sufficient to lower EE.

Of course, we also can not rule out other possibilities accounting for change including repeated testing and regression to the mean. However, other studies have not found such effects (e.g., Tarrier et al., 1988).

As to why EE decreased in this study but not others, some possible reasons are offered. Firstly, the limitations of the measure used to measure EE should be taken into account. Although it has been demonstrated to have reliability, it is a self-report measure. The previous studies (Barrowclough et al., 1987; Tarrier et al., 1988) used the Camberwell Family Interview for a more comprehensive rating.

Second, this study differs from other brief interventions in that it was conducted in New Zealand (rather than Britain or the U.S.) and it was not conducted in a research-based setting.

The positive results achieved could have been influenced by the fact that this study was conducted through the Schizophrenia Fellowship who believe in and support the information principles advocated in the present study. All participants belonged to the Wellington or Manawatu Fellowship, although some had yet to utilise their services. The people administering the measures were the Fellowship field-workers, and the author (a masters student in psychology) conducted the education. Perhaps none of these people were threatening, and all made themselves available for queries, concerns, or support. It was also suggested after the study that it would be advisable at some time to link up with the Fellowship. Perhaps this was a more laid-back (though still experimentally rigorous) approach than previous studies which resulted in a more relaxed atmosphere for participants.

The difference of results between previous studies and the present study could also have been influenced by a cultural difference between Britain, the U.S., and New Zealand. Future research should look at conducting the same study in different environments (e.g., outpatient settings, Fellowships) in different cities throughout N.Z. (i.e., Auckland, Hamilton, Dunedin, and Christchurch) and other countries (e.g., Australia).

Expressed Emotion Sub-findings

Another analysis was conducted with regard to EE. This was to see if treatment produced decrease in EE were dependent upon whether the person was initially high-EE or low-EE. The relatives' total score was dependent on whether the individual was initially high-EE or low-EE. The lack of interaction effects on the Intrusiveness subscale suggests that this decrease was independent of whether they were high-EE or low-EE. For the clients, significant treatment produced reductions in EE were noted for the subscales of Emotional Response, Attitude toward, Tolerance/Expectations and for the total score from pre- to post-test. The lack of interaction effects here suggest that it was irrelevant whether the person was initially high or low in EE.

This shows that low-EE relatives can benefit from education designed to inform and lower EE. The fact is that low-EE families may not necessarily be problem-free. If they do not receive any specialist intervention, these relatives may well develop critical and intrusive attitudes. In addition, some low-EE relatives may be borderline cases at risk of becoming high-EE. The fact that no relatives changed from low- to high-EE over the course of the study indicates that a short education programme may be useful as a preventive measure.

It has been theorised (Barrowclough et al, 1992) that brief education has value in that it engages the family in treatment and helps them to assimilate the illness and its problems from a stress vulnerability framework. Pakenham and Dadds (1987; Smith et al, 1989) found that it had value as it led to increased understanding and short-term reduction of family burden, distress, and anxiety, but not EE. More effective management of home life and reduction of distress and anxiety was also found by Abromawitz and Coursey

(1989). However, none of these effects lasted past the six month follow-up. Cozolino et al (1988) found no increase in knowledge at all. Nevertheless, in their study, relatives did report an increased sense of support and decreased feelings of personal guilt in respect of family and aetiology.

A major point here is that no brief programme other than the current study to date has found reductions in EE. Particularly given the significant interaction concerning the relatives' Attitude toward illness subscale of the LEE scale, reflecting the superiority of treatment versus control, providing brief education programmes under the auspices of organisations like the Schizophrenia Fellowship have merit.

Limitations of the Study

The results of the study are qualified by limitations that included a small sample size.

This study used the populations from both the Manawatu Schizophrenia Fellowship and the Wellington Fellowship. As outlined in the Method, a field-worker from each Fellowship contacted all of those who met the inclusionary criteria. About one fourth of those contacted participated in the study. There were numerous difficulties in obtaining even 39 participants.

While there were many reasons for this, the main one was likely the fact that both a key family member and the client needed to want to be involved. The numbers could easily have been tripled if the study had included both a 'relatives only' and 'clients only' group. In many cases, relatives were eager to participate but their diagnosed family member was ill or not willing. In other cases, the client was eager to participate with their families, but the family members did not want to participate. Many other families who also expressed interest could not participate because of overseas holidays, family deaths, illnesses, hospitalisations and moves.

The present study was completed as a Masters thesis by a single author. This meant limited time, man-power, and resources. Even with the help of two field-workers who

were also the independent raters, and with the support of a supervisor and two fellowships, extensions were needed to finish this treatment outcome study satisfactorily.

If this had been part of a PhD thesis, thus allowing for much more time, a bigger sample would have been obtained as various scheduling and timing problems could have been overcome.

Another limitation which could have realistically affected the outcome of the study was in the choice of measure for EE. The LEE scale was chosen over the Camberwell Family Interview (CFI) partially because the CFI is a long and involved interview and perhaps not suited for the every-day setting that the brief educational intervention was being trialled for, whereas the LEE scale is a quick, easy to administer and score pen and pencil measure with documented reliability and validity.

Additionally, the CFI was not chosen because one has to be trained to use it and it is then scored by experts. Unfortunately, these experts are in London, and it was impossible for the author to be trained in its use, even if it could be scored by an expert in the CFI.

This has perhaps had effects on the findings. It is easy to respond in a socially desirable manner on this measure 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 may be likely that the EE score that some people received did not accurately reflect their EE status. Most people recommended that improvements could be made by introducing a scale with a Likert type rating instead of using mere True/False responses.

But many others did not do this as they appeared to answer honestly. In addition, the LEE has been shown to reliably correlate with the CFI. Thus, while there are problems with the singular use of a self-report measure, the current study also utilised a

multimethod approach including a structured interview that also reflected positive change.

Conclusions

This thesis has described the development, implementation and initial results of a brief education programme which aimed to 1) inform relatives and clients about schizophrenia with a particular focus on strategies found to be helpful in coping with schizophrenia symptoms on a daily basis, and 2) to lower EE.

Particularly in terms of knowledge and relatives' attitude towards the illness, the effectiveness of this programme has been demonstrated. However, the longer term maintenance related to improvements has not been evaluated beyond three months. However, it is also the case that only 1/19 clients relapsed nine months following intervention. This is encouraging.

Many relatives brought to the educational session perhaps well-developed and systemised knowledge of their own, and the difficulties involved in changing beliefs and attitudes should not be under-estimated. These results suggest that educational sessions are likely to have more impact on relatives of clients with a relatively short history of the illness and perhaps when carried out in comfortable, supportive settings.

Low-EE relatives most definitely should not be excluded from education, as not only does this study suggest that they are amenable to learning information about schizophrenia and how to help the client (particularly concerning aetiology and prognosis) but that education may prevent them becoming high in EE.

Also, even though the present study has achieved positive results, it is important to note that brief education is clearly not enough for everyone. Some clients and relatives need more in the way of problem solving skills, communication skills, and regular one-to-one discussions with the appropriate people. Sometimes the more comprehensive intervention is the most appropriate treatment, especially for those who have lived with the diagnosis for longer and have developed a mindset about schizophrenia.

Appendix A

PROVIDING INFORMATION TO RELATIVES ABOUT EXPRESSED EMOTION AND SCHIZOPHRENIA

INFORMATION SHEET

What is this study about?

The term Expressed Emotion relates to communication patterns that can be stressful in families. This study aims to enhance family members knowledge about schizophrenia and expressed emotion and awareness of their current coping strategies with a brief educational programme, intended to help lower any conflict in the home.

This study will provide information on the nature and course of schizophrenia, expressed emotion, and their consequences. It will also discuss some coping strategies for both those with schizophrenia, and their families, thought to be helpful in coping with schizophrenia on a daily basis.

The project is being run by Alicia Moxon as a masterate research project and is supervised by Dr. Kevin Ronan in the Department of Psychology at Massey University.

What would I have to do?

If you agree to take part in this study you would need to complete one questionnaire and one interview on expressed emotion and knowledge about schizophrenia (this is to determine what information you already know, and each would take approximately 20 mins). You would also need to participate in one education session (2 hours long) about schizophrenia (symptoms, causes, medication, and treatment) and expressed emotion. After the education session the interview and questionnaire would be administered again. So in total, the study spans 3-4 weeks and involves only 2 hour blocks of your time.

Relatives with schizophrenia and their families will receive the education seperately, but be given the oppurtunity to get together at the end of the last session to disscuss what they have learned.

There will be two groups of families participating (remember everyone receives the information individually, not in a group situation) with no differences between the two groups, except that one group will begin the programme immediately and the other group will begin the programme when the first group has finished. The second group will also need to complete the questionnaire once more than the first group, and both groups will need to return three months later to complete the questionnaire one last time, and discuss how things are going since the education. You will not receive the information in a group situation, the word group has been used here merely to say that some people will receive the information at a different period of time to the others.

What can I expect from the researcher?

If you decide to participate in this study, you have the right to:

- ♦ choose not to participate
- ♦ refuse to answer any questions, or withdraw from the study at any time.
- ♦ ask any further questions about the research that occur to you during your participation.
- ♦ have your questions answered by the researcher and to discuss any aspects of the study

before agreeing to participate in the study.

- ♦ provide information on the understanding that it is completely confidential to the researcher. All records (including cassettes) are identified only by code number, and are seen only by the researcher and supervisor, and are to be used only for the purposes of the research. It will not be possible to identify individuals in any reports of the results.
- ♦ have access to a summary of the findings of the study when it is concluded.

If you are interested in taking part and would like me to contact you to answer any questions or to arrange a meeting, please phone on who will contact me. Or contact my supervisor Dr. Ronan onext.....

Alicia Moxon

Appendix B

**PROVIDING INFORMATION TO RELATIVES ABOUT EXPRESSED
EMOTION AND SCHIZOPHRENIA**

CONSENT FORM A

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

I also understand that I have the right to withdraw from the study at any time and the right to refuse to answer any particular questions in the study.

I agree to provide information to the researchers on the understanding that it is completely confidential and that my name will not be used without my permission. *(The information will be used only for this research and publications arising from this research project).*

I also agree that my psychiatrist can be contacted only to confirm the diagnosis of schizophrenia, not for any other reasons.

I agree/do not agree to have the Knowledge about schizophrenia interview audio-taped for the purpose of this study only *(Only the researcher will have access to these tapes, thus only she will know the identity of the individuals. At the end of the study, the cassette-tapes will be cleared, or returned to participants).*

I agree to participate in this study under these conditions and those set out in the information sheet, and I agree that my family can be asked to participate also.

Signed:

Name:

Date:

Appendix C

**PROVIDING INFORMATION TO RELATIVES ABOUT EXPRESSED
EMOTION AND SCHIZOPHRENIA**

CONSENT FORM B

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

I also understand that I have the right to withdraw from the study at any time and the right to refuse to answer any particular questions in the study.

I agree to provide information to the researchers on the understanding that it is completely confidential and that my name will not be used without my permission. *(The information will be used only for this research and publications arising from this research project).*

I agree/do not agree to have the Knowledge about schizophrenia interview audio-taped for the purpose of this study only *(Only the researcher will have access to these tapes, thus only she will know the identity of the individuals. At the end of the study, the cassette-tapes will be cleared, or returned to participants).*

I agree to participate in this study under these conditions and those set out in the information sheet.

Signed:

Name:

Date:

Appendix D

PATIENT AND FAMILY HISTORY INTERVIEW

Background Information

Name of person diagnosed with schizophrenia: _____
Name of relatives: _____
Person with schizophrenia's sex: _____
Person with schizophrenia's age: _____
What is _____'s ethnicity? _____
What is _____'s education level? (Eg., school cert, or a polytech course) _____
Where does _____ live? _____
Who are they living with? _____
What is _____'s marital status? _____
What is _____'s employment status? _____
What is the relatives relationship to _____? _____
What is the relatives employment status, and education level? _____

Psychiatric History

Who is _____'s current psychiatrist, & their phone number? (this is merely to confirm the diagnosis of schizophrenia) _____
What medication is _____ on, & How long have they been on it? _____
When did _____'s trouble begin? (age of onset) _____
Was there a sudden or gradual deterioration? _____
How long has _____'s problem being going on? _____
How has _____ been doing over the last three months? _____

Have you ever attended any courses run by the fellowship?
What do you think the 5 most prevalent symptoms are?

- a) _____
- b) _____
- c) _____
- d) _____
- e) _____

Thank-you for your co-operation, and I want you to rest assured that the information that you have shared with me, will only be seen by my supervisor and myself.

Knowledge About Schizophrenia Interview (KASI)

INTRODUCTION

I'd like to ask you some questions about ...'s admission to hospital, what you know about the reasons for it; what ... was treated for; what the treatment was and so on.

This is to help us give you and other relatives any information about your relative's condition that you might need. We just want to find out what you think or know already.

SECTION 1: DIAGNOSIS

1:1 What have you been told by the doctors/nurses or other people about the kind of problem that ... was treated for?

(Question if necessary to identify source)

.....

..... Source:

1:2 (If a diagnosis is not given): Do you know the name of the problem/diagnosis?

.....

1:3 (If answers to 1:1, and 1:2 are inadequate): What kind of problem do you think ... was treated for?

.....

.....

1:4 (If gives some diagnosis): What do you understand by (insert name of problem given). Do you think it is:

YES NO DON'T KNOW

(a) Having a minor nervous condition,
or having been 'overdoing it' lately?

☐
☐
☐

(b) A severe mental illness which can
affect all aspects of a person's life?

☐
☐
☐

(c) Other (specify
.....).

☐
☐
☐

2:1 You have mentioned that...s problems affected her/him by: (*List 'symptoms' that the relative has mentioned in the RAI or other interviews) Do you think that this is...s natural self, or do you think its part of '(insert name of problem given)'?

	Natural Self	Illness	Don't Know
(a)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2:2 Do you know of any other ways in which she/he was affected e.g. strange ideas or difficulties with her/his thinking?

.....

.....

2:3 Do you think ... could help or control '.....' repeat 'symptoms' listed in 2:1 and elicited in 2:2?

	YES	NO	DON'T KNOW
(a)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(f)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(g)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(h)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2:4 Do you know the most common and important symptoms (difficulties) of people who have '(insert whatever relative calls person's illness)'?

.....

.....

* See Barrowclough *et al.*, 1987.

2:5 Do you think the most common and important symptoms are:

	YES	NO	DON'T KNOW
(a) Hallucinations – hearing, seeing or smelling things which others can't hear, see or smell.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) delusions – totally false beliefs others don't share.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) disturbances of thinking such as thoughts being put into your head or broadcast to other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 3: AETIOLOGY

3:1 What do you think is the cause of ...'s '(insert whatever relative calls person's illness)'?

.....

.....

.....

.....

3:2 Do you think any of the following might have caused it?

	YES	NO	DON'T KNOW
(a) A biological illness affecting the way the brain works?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) The way someone is brought up? (e.g. having an unhappy childhood)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) It is inherited (runs in families)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) (add causes mentioned by relative)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

.....

3:3 Of all things just mentioned; what do you think is the main cause?

.....

.....

3:4 Ask only if relative gives an 'incorrect' answer to any of previous questions in this section:

You said that you think ... may cause 'insert relatives name for condition. Is there anything you might do to help remedy this/sort this out?

.....

.....

SECTION 4: MEDICATION

4:1 Has the doctor or psychiatrist prescribed any tablets or injections for ... ?

YES/NO/DON'T KNOW

TABLETS/INJECTIONS/DON'T KNOW WHICH

4:2 What is the name of the tablets/injections?

.....

4:3 How often will ... take these tablets/injections?

.....

4:4 Where will ... get these from?

.....

4:5 For how long will ... take these tablets/injections?

a few weeks/a few months/a year/2 years/more than 2 years

4:6 Do you think these tablets/injections should be taken (read out all alternatives before relative selects choice(s).

	YES	NO	DON'T KNOW
(a) When ... thinks she/he needs them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Until she/he seems better again?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) When you (or other friends/ relatives) think he needs them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) As the doctor says/prescribes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Not at all?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4:7 Do you know of any side effects which might occur as a result of taking the tablets/injections?

.....

.....

.....

.....

SECTION 5: COURSE AND PROGNOSIS

	YES OR POSSIBLY	NO	DON'T KNOW
5:1 Do you think that . . . may have problems again?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5:2 Which of the following are likely to make '(insert whatever relative calls condition)' worse, or bring her/his problems back?

	YES	NO	DON'T KNOW
(a) Having nothing to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Stressful life problems, (e.g. moving house, getting divorced)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Being pushed and nagged by the family at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Not taking her/his tablets/injections?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Anything else? (include items previously mentioned by relatives)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5:3 Suppose . . . seemed and felt completely better and decided to stop taking the tablets/injections. What do you think would happen? (Read out all alternatives before relative selects choice(s).)

	YES	NO	DON'T KNOW
(a) She/he would be better off without them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) It would make no difference to her/him?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) She/he might start to get worse again after a while?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 6: MANAGEMENT

6:1 Do you think there is anything you can do to help ...'s '(insert whatever relative calls condition)'?

.....

.....

.....

.....

6:2 Do you think there is anything you should not do?

.....

.....

.....

Do you think any of the following might help?

	YES	NO	DON'T KNOW
(a) Encouraging him/her to take her/his tablets or injections?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Looking after him/her by doing his/her washing, cooking etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Spending as much time as possible with her/him?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Encouraging her/him to gradually get back to doing things for her/himself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Giving her/him a good push to get going?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6:4 *N.B.* Ask only if relative has mentioned a potentially detrimental management strategy in this section *or elsewhere* in the interview:

ment strategy in this section *or elsewhere* in the interview:

You mentioned that you ... (specify strategy) ...

Probe: e.g. Could you tell me more about this?

How would you go about doing this?

References

- Barrowclough, C., Tarrier, N., Watts, S., Vaughn, C., Bamrah, J.S., Freeman, H.L. (1987) Assessing the functional value of relatives' knowledge about schizophrenia. A preliminary report. *British J. Psychiatry*, 151, 1-8.

Appendix F

LEE
LEE
LEE

LEVEL OF EXPRESSED EMOTION SCALE**Client Version**

John D. Cole, Ph.D.
Shahe S. Kazarian, Ph.D.

Instructions:

The following are a number of statements that describe the way in which someone may act towards you. Please identify the person who has been most influential in your life during the past three months. Examples of influential persons could be: mother, father, brother, sister, husband, wife, relative (e.g., aunt, grandfather) and friend. Then, read each statement and indicate whether this person has acted in these ways towards you over the past three months.

Mark your answers on the separate Answer Sheet provided. Simply circle the (T) box if you feel that the item is TRUE. Circle the (F) box if you feel the item is FALSE. It is important to make sure that the statement number agrees with the number of your response on the Answer Sheet.

1. Understands if sometimes I don't want to talk.
2. Calms me down when I'm upset.
3. Says I lack self-control.
4. Is tolerant with me even when I'm not meeting his/her expectations.
5. Doesn't butt into my conversations.
6. Doesn't make me nervous.
7. Says I just want attention when I say I'm not well.
8. Makes me feel guilty for not meeting his/her expectations.
9. Isn't overprotective with me.
10. Loses his/her temper when I'm not feeling well.
11. Is sympathetic towards me when I'm ill or upset.
12. Can see my point of view.
13. Is always interfering.
14. Doesn't panic when things start going wrong.
15. Encourages me to seek outside help when I'm not feeling well.
16. Doesn't feel that I'm causing him/her a lot of trouble.
17. Doesn't insist on doing things with me.
18. Can't think straight when things go wrong.
19. Doesn't help me when I'm upset or feeling unwell.
20. Puts me down if I don't live up to his/her expectations.
21. Doesn't insist on being with me all the time.
22. Blames me for things not going well.
23. Makes me feel valuable as a person.
24. Can't stand it when I'm upset.
25. Leaves me feeling overwhelmed.
26. Doesn't know how to handle my feelings when I'm not feeling well.
27. Says I cause my troubles to occur in order to get back at him/her.
28. Understands my limitations.
29. Often checks up on me to see what I'm doing.
30. Is able to be in control in stressful situations.
31. Tries to make me feel better when I'm upset or ill.
32. Is realistic about what I can and cannot do.
33. Is always nosing into my business.
34. Hears me out.
35. Says it's not OK to seek professional help.
36. Gets angry with me when things don't go right.

- | | |
|--|--|
| 37. Always has to know everything about me. | 49. Doesn't pry into my life. |
| 38. Makes me feel relaxed when he/she is around. | 50. Is impatient with me when I'm not well. |
| 39. Accuses me of exaggerating when I say I'm unwell. | 51. Doesn't blame me when I'm feeling unwell. |
| 40. Will take it easy with me, even if things aren't going right. | 52. Expects too much from me. |
| 41. Insists on knowing where I'm going. | 53. Doesn't ask a lot of personal questions. |
| 42. Gets angry with me for no reason. | 54. Makes matters worse when things aren't going well. |
| 43. Is considerate when I'm ill or upset. | 55. Often accuses me of making things up when I'm not feeling well. |
| 44. Supports me when I need it. | 56. "Flies off the handle" when I don't do something well. |
| 45. Butts into my private matters. | 57. Gets upset when I don't check in with him/her. |
| 46. Can cope well with stress. | 58. Gets irritated when things don't go right. |
| 47. Is willing to gain more information to understand my condition, when I'm not feeling well. | 59. Tries to reassure me when I'm not feeling well. |
| 48. Is understanding if I make mistakes. | 60. Expects the same level of effort from me, even if I don't feel well. |

THE LEE SCALE (Client Version): ANSWER SHEET

YOUR NAME: _____ AGE: _____ SEX: (circle one) Male Female DATE: _____

MARITAL STATUS: (circle one)

Single

Married/Common-Law

Separated

Divorced

Widowed

Indicate who has been the most influential person in your life over the past three months:
(circle one)

Mother

Father

Brother

Sister

Spouse

Other relative (e.g., Aunt, Grandfather)

Friend

Other (Please Specify) _____

Have you been living with your influential person during the past three months?
(circle one) Yes No

How many waking hours on a typical weekday have you been spending with your influential person during the past three months? _____ hours per week day

How many waking hours on a typical weekend have you been spending with your influential person during the past three months? _____ hours per weekend

Instructions for each item:

Circle the "T" box if you feel the item is TRUE

Circle the "F" box if you feel the item is FALSE

1	<input type="checkbox"/> T <input type="checkbox"/> F	16	<input type="checkbox"/> T <input type="checkbox"/> F	31	<input type="checkbox"/> T <input type="checkbox"/> F	46	<input type="checkbox"/> T <input type="checkbox"/> F
2	<input type="checkbox"/> T <input type="checkbox"/> F	17	<input type="checkbox"/> T <input type="checkbox"/> F	32	<input type="checkbox"/> T <input type="checkbox"/> F	47	<input type="checkbox"/> T <input type="checkbox"/> F
3	<input type="checkbox"/> T <input type="checkbox"/> F	18	<input type="checkbox"/> T <input type="checkbox"/> F	33	<input type="checkbox"/> T <input type="checkbox"/> F	48	<input type="checkbox"/> T <input type="checkbox"/> F
4	<input type="checkbox"/> T <input type="checkbox"/> F	19	<input type="checkbox"/> T <input type="checkbox"/> F	34	<input type="checkbox"/> T <input type="checkbox"/> F	49	<input type="checkbox"/> T <input type="checkbox"/> F
5	<input type="checkbox"/> T <input type="checkbox"/> F	20	<input type="checkbox"/> T <input type="checkbox"/> F	35	<input type="checkbox"/> T <input type="checkbox"/> F	50	<input type="checkbox"/> T <input type="checkbox"/> F
6	<input type="checkbox"/> T <input type="checkbox"/> F	21	<input type="checkbox"/> T <input type="checkbox"/> F	36	<input type="checkbox"/> T <input type="checkbox"/> F	51	<input type="checkbox"/> T <input type="checkbox"/> F
7	<input type="checkbox"/> T <input type="checkbox"/> F	22	<input type="checkbox"/> T <input type="checkbox"/> F	37	<input type="checkbox"/> T <input type="checkbox"/> F	52	<input type="checkbox"/> T <input type="checkbox"/> F
8	<input type="checkbox"/> T <input type="checkbox"/> F	23	<input type="checkbox"/> T <input type="checkbox"/> F	38	<input type="checkbox"/> T <input type="checkbox"/> F	53	<input type="checkbox"/> T <input type="checkbox"/> F
9	<input type="checkbox"/> T <input type="checkbox"/> F	24	<input type="checkbox"/> T <input type="checkbox"/> F	39	<input type="checkbox"/> T <input type="checkbox"/> F	54	<input type="checkbox"/> T <input type="checkbox"/> F
10	<input type="checkbox"/> T <input type="checkbox"/> F	25	<input type="checkbox"/> T <input type="checkbox"/> F	40	<input type="checkbox"/> T <input type="checkbox"/> F	55	<input type="checkbox"/> T <input type="checkbox"/> F
11	<input type="checkbox"/> T <input type="checkbox"/> F	26	<input type="checkbox"/> T <input type="checkbox"/> F	41	<input type="checkbox"/> T <input type="checkbox"/> F	56	<input type="checkbox"/> T <input type="checkbox"/> F
12	<input type="checkbox"/> T <input type="checkbox"/> F	27	<input type="checkbox"/> T <input type="checkbox"/> F	42	<input type="checkbox"/> T <input type="checkbox"/> F	57	<input type="checkbox"/> T <input type="checkbox"/> F
13	<input type="checkbox"/> T <input type="checkbox"/> F	28	<input type="checkbox"/> T <input type="checkbox"/> F	43	<input type="checkbox"/> T <input type="checkbox"/> F	58	<input type="checkbox"/> T <input type="checkbox"/> F
14	<input type="checkbox"/> T <input type="checkbox"/> F	29	<input type="checkbox"/> T <input type="checkbox"/> F	44	<input type="checkbox"/> T <input type="checkbox"/> F	59	<input type="checkbox"/> T <input type="checkbox"/> F
15	<input type="checkbox"/> T <input type="checkbox"/> F	30	<input type="checkbox"/> T <input type="checkbox"/> F	45	<input type="checkbox"/> T <input type="checkbox"/> F	60	<input type="checkbox"/> T <input type="checkbox"/> F

Appendix G

LEE
LEE
LEE

LEVEL OF EXPRESSED EMOTION SCALE**Relative Version**

John D. Cole, Ph.D.
Shahe S. Kazarian, Ph.D.

Instructions:

The following are a number of statements that describe the way in which you may act towards someone. Please read each statement and indicate whether you have been acting in these ways towards your relative (son, daughter, spouse, etc.) over the past three months.

Mark your answers on the separate Answer Sheet provided. Simply circle the (T) box if you feel that the item is TRUE. Circle the (F) box if you feel the item is FALSE. It is important to make sure that the statement number agrees with the number of your response on the Answer Sheet.

1. I say I understand if sometimes he/she doesn't want to talk.
2. I calm him/her down when he/she is upset.
3. I say he/she lacks self-control.
4. I am tolerant with him/her even when he/she doesn't meet my expectations.
5. I don't butt into his/her conversations.
6. I don't make him/her nervous.
7. I say he/she just wants attention when he/she says he/she is not well.
8. I make him/her feel guilty for not meeting my expectations.
9. I am not overprotective with him/her.
10. I lose control of my temper.
11. I am sympathetic towards him/her when he/she is not feeling well.
12. I can see his/her point of view.
13. I am always interfering.
14. I don't panic when things start going wrong.
15. I encourage him/her to seek outside help when he/she is not feeling well.
16. I don't feel that he/she is causing me a lot of trouble.
17. I don't insist on doing things with him/her.
18. I can't think straight when things go wrong.
19. I don't help him/her when he/she is upset or feeling unwell.
20. I put him/her down if he/she doesn't live up to my expectations.
21. I don't insist on being with him/her all the time.
22. I blame him/her for things not going well.
23. I make him/her feel valuable as a person.
24. I can't stand it when he/she is upset.
25. I leave him/her feeling overwhelmed.
26. I don't know how to handle his/her feelings when he/she is not feeling well.
27. I say he/she causes his/her troubles to occur in order to get back at me.
28. I understand his/her limitations.
29. I often check up on him/her to see what he/she is doing.
30. I am able to be in control in stressful situations.
31. I try to make him/her feel better when he/she is upset or ill.
32. I am realistic about what he/she can and cannot do.
33. I am always nosing into his/her business.
34. I hear him/her out.
35. I say it is not OK to seek professional help.
36. I get angry with him/her when things don't

- | | |
|---|---|
| 37. I always have to know everything about him/her. | 49. I don't pry into his/her life. |
| 38. I make him/her feel relaxed when I am around. | 50. I am patient with him/her when he/she is not well. |
| 39. I accuse him/her of exaggerating when he/she says he/she is unwell. | 51. I don't blame him/her when he/she is feeling unwell. |
| 40. I will take it easy with him/her, even if things aren't going right. | 52. I expect too much from him/her. |
| 41. I insist on knowing where he/she is going. | 53. I don't ask a lot of personal questions. |
| 42. I get angry with him/her for no reason. | 54. I make matters worse when things aren't going well. |
| 43. When he/she is upset, I am a considerate person. | 55. I often accuse him/her of making things up when he/she is not feeling well. |
| 44. I support him/her when he/she needs it. | 56. I "fly off the handle" when he/she doesn't do something well. |
| 45. I butt into his/her private matters. | 57. I get upset when he/she doesn't check in with me. |
| 46. I can cope well with stress. | 58. I get irritated when things don't go right. |
| 47. I am willing to gain more information to understand his/her condition, when he/she is not feeling well. | 59. I try to reassure him/her when he/she is not feeling well. |
| 48. I am understanding if he/she makes a mistake. | 60. I expect the same level of effort from him/her, even if he/she doesn't feel well. |

THE LEE SCALE (Relative Version): ANSWER SHEET

YOUR NAME: _____ AGE: _____ SEX: (circle one) Male Female DATE: _____

MARITAL STATUS: (circle one)

Single

Married/Common-Law

Separated

Divorced

Widowed

Indicate your relationship to your relative:
(circle one)

Mother

Father

Brother

Sister

Spouse

Friend

Other (Please Specify) _____

Has your relative been living with you during the past three months?
(circle one) Yes No

How many waking hours on a typical weekday have you been spending with your relative during the past three months? _____ hours per week day

How many waking hours on a typical weekend have you been spending with your relative during the past three months? _____ hours per weekend

Instructions for each item:

Circle the "T" box if you feel the item is TRUE.

Circle the "F" box if you feel the item is FALSE.

1	<input type="checkbox"/> T <input type="checkbox"/> F	16	<input type="checkbox"/> T <input type="checkbox"/> F	31	<input type="checkbox"/> T <input type="checkbox"/> F	46	<input type="checkbox"/> T <input type="checkbox"/> F
2	<input type="checkbox"/> T <input type="checkbox"/> F	17	<input type="checkbox"/> T <input type="checkbox"/> F	32	<input type="checkbox"/> T <input type="checkbox"/> F	47	<input type="checkbox"/> T <input type="checkbox"/> F
3	<input type="checkbox"/> T <input type="checkbox"/> F	18	<input type="checkbox"/> T <input type="checkbox"/> F	33	<input type="checkbox"/> T <input type="checkbox"/> F	48	<input type="checkbox"/> T <input type="checkbox"/> F
4	<input type="checkbox"/> T <input type="checkbox"/> F	19	<input type="checkbox"/> T <input type="checkbox"/> F	34	<input type="checkbox"/> T <input type="checkbox"/> F	49	<input type="checkbox"/> T <input type="checkbox"/> F
5	<input type="checkbox"/> T <input type="checkbox"/> F	20	<input type="checkbox"/> T <input type="checkbox"/> F	35	<input type="checkbox"/> T <input type="checkbox"/> F	50	<input type="checkbox"/> T <input type="checkbox"/> F
6	<input type="checkbox"/> T <input type="checkbox"/> F	21	<input type="checkbox"/> T <input type="checkbox"/> F	36	<input type="checkbox"/> T <input type="checkbox"/> F	51	<input type="checkbox"/> T <input type="checkbox"/> F
7	<input type="checkbox"/> T <input type="checkbox"/> F	22	<input type="checkbox"/> T <input type="checkbox"/> F	37	<input type="checkbox"/> T <input type="checkbox"/> F	52	<input type="checkbox"/> T <input type="checkbox"/> F
8	<input type="checkbox"/> T <input type="checkbox"/> F	23	<input type="checkbox"/> T <input type="checkbox"/> F	38	<input type="checkbox"/> T <input type="checkbox"/> F	53	<input type="checkbox"/> T <input type="checkbox"/> F
9	<input type="checkbox"/> T <input type="checkbox"/> F	24	<input type="checkbox"/> T <input type="checkbox"/> F	39	<input type="checkbox"/> T <input type="checkbox"/> F	54	<input type="checkbox"/> T <input type="checkbox"/> F
10	<input type="checkbox"/> T <input type="checkbox"/> F	25	<input type="checkbox"/> T <input type="checkbox"/> F	40	<input type="checkbox"/> T <input type="checkbox"/> F	55	<input type="checkbox"/> T <input type="checkbox"/> F
11	<input type="checkbox"/> T <input type="checkbox"/> F	26	<input type="checkbox"/> T <input type="checkbox"/> F	41	<input type="checkbox"/> T <input type="checkbox"/> F	56	<input type="checkbox"/> T <input type="checkbox"/> F
12	<input type="checkbox"/> T <input type="checkbox"/> F	27	<input type="checkbox"/> T <input type="checkbox"/> F	42	<input type="checkbox"/> T <input type="checkbox"/> F	57	<input type="checkbox"/> T <input type="checkbox"/> F
13	<input type="checkbox"/> T <input type="checkbox"/> F	28	<input type="checkbox"/> T <input type="checkbox"/> F	43	<input type="checkbox"/> T <input type="checkbox"/> F	58	<input type="checkbox"/> T <input type="checkbox"/> F
14	<input type="checkbox"/> T <input type="checkbox"/> F	29	<input type="checkbox"/> T <input type="checkbox"/> F	44	<input type="checkbox"/> T <input type="checkbox"/> F	59	<input type="checkbox"/> T <input type="checkbox"/> F
15	<input type="checkbox"/> T <input type="checkbox"/> F	30	<input type="checkbox"/> T <input type="checkbox"/> F	45	<input type="checkbox"/> T <input type="checkbox"/> F	60	<input type="checkbox"/> T <input type="checkbox"/> F

Appendix H

PROVIDING INFORMATION TO RELATIVES ABOUT EXPRESSED EMOTION AND SCHIZOPHRENIA

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Alicia M. Moxon

1998

Ultimate Aims

The present study will attempt to deliver a short, uncomplicated education programme that is applicable to everyday settings, which is designed to retain the effectiveness of the programmes designed and utilised in research settings. It will aim to enhance family members knowledge about schizophrenia and expressed emotion, as well as the awareness of current coping strategies by conducting a brief educational intervention. It is theorised that education concerning the illness and its management will alter the views and attributions that relatives make about the causality of the person's symptomatic behaviour, thereby reducing the criticism, hostility, or emotional overinvolvement that may follow from misinformation, feelings of disappointment, and less effective coping skills. It is theorised that this reduction in criticism, hostility, and emotional overinvolvement will improve the emotional climate in which the individual diagnosed with schizophrenia resides.

Thus, the ultimate aim of this study is to increase the stability and constancy of the participant's home environment by decreasing the family's guilt and anxiety, and increasing their self-confidence and awareness through the provision of information concerning the nature and course of schizophrenia, expressed emotion, and their consequences, and through the provision of specific coping strategies thought to be helpful in coping with schizophrenic symptoms on a daily basis.

Outline for the Education Programme

Throughout the education this is the format that will be followed:

- the clients and consumers will be invited to actively participate and share in the presentation by describing their experiences of the disorder and it's treatment.
- reluctant clients and consumers will be encouraged to participate, and all efforts will be praised, no matter what size.
- each issue will be presented in no more than five minute segments. Then participants will be asked to describe their own experiences, concerns, or queries. Participants will be encouraged to summarise the key points they have understood at the end of each issue.

Session Two (1 hour)

Give participants an outline for the session.

Give participants the education booklet.

Talk about - diagnosis of schizophrenia

- symptomology
- course and prognosis
- aetiology
- medication and side-effects

10 minute break for coffee.

Talk about - common emotional and behavioural reactions

- how the family can help

Conduct 10-15 minute relaxation

Make appointment for next session.

Session Three (1-1 1/2 hours)

Roughly 1/2 hour for questions/feedback time.

The KASI is completed by relatives, the LEE scale by relatives and consumers.

Note- Permission was given by Nicholas Tarrier and Ian Falloon to respectively incorporate Nicholas Tarrier and Christine Barrowclough's (1992) information booklet and Falloon, Graham-Hole & Fadden's (1997) *Integrated Mental Health Care* into this manual.

This is the first lecture that will be given to the relatives. Allowing time for questions and discussions, it will take approximately 45-50 minutes. This is followed by a 10 minute coffee break.

Information About Schizophrenia for Friends & Relatives

Well I thought to start with I could give you an idea of what is going to happen, so this is the outline:

- we'll discuss what schizophrenia is and the different symptoms that are involved with it, 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 I figure after that we might want a break, so if you feel like it we can take a short break for a drink or something.

The second part of this session will provide some coping skills that research has shown can sometimes help, including relaxation. It may sound corny but it truly helps! And that will take about one hour.

Finally, you'll make an appointment to come back in about 5 days to discuss with your family member and myself the main points of this session, and any further questions or concerns either of you have. This isn't a test, it's just an opportunity to come together and work out queries and concerns. And that's it for this session.

Please, ask questions whenever you want or jump-in at any time.

* * * * *

I'm going to give you a hand-out, it's written by two (very experienced) people in England in association with the British schizophrenia fellowship. It's basically information for those suffering from schizophrenia and their families. This session will be loosely based on it, so if you wish you can follow it or refer to it as we go, but basically its for you to take home and refer to if you want to check something or have a question before our next meeting.

What I am going to talk about is based as close as possible on the average situation, and as you know every situation is different and you know better than I do about your situation. So if you do have anything you want to say just jump-in with it.

WHAT IS SCHIZOPHRNIA?

So, schizophrenia is a word just about everyone has heard. Most people are not sure what schizophrenia really is, what causes it, and what can be done for it.

There are a few things that are definitely not schizophrenia which need to be cleared up. I am sure you will have heard people say that schizophrenia is having more than one personality. There is actually a very rare mental disorder where people seem to have many different personalities at different times, a bit like an actor playing different parts in different films. This is not schizophrenia.

Schizophrenia means that a person finds it difficult to decide what is real and what is not real. This inability to tell real from not real is sometimes called psychosis. It is a bit like having dreams when you are wide awake. Everything that is going on seems quite real at the time, often a little strange and frightening, but quite real. It is usually only when that episode of schizophrenia is over, that the individual can realise that many of the things that they thought were happening were probably not -- in the same way we realise that our dreams were not real after we have woken up. But like everything, there are exceptions and there are some people who are aware that this is happening, and some who lack insight.

Another source of confusion is that many people equate schizophrenia with “insanity”, “madness”, or being weird. These terms are not used in mental health, but are often used to describe strange, irrational behaviour. At times a person suffering from schizophrenia may act in an unusual manner, but more often they will behave quite appropriately.

People who have had mental disorders have also been considered to be violent and dangerous. Occasionally individuals suffering from schizophrenia may have violent outbursts, but generally they are quiet, timid and fearful.

WHAT, THEN, IS SCHIZOPHRENIA?

Schizophrenia is a major mental illness. It affects about one person in every hundred in all countries throughout the world. More hospital beds are filled by people suffering from schizophrenia than from any other single illness. It is described as a major disorder because it has a great effect on nearly every aspect of a person's life. Everything that is important in our lives may be affected by schizophrenia.

There are many problems which are commonly found in schizophrenia, yet those suffering from schizophrenia can differ widely in the symptoms which they exhibit. The range of potential problems (like any illness) is so extensive that it is extremely unlikely that an individual will exhibit all of the symptoms of schizophrenia at one time. It is more likely that each individual will exhibit a cluster of possible symptoms varying in number and severity.

The person's thinking at times may be muddled and confused. This means that they may have trouble handling everyday problems. He or she may not be able to work as well as before; it may be hard to concentrate and to think quickly and clearly. He or she may have similar problems with other activities. The person may find it difficult to make conversation or show feelings, and this can make it hard for them to communicate with others. At times the person may be so taken up with their thoughts and feelings that they forget to take care of even their most basic of needs like sleep, food and cleanliness. These are called negative symptoms.

Qn: Have you seen any of these symptoms in your relative?

HOW DO WE KNOW WHEN A PERSON HAS SCHIZOPHRENIA?

We know a person has schizophrenia when key symptoms (like hallucinations or delusions) are present. These feature changes in a person's thoughts and feelings, and to a lesser extent, in their behaviour. Doctors find out that the person has these symptoms mainly from what the client tells or shows them. At the present time there are no special blood tests or X-rays to help the doctors, they will depend almost entirely on what they have been told or have seen. Contrary to popular belief, psychiatrists and psychologists cannot read people's minds, they can only make a diagnosis from what they have been told and with consultation with a diagnostic manual used worldwide. The characteristic symptoms they use to decide whether an individual suffers from schizophrenia include what are known as positive and negative symptoms.

Positive Symptoms

Positive symptoms are the type of symptoms that the person may experience. It doesn't mean that they are good, what positive means is that there is an excess of things, like changes and distortions in perceptions and thought processes. These include disturbances of thinking, delusions, and hallucinations.

Disturbances of thinking involves thoughts being put into your head which are not your own thoughts. They may seem to come from other people by telepathy or radio-waves, laser beams, or any number of things. Thoughts disappearing from your head, as if they are being taken out, or stolen by someone. Your mind is quite blank and you are unable to think about anything. This is not the same as when you forget a thought, or when you are nervous and seem to lose track of your thoughts. Thoughts seeming to be spoken out loud as if somebody close by could hear them. Sometimes feeling that the thoughts are being broadcast from your head. In this way everybody knows what you are thinking and none of your thoughts are private.

Another disturbance in thinking may occur with thought processes, which become so jumbled that the person does not think in a coherent manner. This may be reflected in the person's speech in which the grammar may become distorted, or there may be dramatic and unexpected changes from topic to topic or a lack of logical connection between one part of a sentence or another. Sometimes the person's speech may include made up words or odd expressions, which can make them difficult to communicate with. This disorganisation of thought can also be accompanied by disorganisation of behaviour - which can range from odd to disorganised.

This kind of thinking can make the person really anxious and tired. Trying to keep up with your own thoughts and trying to make sense out of them can wear some people down.

Qn: Have you ever noticed anything like this?

The second major positive symptoms are **Delusions**. These are false beliefs that seem quite real to people having them, but not to others. Some examples of these delusions common in schizophrenia are:

- ✱ a belief that some other person or force has control of your thoughts or actions. That you are a zombie with no free will and another person has taken over your brain or body.
- ✱ a belief that somebody is trying to harm you, perhaps trying to kill you for no good reason. You are being unjustly persecuted.
- ✱ a belief that what you see or read about have a special message for you. E.g., seeing a red car may mean that the world is about to end.
- ✱ a belief that you are a particular person (such as the Queen or Jesus) with magical powers or abilities (such as controlling the weather).
- ✱ Those delusions might not be so frequent, but often there are small ones that the individual has to cope with on a daily basis and this can be tiring also.

These ideas often come on quite suddenly. They are unusual so that friends and family realise that they are unlikely to be really true. When the person has recovered they may be surprised what they believed when ill. Again, it is a little like waking up from a dream.

Qn: Has ____ experienced any of these difficulties, or unusual ideas?
What did you think was going on?

The third major positive symptoms are **Hallucinations**, which are false sensations. This means that the person hears, sees or smells things that are not heard, seen or smelt by others. Hearing voices when nobody is in the room is a very common symptom of schizophrenia. The voices seem real and may appear to come from the next room or outside. Sometimes they may seem to come from inside a person's head or, less often, from a part of their body. Sometimes the person believes that someone or something is touching them when there is no-one there and nothing to explain this.

A diagnosis of schizophrenia is usually made because certain key positive symptoms (like the hallucinations or delusions) appear to be present. However, other symptoms which are termed negative symptoms are often present at sometime during the illness.

Negative symptoms

Unlike positive symptoms, which are dramatic changes in the person's experience, the negative symptoms are usually shown as changes in the person's behaviour. They are called negative because they indicate decreases or absences of behaviour. These type of symptoms include:

- ✱ an absence of motivation or enthusiasm to do anything.
- ✱ a general inactivity and a decrease in all activity levels. This may range from hobbies and leisure pursuits to simple and basic self-care activities such as washing and grooming.
- ✱ an inability to show emotion, the person may appear flat or disinterested.
- ✱ an apparent disinterest in conversation and talking. The person will not start conversations and frequently answer in single words if at all.
- ✱ an inability to enjoy some activities that used to give pleasure.
- ✱ an apparent difficulty in getting on with people even close relatives, so that contact with others is often be avoided.

These negative symptoms can be very distressing for relatives, even more so than the positive symptoms. This is because all life can appear to go out of the person so that nothing interests them and they become cold and withdrawn. It is important to remember that your relative will not suffer from all of these things at one time, and even the things that they do suffer from are episodic. That is they are not there forever, they will wax and wane over time, and gradually improve with support, patience and encouragement. It is also important to remember that these symptoms are part of the illness, they are not doing these things on purpose.

Another symptom of schizophrenia is changed feelings and emotions, which is the experience that your feelings have disappeared or are much less intense. Both happy feelings and sad feelings may be affected. At other times a person with schizophrenia may find their feelings become uncontrollable so that they may laugh or cry when they are not feeling happy or sad, or look flat when they are feeling happy or sad.

WHAT USUALLY HAPPENS TO PEOPLE WITH SCHIZOPHRENIA?

Schizophrenia is an illness that usually begins when a person is in their early 20s, but it may occur at any time in a person's life. A number of people suffer from only one episode of the illness and never have a further attack. But many sufferers will have periods when the major symptoms return. These periods are called relapses. For many schizophrenia is a life long concern. However, with improved medical treatment and newer anti-psychotics the outlook for schizophrenia is better than it has been in past years, & even the most severe cases of schizophrenia gradually get better over time.

Schizophrenia affects many young people in the prime of their lives. It is a major setback in their plans and hopes for the future. As a result, it is not uncommon for a person to become unhappy, feel overwhelmed and despairing. Such depression sometimes resembles that of a depressive disorder, so it is important that this problem is recognised and treated effectively.

WHAT CAUSES SCHIZOPHRENIA?

Schizophrenia is thought to result from a combination of causes including bio-chemicals, genetics and stress. That is to say, it is probably caused by a disturbance in the working of the brain & life stress. Since the illness often occurs when the person is under stress, it is thought that stress may act as a trigger to bring on the illness.

The brain works through exchanges of special chemicals called neurotransmitters. Although it is not exactly clear what goes wrong when a person develops schizophrenia, it seems that these chemicals in the brain are affected. A chemical imbalance results and produces the symptoms of hallucinations, delusions and thinking

difficulties. It is also noted that taking certain types of medication, which are of course forms of chemicals, appears to correct the chemical imbalance and improve the symptoms of schizophrenia.

Many scientists have worked on the problem of finding the exact nature and cause of the brain chemistry without reaching any general agreement. New theories appear every few months, and it is easy to become confused. Some theories you may have heard about have not yet been substantiated. E.g., there is no scientific proof that vitamin deficiency causes schizophrenia, or that vitamin therapy helps schizophrenia, except of course where a person has a vitamin deficiency as a result of poor nutrition, but that is not linked with schizophrenia.

At the present we still do not know the exact cause of schizophrenia, nor do we have a complete cure. We do, however, have treatment that can minimize the impact of the disorder on your lives.

Qn: I'll explain it a bit more.

Schizophrenia is an illness that can be inherited. That does not mean that if someone in your family has the illness everybody else will get it. Nor does it mean that a person with schizophrenia should not marry and have children. It was mentioned before that people in general have about a 1 in 100 chance of getting the illness, but if a close relative like a parent or brother suffers from schizophrenia then your chances are about 1 in 10 that you may be at risk to get the disorder.

People who are at risk of getting schizophrenia possibly lack some chemical or enzyme in the brain that may be responsible for the development of the chemical imbalance associated with schizophrenia. This imbalance probably only develops into schizophrenia when the person who has this vulnerability experiences certain stressful situations.

Stress and schizophrenia

One of the greatest periods of stress, especially for young men, is in early adult life (early to mid 20s). At this time they are striving to get a good job, make friends and become independent. This is the most common time for schizophrenia to begin in men. In women, major life stress often starts later, when they have children (late 20s).

Several studies show that major stressful events such as a death in the family, loss of a job or breakup of a relationship can make schizophrenia worse or trigger off a relapse of symptoms.

Other studies show that once a person has schizophrenia the personal environment in which he or she lives can help considerably if those people in daily contact can provide support by encouraging gradual regaining of former skills and interests. It is impossible to totally avoid stress, but friends and family are most helpful when they help one another to cope with difficulties in their lives.

There is absolutely no evidence that families cause schizophrenia.

A few years ago, many psychiatrists believed that schizophrenia was entirely caused by the way the parents brought up their children. While we know how important this is, **there is no scientific evidence that poor child care or an unhappy childhood causes schizophrenia**, and I want to repeat that, families do not cause schizophrenia.

Qn: does that make more sense now? *(If looking puzzled)*

MEDICATION

I realise that you probably know lots about the medication and probably more than me, but I thought that I could just share some of the research with you as you may find it helpful.

Medication was introduced for the treatment of schizophrenia about 40 years ago. It is the main form of treatment. There are several different types of drugs used in the treatment of schizophrenia, with different brand names. The ones for schizophrenia are called neuroleptics or major tranquillisers. Medication may be given in the form of tablets or injections. Injections are often helpful as they are less likely to be forgotten and smaller amounts are used. All of the different types of medication have similar helpful effects, but different side-effects.

The strengths of the medications differ considerably. E.g., 100mg of chlorpromazine is about the same strength as 2mg of fluphenazine. You will notice that the same medicine often has more than one name e.g., chlorpromazine = Largactil or Thorazine. The longer usually more complicated name is the chemical name while the shorter name is the brand name.

There are two ways in which medication is used in the treatment of schizophrenia.

1. to reduce the symptoms of an acute attack of the illness
2. once the symptoms of delusions, hallucinations and thinking difficulties have been relieved the same medication is used to prevent further recurrences of the illness. Although this dosage is usually lower.

If the person with schizophrenia stops taking the medication against the doctor's advice the chances of them having a further attack of schizophrenia are more than doubled, furthermore, the symptoms are likely to be more severe. This is why it is important to take the medication that the doctor prescribes even when the person feels completely well.

Unfortunately the medication used for the treatment of schizophrenia can sometimes produce unwanted side-effects. These are not usually serious and should be discussed with the doctor. Some of these side-effects include drowsiness, shakiness, restlessness, and muscle stiffness. Others are sensitivity to sunburn, increased appetite, dry mouth and dizziness especially when standing up suddenly.

Some of these effects the person can avoid themselves, but if your relative is worried about anything to do with the medication, go & see your doctor.

SOME REMIDIES FOR SIDE-EFFECTS

Maybe you've noticed some of these side-effects and may have wondered what was happening and how to cope with them, so it might be helpful if I went through some of the side-effects and explained them.

Of the side-effects, drowsiness tends to be the biggest problem. It can be overcome by taking the main dose of medication before they go to bed. The drowsiness will be helpful in getting a good night's sleep and may have worn off by morning. Structured activities, with variety and interest can decrease drowsiness.

Dizziness is usually a result of blood pressure falling when a person gets up too quickly. This can be a result of the drugs, but usually goes away once the person becomes used to the drugs. It can be avoided if the individual rises more slowly.

Perhaps the most distressing side-effect for families is the "zombie-like" look that those on antipsychotic drugs sometimes develop. It is a combination of slow movements, expressionless face, and stiff arms and legs. It goes away when the dose of antipsychotic drugs is lowered or when other drugs are added. Although the stiffness temporarily looks strange to others, it is not uncomfortable for your family member. What is uncomfortable are the feelings of restlessness, not being able to sit still. Walking around is easier than

sitting still which is why your relative may have the tendency to pace or wiggle their legs. This can be annoying, but it is a side-effect of medication, not something that is altogether controllable.

Muscle spasms can be a reaction to drugs but these are usually early side-effects which cease once the drug doses are properly adjusted. Although the tremor may remain. Tremor of the fingers and sometimes the tongue, hands and feet can be quite noticeable, and can be mistaken for nerves. It tends to get better when the individual is calm, but basically it is a side-effect.

The most worried about side-effects are the loss of spontaneity and creativity. These may be more side-effects of the illness than of drugs. Nevertheless, people often feel that these empty feelings are due to the drugs they are taking. It is important to realise that these feelings, temporarily, may be a necessary price for staying free of the fear of psychosis. It is important to keep on with the drugs at this stage - to correct the side-effects which are controllable and to try and endure those which are not.

While medication helps most people with schizophrenia by reducing symptoms it does not change a person's entire personality, help a person learn new skills, get a job or make new friends. Other forms of rehabilitation are necessary in combination with the medication for the best results (this will be discussed further on).

Well that's it, is there anything you want to clarify. Do you want a little coffee break? = 10 mins

This is the second lecture that will be given to the relatives. Allowing time for questions and discussions, it will take approximately 30-40 minutes. This will be followed by some practical relaxation techniques (20 minutes). That ends session two.

Information about Schizophrenia for Friends & Relatives II

O.K, like earlier, I want to give you an idea of what is going to happen in the next hour. So this is how it should flow:

- we'll talk about how you cope or deal with your relative's illness - And I will talk about some things that research has shown can sometimes help people to deal with the illness.
- and lastly we'll actually do some relaxation, this has been proven to be successful when you are at the end of your tether!, or for getting to sleep at night after a hard day.

In an era of community care, an increasing burden of care is being left to the families of those suffering from schizophrenia. Research has shown that between 46% and 65% of those hospitalized with schizophrenia return on discharge to live with their families, and as you know even when your family member isn't in the same house as you, it isn't like they have moved out, it's just like your roof-line has been extended to where they sleep.

The return of your family member can be a major upheaval for all of you. You may feel anxious because you don't know what to expect, helpless and depressed because you can't change the illness or make it 'all better' as parents try and want to do. Watching someone you care for start behaving in bizarre and unusual ways is very upsetting. Feeling anxious or fearful about the reason for these behaviours, or how long they will last is perfectly normal. You may also feel guilty that you may be too overbearing or uninvolved, rigid or lax, punishing or protective. "When something goes wrong, most people look to themselves to see what they could have done differently, and most people find something that they can worry about. These concerns tend to be reinforced by the messages of the popular media (like on T.V and in magazines) that emphasize the connection between good parenting and a child's success" (Anderson, Reiss & Hogarty, 1987, p 109). So, basically if you are a parent, you blame yourself for everything whether you deserve it or not, and usually you don't!

It is also perfectly understandable if sometimes you get frustrated. When someone in a family is diagnosed with schizophrenia, it is difficult to try and do all you can to help that person, while at the same time keep your family life stable. And even though you know that your family member is ill, "it is impossible to avoid feeling angry at behaviours that seem thoughtless, inconvenient or irritating" (Anderson et al, p110). Underneath all of these emotions relatives usually experience at one time or another a sense of grief for the loss of health, personality and vitality in the person they love.

These are all perfectly normal and appropriate emotions and in such a difficult and confusing situation it is completely understandable why someone would have them.

You are not alone in experiencing these feelings, most other people who have a family member with schizophrenia experience them at some time or another. I've got a couple of examples here that may sound familiar.

"Since he's been sick, I've had to do everything. I work, I take care of the kids. It's been so frustrating. The kids don't bring friends home. I think they're embarrassed. One of them isn't doing well in school. We all pay a price.

He's our only son. He won't let anyone help him. Our hearts are breaking. When he suffers, we suffer. We don't go out anymore. We can't enjoy ourselves knowing he's sick." (Anderson et al, p108).

Qn: Does that sound familiar?

Common behavioural reactions

As well as reacting emotionally, you may find yourself behaving in certain ways almost without thinking. Some people find themselves instinctively trying to make the situation as normal as possible. This can happen say, when your family member is experiencing a hallucination. With some people it is not readily apparent that they are having a hallucination, and it may look as though they're just daydreaming, but in their minds they are hearing amazing, strange and often very scary things.

So because sometimes it is difficult to tell, the most common thing to do is to try and coax them out of it or convince them that they are not really seeing or hearing what they are. This does not usually work, and as you probably know it can be very tiring.

One thing that some families have found works for them, is instead of responding to what the person is saying - they try to sense what the person is feeling, such as the anxiety or fear. And then they can say something reassuring like "That doesn't make sense to me, but I can appreciate how upsetting it must be to you if you believe it" (Anderson et al, 1986, p120), or "It sounds as though you feel really alone, that must be tough". That won't stop delusions, but it gives added reassurance to your family member that you are behind them.

Another thing that can be tiring and also very frustrating is trying to make sense out of your family members nonsensical communication. That is, when they say something that does not make sense, looking for the reason behind the words, or a core of reality in their irrational wanderings. Mostly sense can not be made out of such statements, they are merely aimless and very loose associations of words. So trying to understand what they are trying to say to you is perfectly normal, but frustrating and exhausting.

Qn: Have you found this?

There are three further things that almost all family members tend to do: increasing their own responsibilities, limiting their own interests and activities to support their family member, and provide almost constant supervision. Unfortunately, although these things may work temporarily, they can be to the detriment of the whole family, especially you.

Increasing your own responsibilities by taking on some of your family members chores is great for your family member as it helps them to cope better on a daily basis. But there is a limit to how long one person can carry extra burdens without some support. This is especially true when you limit your own activities to try and provide support whenever ____ needs it. It is understandable that when ____ is disturbed you might try to plan your routine around them so that you can provide supervision and support for their benefit, but most families cannot maintain this without sharing the load between them.

The reason I mentioned those responses is because I wanted to illustrate how important it is for you yourselves to have help and support, as if you do not get support not only will you get run-down and exhausted, but you will be less able to continue to help ____ effectively. It is imperative that all family members look after themselves for the benefit of the whole family.

Sharing experiences with others in the same situation is a good way to not only get new ideas about managing schizophrenia, but to provide friendship, discuss problems, let off steam, and lessen the feeling that you are on your own. Many studies have shown that people who have major health problems recover

more rapidly and then stay well longer when they have one or more friends or family members who are around to help them solve problems and deal with the stress in their lives. In other words, if you can find somebody to help you with the everyday hassles as well as the bigger crises in your life, you can double your chances of staying well and enjoy exactly the sort of life that you would like to have. This is one of the most powerful medicines.

If you don't feel comfortable talking to friends and family, the people at the fellowship are always here to talk.

Well, they were just a few examples of things that some families do to try and cope with having a family member diagnosed with mental illness. None of them are wrong, they are all perfectly normal ways of trying to control a difficult situation.

Qn: How have you dealt with it?

WHAT THE FAMILY CAN DO TO HELP

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.

1. Relatives can encourage the person to take the medication that has been prescribed.

Often people feel that they do not need medication, especially if they are feeling well again. But it is important to take the tablets or get the injections as they have been prescribed. You can play an important role here by encouraging their family member to do this. Sometimes, when the person is feeling better, he or she does not need to take further tablets or injections, and this should be discussed with the doctor. Sometimes the medication will produce side effects (as we discussed earlier), these should be discussed with the doctor.

2. The person with schizophrenia can be very sensitive to stress or change, and this is in part what expressed emotion is about - this sensitivity. People diagnosed with schizophrenia, and because of their symptoms, often have a lower stress tolerance, and this includes a lower tolerance for the normal stresses and hassles which crop up in the home. So what may seem normal to you and I - such as asking someone to do the washing, can be misunderstood and seen as a criticism that they haven't done it in the past.

Concern or worry for their well-being is also often misunderstood as are some positive emotions like enthusiasm or encouragement -but only when they are in the extreme. Take the same example as before, where you ask someone to do the washing, well say they do it and you are just so pleased that they listened that you say how happy you are and how wonderful they are for doing it. This can also be misunderstood, but in the same way as before - as a criticism that they haven't done it before. Teenagers are exactly the same, but usually more vocal about it.

Expressed emotion is not the emotion that is let out into your environment, rather it is the quality of one person's relationship with another person, usually in the home. So in the instance where someone has schizophrenia it would be about their vulnerability to stress and how this is influenced (not caused) by the persons in the home. And as it has been mentioned above and earlier, there are about three broad areas that can influence this sensitivity. These are conflict or criticism in the home -and as I mentioned earlier sometimes comments can be misinterpreted to mean criticism when they don't -, any extreme involvement, whether positive or negative, and decreasing your own personal activities, hobbies or support avenues. I cannot stress this enough, families need support too.

There are some small ways in which relatives can help decrease the stress, and also some of the emotions that are natural in the home, around their family member. Some of them are really simple and you probably do some of them already.

Basically, relatives and friends can help by trying to reduce stressful events or by helping the person cope with stress. Expressed emotion can kind of be compared to the music playing in a Doctor's or Dentist's surgery, it's always middle of the range - not too loud or soft, alternative or classical. In fact they often have an easy-listening radio station on. And this is what is sometimes helps lower stress in the home. If you can try to lessen the ups and downs, such as conflicts, extreme concern or enthusiasm it can help.

- (a) the person can be stressed by dramatic changes in routine or lifestyle. Such as moving house or a sibling leaving home. When these things cannot be avoided, try to give the person advanced notice. Explain the situation clearly so that any problems can be solved. If you know some changes are coming, it sometimes helps to make them gradually, so that your family member can become accustomed to them.
 - (b) If the person becomes anxious or worried, even by what seem to be trivial things, encourage them to relax. As difficult as it may seem, be patient with them and try to calm the situation down.
 - (c) Sometimes the person may become depressed and fed up. In some instances this is because they are frustrated with themselves. Many people diagnosed with schizophrenia tend to compare their abilities to what they were before they were ill, or to their peers, and find them lacking. One thing that can help people doing this is to, instead of comparing their current abilities with their previous abilities, comparing their abilities with say 3 months ago. In this way each small positive change may help them to accept themselves and find something good in their behaviours to reward. This can be very hard for them so being sympathetic, encouraging and supportive may help your family member build up their confidence and begin to accept themselves. This can be very tiring so again, having set times to yourself can be beneficial for you.
3. Living with a person with schizophrenia can be very difficult.
- (a) They may behave in a strange way. They may spend all day in bed or take hours to get things done. They may seem not to care about themselves or others. It is easy to get upset at this, and as difficult as it is encouraging gradual change is good - even if its one less smoke a day or one more outing a week it is good. Difficult and slow, but good. It may sound as though on one hand I'm telling you to encourage them & on the other I'm telling you not to. But what I'm trying to say is, by all means encourage, but do it gently.

Qn: Does that make more sense ?

- (b) At times you may feel very worried, or find that you are always wondering what will happen next and how you will cope. It helps to have time out from each other, and hobbies or activities which you can enjoy separately. In this way the person is encouraged to lead an independent life and gain confidence in themselves.
- (c) You may find that you become anxious or depressed yourself. It is often helpful to talk over your feelings with someone else. Try to keep your own interest and hobbies going. You need time for yourself and this will take your mind off things. Getting very worried and overconcerned can make things harder for you.

If a crisis occurs, do not feel guilty or blame yourself. You cannot anticipate everything. Try to cope with situations as calmly as possible as they arise, it is difficult, but try to stay relaxed. Sometimes there are no right answers, but learning comes from experience.

4. Family Problem Solving

Living with someone who suffers from schizophrenia can cause tensions at home, and can increase the impact of other problems. Sometimes it can be useful to get the family together to talk things out, as in this way the problems are shared amongst the family and not carried by one person alone - as can sometimes happen. Allowing everyone to express their views and feelings also clears the air, and it can sometimes lead to finding different ways of dealing with the problem. This is a positive approach to solving problems, and often helps avoid arguments and further stress.

So in summary: Relatives can help by

- encouraging the person to take their medication
- staying calm and relaxed themselves
- being gently encouraging and positive
- solving family problems in a calm way

I want to emphasize two further things

- families do not cause schizophrenia, but they can significantly help people once they have it.
- research supports the concept of talking with others and sharing your problems, as this can take some of the stress off you.

This is the first lecture that will be given to the relatives. Allowing time for questions and discussions, it will take approximately 45-50 minutes. This is followed by a 10 minute coffee break.

Information About Schizophrenia for Consumers

Well I thought to start with I could give you an idea of what is going to happen, so this is the outline:

- we'll discuss what schizophrenia is and the different symptoms that are involved with it, 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 I figure after that we might want a break, so if you feel like it we can take a short break for a drink or something.

The second part of this session will provide some coping skills that research has shown can sometimes help, including relaxation. It may sound corny but it truly helps! And that will take about one hour.

Finally, you'll make an appointment to come back in about 5 days to discuss with your family member and myself the main points of this session, and any further questions or concerns either of you have. This isn't a test, it's just an opportunity to come together and work out queries and concerns. And that's it for this session.

Please, ask questions whenever you want or jump-in at any time.

* * * * *

I'm going to give you a hand-out, it's written by two (very experienced) people in England in association with the British schizophrenia fellowship. It's basically information for those suffering from schizophrenia and their families. This session will be loosely based on it, so if you wish you can follow it or refer to it as we go, but basically its for you to take home and refer to if you want to check something or have a question before our next meeting.

What I am going to talk about is based as close as possible on the average situation, and as you know every situation is different and you know better than I do about your situation. So if you do have anything you want to say just jump-in with it.

WHAT IS SCHIZOPHRNIA?

So, schizophrenia is a word just about everyone has heard. Most people are not sure what schizophrenia really is, what causes it, and what can be done for it.

There are a few things that are definitely not schizophrenia which need to be cleared up. I am sure you will have heard people say that schizophrenia is having more than one personality. There is actually a rare disorder where people seem to have many different personalities at different times, a bit like an actor playing different parts in different films. This is not schizophrenia.

Schizophrenia basically means that a person finds it difficult to decide what is real and what is not real. This inability to tell real from not real is sometimes called psychosis. It is a bit like having dreams when you are wide awake. Everything that is going on seems quite real at the time, often a little strange and frightening, but quite real. It is usually only when that episode of schizophrenia is over, that the individual may realise that many of the things that they thought were happening were probably not -- in the same way we realise that our dreams were not real after we have woken up. But like everything, there are exceptions and there are some people who are aware that this is happening, and some who don't.

WHAT, THEN, IS SCHIZOPHRENIA?

Schizophrenia is a mental illness. It affects about one person in every hundred in all countries throughout the world. More hospital beds are filled by people suffering from schizophrenia than from any other single illness. It is described as a major disorder because it has a great effect on nearly every aspect of a person's life. Everything that is important in our lives may be affected by schizophrenia.

There are many problems which are commonly found in schizophrenia, yet those suffering from schizophrenia can differ widely in the symptoms which they exhibit. The range of potential problems (like any illness) is extensive and it is extremely unlikely that an individual will exhibit all of the symptoms of schizophrenia at one time. It is more likely that each individual will exhibit a cluster of possible symptoms varying in number and severity.

The person's thinking at times may be muddled and confused. He or she may not be able to work as well as before; it may be hard to concentrate and to think quickly and clearly. He or she may have similar problems with other activities. The person may find it difficult to make conversation or show feelings, and this can make it hard for them to communicate with others.

Qn: Have you ever experienced any of these symptoms?

HOW DO WE KNOW WHEN A PERSON HAS SCHIZOPHRENIA?

We know a person has schizophrenia when key symptoms (like hallucinations or delusions) are present. These feature changes in a person's thoughts and feelings, and to a lesser extent, in their behaviour. Doctors find out that the person has these symptoms mainly from what the client tells or shows them. At the present time there are no special blood tests or X-rays to help the doctors, they will depend almost entirely on what they have been told or have seen. Contrary to popular belief, psychiatrists and psychologists cannot read people's minds, they can only make a diagnosis from what they have been told and with consultation with a diagnostic manual used worldwide. The characteristic symptoms they use to decide whether an individual suffers from schizophrenia include what are known as positive and negative symptoms.

Positive Symptoms

Positive symptoms are the type of symptoms that the person may experience. It doesn't mean that they are good, what positive means is that there is an excess of things, like changes and distortions in perceptions and thought processes. These include disturbances of thinking, delusions, and hallucinations.

Disturbances of thinking may involve thoughts being put into your head which are not your own thoughts. They may seem to come from other people by telepathy or radio-waves, laser beams, or any number of things. Thoughts disappearing from your head, as if they are being taken out, or stolen by someone. Your mind may be blank and you may be unable to think about anything. This is not the same as when you forget a thought, or when you are nervous and seem to lose track of your thoughts. Thoughts seeming to be spoken out loud as if somebody close by could hear them. Sometimes feeling that the thoughts are being broadcast from your head. In this way everybody knows what you are thinking and none of your thoughts are private.

Another disturbance in thinking may occur with thought processes, which become jumbled and the person may find it difficult to think in a coherent manner. This may be reflected in the person's speech in which the grammar may become distorted, or there may be changes from topic to topic or a lack of logical connection between one part of a sentence or another. Sometimes the person's speech may include words or expressions, which can make it difficult to communicate with others.

This kind of thinking can make some people really anxious and tired. Trying to keep up with your own thoughts and trying to make sense out of them can wear some people down.

Qn: Have you ever noticed anything like this?

The second major positive symptoms are **Delusions**. These are false beliefs that seem quite real to people having them, but not to others. Some examples of these delusions common in schizophrenia are:

- ✱ a belief that some other person or force has control of your thoughts or actions. That you have no free will and another person has taken over your brain or body.
- ✱ a belief that somebody is trying to harm you, for no good reason. You are being unjustly persecuted.
- ✱ a belief that what you see or read about have a special message for you. E.g., seeing a red car may mean that the world is about to end.
- ✱ a belief that you are a particular person (such as the Queen or Jesus) with magical powers or abilities (such as controlling the weather).
- ✱ Those delusions might not be so frequent, but often there are small ones that some individuals have to cope with on a daily basis and this can be tiring also.

Qn: Have you ever experienced any of these difficulties, or unusual ideas?
What did you think was going on?

The third major positive symptoms are **Hallucinations**, which are false sensations. This means that the person hears, sees or smells things that are not heard, seen or smelt by others. Hearing voices when nobody is in the room is a very common symptom of schizophrenia. The voices seem real and may appear to come from the next room or outside. Sometimes they may seem to come from inside a person's head or, less often, from a part of their body. Sometimes the person may believe that someone or something is touching them when there is no-one there and nothing to explain this.

A diagnosis of schizophrenia is usually made because certain key positive symptoms (like the hallucinations or delusions) appear to be present. However, other symptoms which are termed negative symptoms are often present at sometime during the illness.

Negative symptoms

Unlike positive symptoms, which are dramatic changes in the person's experience, the negative symptoms are usually shown as changes in the person's behaviour. They are called negative because they indicate decreases or absences of behaviour. These type of symptoms may include:

- ✱ an absence of motivation or enthusiasm.
- ✱ a general inactivity and a decrease in all activity levels. Some people find they don't enjoy doing the same things that they used to.
- ✱ an inability to show emotion, the person may appear flat or disinterested.
- ✱ an apparent disinterest in conversation and talking.
- ✱ and sometimes an apparent difficulty in getting on with people even close relatives, so that contact with others is often be avoided.

These negative symptoms can be very distressing, even more so than the positive symptoms. It is important to remember that individuals will not suffer from all of these things at one time, and even the things that they do suffer from are episodic. That is they are not there forever, they will wax and wane over time, and gradually improve with support, patience and encouragement. It is also important to remember that these symptoms are part of the illness, they are not done on purpose.

Another symptom of schizophrenia is changed feelings and emotions, which is the experience that your feelings have disappeared or are much less intense. Both happy feelings and sad feelings may be affected.

At other times a person with schizophrenia may find their feelings become uncontrollable so that they may laugh or cry when they are not feeling happy or sad, or look flat when they are feeling happy or sad.

WHAT USUALLY HAPPENS TO PEOPLE WITH SCHIZOPHRENIA?

Schizophrenia is an illness that usually begins when a person is in their early 20s, but it may occur at any time in a person's life. A number of people suffer from only one episode of the illness and never have a further attack. But many sufferers will have periods when the major symptoms return. These periods are called relapses. For many schizophrenia is a life long concern. However, with improved medical treatment and newer anti-psychotics the outlook for schizophrenia is better than it has been in past years, & even the most severe cases of schizophrenia gradually get better over time.

Schizophrenia affects many young people in the prime of their lives. It may be a major setback in their plans and hopes for the future. As a result, it is not uncommon for a person to become unhappy, feel overwhelmed and despairing. Such depression sometimes resembles that of a depressive disorder, so it is important that this problem is recognised and treated effectively. Talk to someone if you are feeling down.

WHAT CAUSES SCHIZOPHRENIA?

Schizophrenia is thought to result from a combination of causes including bio-chemicals, genetics and stress. That is to say, it is probably caused by a disturbance in the working of the brain & life stress. Since the illness often occurs when the person is under stress, it is thought that stress may act as a trigger to bring on the illness.

The brain works through exchanges of special chemicals called neurotransmitters. Although it is not exactly clear what goes wrong when a person develops schizophrenia, it seems that these chemicals in the brain are affected. A chemical imbalance results and produces the symptoms of hallucinations, delusions and thinking difficulties. It is also noted that taking certain types of medication, which are of course forms of chemicals, appears to correct the chemical imbalance and improve the symptoms of schizophrenia.

Many scientists have worked on the problem of finding the exact nature and cause of the brain chemistry without reaching any general agreement. New theories appear every few months, and it is easy to become confused. Some theories you may have heard about have not yet being substantiated. E.g., there is no scientific proof that vitamin deficiency causes schizophrenia, or that vitamin therapy helps schizophrenia, except of course where a person has a vitamin deficiency as a result of poor nutrition, but that is not linked with schizophrenia.

At the present we still do not know the exact cause of schizophrenia, nor do we have a complete cure. We do, however, have treatment that can minimize the impact of the disorder on your lives.

Qn: I'll explain it a bit more.

Schizophrenia is an illness that can be inherited. That does not mean that if someone in your family has the illness everybody else will get it. Nor does it mean that a person with schizophrenia should not marry and have children. It was mentioned before that people in general have about a 1 in 100 chance of getting the illness, but if a close relative like a parent or brother suffers from schizophrenia then your chances are about 1 in 10 that you may be at risk to get the disorder.

People who are at risk of getting schizophrenia possibly lack some chemical or enzyme in the brain that may be responsible for the development of the chemical imbalance associated with schizophrenia. This imbalance probably only develops into schizophrenia when the person who has this vulnerability experiences certain stressful situations.

Stress and schizophrenia

One of the greatest periods of stress, especially for young men, is in early adult life (early to mid 20s). At this time they are striving to get a good job, make friends and become independent. This is the most common time for schizophrenia to begin in men. In women, major life stress often starts later, when they have children (late 20s).

Several studies show that major stressful events such as a death in the family, loss of a job or breakup of a relationship can make schizophrenia worse or trigger off a relapse of symptoms.

Other studies show that once a person has schizophrenia the personal environment in which he or she lives can help considerably if those people in daily contact can provide support by encouraging gradual regaining of former skills and interests. It is impossible to totally avoid stress, but friends and family are most helpful when they help one another to cope with difficulties in their lives.

There is no evidence that families cause schizophrenia.

A few years ago, many psychiatrists believed that schizophrenia was entirely caused by the way the parents brought up their children. While we know how important this is, **there is no scientific evidence that poor child care or an unhappy childhood causes schizophrenia**, and I want to repeat that, families do not cause schizophrenia.

Qn: does that make more sense now? (*If looking puzzled*)

MEDICATION

I realise that you probably know lots about the medication and probably more than me, but I thought that I could just share some of the research with you as you may find it helpful.

Medication was introduced for the treatment of schizophrenia about 40 years ago. It is the main form of treatment. There are several different types of drugs used in the treatment of schizophrenia, with different brand names. The ones for schizophrenia are called neuroleptics or major tranquillisers. Medication may be given in the form of tablets or injections. Injections are often helpful as they are less likely to be forgotten and smaller amounts are used. All of the different types of medication have similar helpful effects, but different side-effects.

The strengths of the medications differ considerably. E.g., 100mg of chlorpromazine is about the same strength as 2mg of fluphenazine. You will notice that the same medicine often has more than one name e.g., chlorpromazine = Largactil or Thorazine. The longer usually more complicated name is the chemical name while the shorter name is the brand name.

There are two ways in which medication is used in the treatment of schizophrenia.

1. to reduce the symptoms of an acute attack of the illness
2. once the symptoms of delusions, hallucinations and thinking difficulties have been relieved the same medication is used to prevent further recurrences of the illness. Although this dosage is usually lower.

If the person with schizophrenia stops taking the medication against the doctor's advice the chances of them having a further attack of schizophrenia are more than doubled, furthermore, the symptoms are likely to be more severe. This is why it is important to take the medication that the doctor prescribes even when the person feels completely well.

Unfortunately the medication used for the treatment of schizophrenia can sometimes produce unwanted side-effects. These are not usually serious and should be discussed with the doctor. Some of these side-

effects include drowsiness, shakiness, restlessness, and muscle stiffness. Others are sensitivity to sunburn, increased appetite, dry mouth and dizziness especially when standing up suddenly.

Some of these effects the person can avoid themselves, but if your relative is worried about anything to do with the medication, go & see your doctor.

SOME REMEDIES FOR SIDE-EFFECTS

Maybe you've noticed some of these side-effects and may have wondered what was happening and how to cope with them, so it might be helpful if I went through some of the side-effects and explained them.

Of the side-effects, drowsiness tends to be the biggest problem. It can be overcome by taking the main dose of medication before they go to bed. The drowsiness will be helpful in getting a good night's sleep and may have worn off by morning. Structured activities, with variety and interest can decrease drowsiness.

Dizziness is usually a result of blood pressure falling when a person gets up too quickly. This can be a result of the drugs, but usually goes away once the person becomes used to the drugs. It can be avoided if the individual rises more slowly.

Perhaps the most distressing side-effect is the look that those on antipsychotic drugs sometimes develop. It is a combination of slow movements, expressionless face, and stiff arms and legs. It goes away when the dose of antipsychotic drugs is lowered or when other drugs are added. Although the stiffness temporarily looks strange to others, it is generally not uncomfortable for individuals. What is uncomfortable are the feelings of restlessness, not being able to sit still. Walking around is easier than sitting still which is why your relative may have the tendency to pace or wiggle their legs. This can be annoying, but it is a side-effect of medication, not something that is altogether controllable.

Muscle spasms can be a reaction to drugs but these are usually early side-effects which cease once the drug doses are properly adjusted. Although the tremor may remain. Tremor of the fingers and sometimes the tongue, hands and feet can be quite noticeable, and can be mistaken for nerves. It tends to get better when the individual is calm, but basically it is a side-effect.

The most worried about side-effects for some are the loss of spontaneity and creativity. These may be more side-effects of the illness than of drugs. Nevertheless, people often feel that these empty feelings are due to the drugs they are taking. It is important to realise that these feelings, temporarily, may be a necessary price for staying free of the fear of psychosis. It is important to keep on with the drugs at this stage - to correct the side-effects which are controllable and to try and endure those which are not.

While medication helps most people with schizophrenia by reducing symptoms it does not change a person's entire personality, help a person learn new skills, get a job or make new friends. Other forms of rehabilitation are necessary in combination with the medication for the best results (this will be discussed further on).

Well that's it, is there anything you want to clarify. Do you want a little coffee break? = 10 mins

This is the second lecture that will be given to the relatives. Allowing time for questions and discussions, it will take approximately 30-40 minutes. This will be followed by some practical relaxation techniques (20 minutes). That ends session two.

Information about Schizophrenia for Consumers II

O.K, like earlier, I want to give you an idea of what is going to happen in the next hour. So this is how it should flow:

- we'll talk about how you cope or deal with your relative's illness - And I will talk about some things that research has shown can sometimes help people to deal with the illness.
- and lastly we'll actually do some relaxation, this has been proven to be successful when you are at the end of your tether!, or for getting to sleep at night after a hard day.

In an era of community care, an increasing number of people are staying home with their families after being diagnosed. Research has shown that between 46% and 65% of those hospitalized with schizophrenia return on discharge to live with their families.

The return of a family member can be stressful for everyone. You may feel anxious because you don't know what to expect, helpless and depressed because you can't change the illness or make it go away.. Feeling anxious or fearful about the reason for unusual behaviours, or how long they will last is perfectly normal. "When something goes wrong, most people look to themselves to see what they could have done differently, and most people find something that they can worry about. These concerns tend to be reinforced by the messages of the popular media (like on T.V and in magazines)" (Anderson, Reiss & Hogarty, 1987, p 109).

These are all perfectly normal and appropriate emotions and in such a difficult and confusing situation it is completely understandable why someone would have them.

Common behavioural reactions

As well as reacting emotionally, you may find yourself behaving in certain ways almost without thinking. Some people find themselves instinctively trying to make the situation as normal as possible. This can happen say, when someone is experiencing a hallucination. With some people it is not readily apparent that they are having a hallucination, and it may look as though they're just daydreaming, but in their minds they are hearing amazing, strange and possibly scary things.

So because sometimes it is difficult to tell, the most common thing to do is to try and coax them out of it or convince them that they are not really seeing or hearing what they are. This does not usually work, and can be very tiring.

One thing that some families have found works for them, is instead of responding to what the person is saying - they try to sense what the person is feeling, such as the anxiety or fear. And then they can say something reassuring like "That doesn't make sense to me, but I can appreciate how upsetting it must be to you if you believe it" (Anderson et al, 1986, p120), or "It sounds as though you feel really alone, that must be tough". That won't stop delusions, but it gives added reassurance to your family member that you are behind them.

Another thing that can be tiring and possibly frustrating is trying to make sense out of communication that doesn't make sense to other people. That is, when something is said or thought that does not make sense, looking for the reason behind the words. So trying to understand them is perfectly normal, but can be frustrating and exhausting.

Qn: Have you found this?

There are three further things that almost all family members tend to do: increasing their own responsibilities, limiting their own interests and activities to support their family member, and provide supervision. Unfortunately, although these things may work temporarily, they can be to the detriment of the whole family.

I want to say how important it is for you to have help and support, as if you do not get support you may get run-down and exhausted. It is also important that your family members look after themselves for the benefit of the whole family.

Sharing experiences with others in the same situation is a good way to not only get new ideas about managing schizophrenia, but to provide friendship, discuss problems, let off steam, and lessen the feeling that you are on your own. Many studies have shown that people who have major health problems recover more rapidly and then stay well longer when they have one or more friends or family members who are around to help them solve problems and deal with the stress in their lives. In other words, if you can find somebody to help you with the everyday hassles as well as the bigger crises in your life, you can double your chances of staying well and enjoy exactly the sort of life that you would like to have. This is one of the most powerful medicines.

If you don't feel comfortable talking to friends and family, the people at the fellowship are always here to talk.

Well, they were just a few examples of things that some families do to try and cope with having a family member diagnosed with mental illness. None of them are wrong, they are all perfectly normal ways of trying to control a difficult situation.

Qn: How have you dealt with it?

WHAT THE FAMILY CAN DO TO HELP

We believe that there are some specific things that research supports which families can do to make things easier. 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.

1. We encourage you to take the medication that has been prescribed.

Often people feel that they do not need medication, especially if they are feeling well again. But it is important to take the tablets or get the injections as they have been prescribed. Sometimes, when the person is feeling better, they do not need to take further tablets or injections, and this can be discussed with your doctor. Sometimes the medication will produce side effects (as we discussed earlier), these should be discussed with the doctor.

2. You might be sensitive to stress or change, and this is in part what expressed emotion is about - this sensitivity. People diagnosed with schizophrenia, and because of their symptoms, may have a lower stress tolerance, and this includes a lower tolerance for the normal stresses and hassles which crop up in the home.

Expressed emotion is not the emotion that is let out into your environment, rather it is the quality of one person's relationship with another person, usually in the home. So in the instance where someone has schizophrenia it would be about their vulnerability to stress and how this is influenced by the persons in the home. And as it has been mentioned above and earlier, there are about three broad areas that can influence this sensitivity. These are conflict or criticism in the home, any extreme involvement, whether

positive or negative, and decreasing your own personal activities, hobbies or support avenues. I cannot stress this enough, the whole family needs support, and interests and hobbies which they can do separately.

There are some small ways in which you and your relatives can help decrease the stress, and also some of the emotions that are natural in the home, around each other. Basically, relatives and friends can help by trying to reduce stressful events or by helping each other with stress. Expressed emotion can kind of be compared to the music playing in a Doctor's or Dentist's surgery, it's always middle of the range - not too loud or soft, alternative or classical. In fact they often have an easy-listening radio station on. And this is what is sometimes helps lower stress in the home. If the ups and downs, such as conflicts, extreme concern or enthusiasm can be lessened, it can help.

- (a) people can get stressed by dramatic changes in routine or lifestyle. Such as moving house or a sibling leaving home. When these things cannot be avoided, try to talk about these things with your family. Problems can be solved.
- (b) If you becomes anxious or worried, even by what seem to be trivial things, we encourage you to relax. As difficult as it may seem, you can calm yourself down.
- (c) Gradual change is good, even if its one less smoke a day or one more outing a week it is good. Difficult and slow, but good. This is true for all people.

Qn: Does that make more sense ?

- (b) At times you may feel worried, or find that you are wondering what will happen next and how you will cope. It helps to have time out from your family, and hobbies or activities which you can enjoy separately.
- (c) You may find that you become anxious or depressed yourself. It is often helpful to talk over your feelings with someone else. Try to keep your own interest and hobbies going. You need time for yourself and this will take your mind off things. Getting very worried and overconcerned can make things harder for you.

If a crisis occurs, do not feel guilty or blame yourself. You cannot anticipate everything. Try to cope with situations as calmly as possible as they arise, it is difficult, but try to stay relaxed. Sometimes there are no right answers, but learning comes from experience.

4. Family Problem Solving

Living with your family at times may be difficult. Sometimes it can be useful to get the family together to talk things out, as in this way the problems are shared amongst the family and not carried by one person alone - as can sometimes happen. Allowing everyone to express their views and feelings also clears the air, and it can sometimes lead to finding different ways of dealing with the problem. This is a positive approach to solving problems, and often helps avoid arguments and further stress.

So in summary: You can help yourself by

- encouraging yourself to take your medication
- staying calm and relaxed
- being positive
- solving family problems with your family

I want to emphasize one further thing

- research supports the concept of talking with others and sharing your problems, as this can take some of the stress off you.

It would be maximally effective if a friend with a low, even, soothing voice could record these relaxation instructions on tape. That way, you can listen to them rather than having to read them.⁵ While your friend is reading the instructions, he or she should pause five seconds for each "(p)" that appears in them.

Let us assume that the instructions have been recorded on tape. You should now find a quiet, dimly lit, private setting with as few distracting stimuli as possible; a comfortable couch, bed, or reclining chair; and a time when you will not be interrupted for twenty to thirty minutes. Lie or sit on the couch, bed, or chair, which should support you with minimal use of your own muscles. Now turn on the tape recorder and follow the instructions.

After you have practiced the relaxation method on several different occasions, you will find that you are able to skip some of the steps and achieve the same deeply relaxed state in a shorter period of time. Eventually, you should be able to go directly to step 20 and achieve a completely relaxed state within a matter of minutes. We recommend that you gradually eliminate steps according to the following pattern:

1. Practice the entire 20 steps in Table 24-2 on at least three occasions spread over a minimum of two days.
2. Make a new tape recording consisting of steps 1, 8, 15, and 20. Use this new tape on at least three occasions spread over a minimum of two days.
3. Make a new tape consisting of steps 1 and 20. Use this new tape on at least two occasions spread over a minimum of one day.

After completing this program, which takes approximately one week, you should be able to relax totally in a matter of minutes.

Table Instructions to Be Recorded on Tape and Played to Achieve Deep Muscle Relaxation*

- 1 Listen closely to these instructions. They will help you to increase your ability to relax. Each time I pause, continue doing what you were doing before the pause. Now, close your eyes and take three deep breaths. (p) (p)
- 2 Make a tight fist with your left hand. Squeeze it tightly. Note how it feels. (p) Now relax. (p)
- 3 Once again, squeeze your left hand tightly and study the tension that you feel. (p) And once again, just relax and think of the tension disappearing from your fingers. (p) (p)
- 4 Make a tight fist with your right hand. Squeeze it as tightly as you can and note the tension in your fingers and your hand, and your forearm. (p) Now relax. (p)
- 5 Once again, squeeze your right fist tightly. (p) And again, just relax. (p) (p)
- 6 Make a tight fist with your left hand and bend your arm to make your left biceps hard. Hold it tense. (p) Now relax totally. Feel the warmth escape down your biceps, through your forearm, and out of your fingers. (p) (p)
- 7 Now make a tight fist with the other hand and raise your hand to make your right biceps hard. Hold it tightly, and feel the tension. (p) Now relax. Concentrate on the feelings flowing through your arm. (p) (p)
- 8 Now, squeeze both fists at once and bend both arms to make them totally tense throughout. Hold it, and think about the tension you feel. (p) Now relax, and feel the total warmth and relaxation flowing through your muscles. All the tension is flowing out of your fingertips. (p) (p)
- 9 Now, wrinkle your forehead and squint your eyes very tight and hard.** Squeeze them tight and hard. Feel the tension across your forehead and through your eyes. Now relax. Note the sensations running through your eyes. Just relax. (p) (p)
- 10 Okay, squeeze your jaws tight together and raise your chin to make your neck muscles hard. Hold it, bite down hard, tense your neck, and squeeze your lips really tight. (p) Now relax. (p) (p)
- 11 Now, all together, wrinkle up your forehead and squeeze your eyes tight, bite down hard with your jaws, raise your chin and tighten up your neck, and make your lips tight. Hold them all and feel the tension throughout your forehead, and eyes, and jaw, and neck, and lips. Hold it. Now relax. Just totally relax and enjoy the tingling sensations. (p) (p) (p)
- 12 Now, squeeze both your shoulders forward as hard as you can until you feel your muscles pulling tightly right across your back, especially in the area between your shoulder blades. Squeeze them. Hold them tight. Now relax. (p) (p)
- 13 Now squeeze your shoulders forward again and, at the same time, suck your stomach in as far as you can and tense your stomach muscles. Feel the tension throughout your stomach. Hold it. (p) Now relax. (p) (p)
- 14 Once more, squeeze your shoulder blades forward again, suck in your stomach as far as you can, tense your stomach muscles, and feel the tension throughout your upper body. Now relax. (p) (p)
- 15 Now, we are going to review all of the muscle systems that we have covered so far. First, take three deep breaths. (p) (p) Ready? Tighten up both fists and bend both of your arms to squeeze your biceps tight. Wrinkle your forehead and squeeze your eyes tight. Bite down hard with your jaws, raise your chin, and hold your lips tight. Squeeze your shoulders forward and suck in your stomach and push your stomach muscles against it. Hold them all. Feel the tremendous tension throughout. Now relax. Take a deep breath. Just feel the tension disappearing. Think about the total relaxation throughout all of your muscles—in your arms, in your head, in your shoulders, in your stomach. Just relax. (p) (p)
- 16 Now, let's go to your legs. Bring your left heel in tight toward your chair, push it down hard, and raise your toes so that your calf and your thigh are extremely tense. Squeeze your toes up and push your heel down hard. (p) Now relax. (p) (p)
- 17 One more time, bring your left heel in tight toward your chair, push it down hard, and raise

- your toes so that your calf and your thigh are extremely tense. Push down on the heel and raise your toes. Now relax. (p) (p)
- 18 Now, bring your right heel in tight toward your chair and push it down and raise your toes so that your calf and your thigh are extremely tense. Push your heel down, squeeze your toes up, and squeeze your leg in tight. (p) Now relax. (p) (p)
- 19 Now, let's do both legs together. Squeeze your heels in tight toward your chair, push down on your heels, and raise your toes as high and as tight as you can. Hold it. (p) Now relax. (p) (p)
- 20 Now, take three deep breaths. (p) Now, tense all the muscles as they are named, exactly as you have practiced: left fist and biceps, right fist and biceps, forehead, eyes, jaw, neck, lips, shoulders, stomach, left leg, right leg. Hold it. (p) Now relax. (p) (p) Breathe in deeply three times and then repeat the total tensing and then the total relaxing, and while you are breathing in deeply and then tensing and then relaxing, notice how relaxed all of your muscles feel. Now tense (p) and relax (p). Now, breathe normally and enjoy the completely tension-free state of your body and muscles. (p) (p) (p) (p) (p) (p) Now turn the tape off.

*Each "(p)" represents a pause of five seconds. (The numerals should not be read out loud.)

**Individuals who wear contact lenses might want to remove them before doing this exercise.

Information About Schizophrenia for Friends and Relatives

WHAT IS SCHIZOPHRENIA?

Schizophrenia is a word just about everyone has heard. Most people are not sure what schizophrenia really is, what causes it, and what can be done for it.

WHAT DO YOU UNDERSTAND BY THE TERM SCHIZOPHRENIA?

There are a few things that are definitely not schizophrenia which need to be cleared up. First, there is the common idea that schizophrenia means having more than one personality or a split personality. This is not schizophrenia. Schizophrenia means that a person finds it difficult to decide what is real and what is not real. It is a bit like having dreams when you are wide awake.

Schizophrenia is like dreaming when you are wide awake.

At times a person who has schizophrenia may act in a strange or odd manner. At other times he or she will behave in quite a reasonable way. It is often thought that people with mental illness are violent and dangerous. Usually this is not true. People suffering from schizophrenia rarely have violent outbursts, but more often they are quiet, shy and fearful.

WHAT, THEN, IS SCHIZOPHRENIA?

Schizophrenia is a major illness. It affects about one person in every hundred in all countries throughout the world. More hospital beds are filled by people suffering from schizophrenia than from any other single illness.

Thought processes which become so jumbled that the person does not think in a coherent manner. This is reflected in the person's speech in which the grammar may become grossly distorted, or there are dramatic and unexpected changes from topic to topic or there is a lack of logical connection between one part of a sentence or another. Sometimes the person's speech may include made up words.

Delusions

Another disturbance of thinking is called a 'delusion'. This is a false belief that seems quite real to the person with schizophrenia. Other people do not share this belief or idea. Some examples of these delusions common in schizophrenia are:

- A belief that some other person or force has control of your thoughts or actions. That you are a zombie with no free will and another person has taken over your brain or body.
- A belief that somebody is trying to harm you, perhaps trying to kill you for no good reason. You are being unjustly persecuted.
- A belief that things that you see or read about have a special message for you. For example, seeing a red car may mean that the world is about to end.
- A belief that you are a special person or have abilities or magical powers. For example, that you are a king or a queen, or that you can cause earthquakes, floods or other natural disasters.

A delusion is a totally false belief others do not share.

These ideas often come on quite suddenly. They are unusual so that friends and family realise that they are unlikely to be really true. When the person has recovered he may be surprised what he believed when ill. It is a little like waking up from a dream.

Hallucinations

Some people have a symptom called an 'hallucination'. An hallucination is a false perception. This means that the person hears things, see things or smells things that are not heard, seen or smelt by other people. It is a little like having a dream when you are wide awake. Hearing voices when nobody is in the room is a very common symptom of schizophrenia. The voices seem real and may appear to come from the next room or outside. Sometimes they may seem to come from inside a person's head or, less often, from a part of his body. Sometimes the person believes that someone or something is touching them when there is no-one there and nothing to explain this.

One in every hundred people develops schizophrenia.

It can affect a person's everyday life in many ways, although the symptoms of schizophrenia are not the same for every person. The person's thinking may be muddled and confused. This means that they may have trouble handling everyday problems.

Schizophrenia can affect all aspects of a person's life.

He or she may not be able to work as well as before; it may be hard to concentrate and to think quickly and clearly. He or she may have similar problems with other activities. The person may find it difficult to make conversation or to show feeling, and this can make it hard to get on with people. At times the person may be so taken up with his thoughts and feelings that he or she fails to take care of even his most basic needs like sleep, food and cleanliness.

HOW DO WE KNOW WHEN A PERSON HAS SCHIZOPHRENIA?

Doctors diagnose schizophrenia when a person has certain key symptoms. They find out that the person has these symptoms mainly from what the patient tells them. Psychiatrists cannot read people's minds. There are no special blood tests or x-rays to help either. They can only make a diagnosis from what they are told. These symptoms include what are termed the Positive and Negative symptoms of schizophrenia.

Positive Symptoms

Positive symptoms are the type of symptoms that the person experiences, these are changes and distortions in their perceptions and thought processes. These type of symptoms include:

Disturbances of thinking

Thoughts being put into your head which are not your own thoughts. They may seem to come from other people by telepathy or radio waves, laser beams and so on.

Thoughts leaving your head, as if they are being taken out by somebody. Your mind is quite blank and you are unable to think about anything. This is not the same as when you forget a thought, or when you are nervous and seem to lose track of your thoughts.

Thoughts seeming to be spoken out loud as if somebody close by could hear them. Sometimes feeling that the thoughts are being broadcast from your head. In this way everybody knows what you are thinking and none of your thoughts are private.

An hallucination is hearing, seeing, smelling something that others do not hear, see or smell.

A diagnosis of schizophrenia is usually made because certain key positive symptoms appear to be present. However, other symptoms which are termed negative symptoms are often present at sometime during the illness.

Negative Symptoms

Unlike positive symptoms, which are dramatic changes in the person's experience, the negative symptoms are usually apparent as changes in the person's behaviour. They are termed negative because they indicate decreases or absences of behaviour. These type of symptoms include:

- An absence of motivation or enthusiasm to do anything.
- A general inactivity and a decrease in all activity levels. This may range from hobbies and leisure pursuits to simple and basic self-care activities such as washing and grooming.
- An inability to show any emotion, the person can appear flat or disinterested.
- An inability to enjoy activities that used to give pleasure.
- An apparent disinterest in conversation and talking. The person will not start conversations and frequently answer in single words if at all.
- An apparent difficulty in getting on with people even close relatives, so that contact with others will be avoided.

These negative symptoms can be very distressing for relatives, even more so than the positive symptoms. This is because all life can appear to go out of the person so that nothing interests them and they become cold and withdrawn. Many relatives also feel the person is being lazy or hurtful.

It is important to remember that these negative symptoms are part of the illness and not the person being lazy or hurtful.

Other symptoms of schizophrenia

Language difficulties

At times people suffering from schizophrenia will talk in a way that is hard to follow. Occasionally people will make up words or use odd expressions. Sometimes they may speak very little and be almost impossible to talk to.

Odd habits

These may include standing or sitting in unusual ways, peculiar mannerisms or habits.

Changed feelings and emotions

Sometimes people suffering from schizophrenia seem to show little or no feelings. At other times they may laugh or cry when they are not feeling happy or sad. Or, a person may not show normal affection for their family and friends.

Unusual Behaviour in Schizophrenia

Problems in speaking

Odd habits

Changed feelings

WHAT USUALLY HAPPENS TO PEOPLE WITH SCHIZOPHRENIA?

Schizophrenia is an illness that usually begins when a person is in their early twenties, but, it may occur at any time in a person's life. A number of people suffer only one episode of the illness and never have a further attack. But many sufferers will have periods when the symptoms return. These periods are called relapses. A few sufferers will have some symptoms all the time. For many schizophrenia is a life long concern. However, with improved medical treatment the outlook for schizophrenia is better than it has been in past years.

Schizophrenia is often a recurring illness.

Schizophrenia affects many young people in the prime of their lives. It is a major setback in their plans and hopes for the future. As a result, it is not uncommon for a person to become depressed.

WHAT CAUSES SCHIZOPHRENIA?

Schizophrenia is probably caused by a disturbance in the working of the brain. Since the illness often occurs when the person is under stress, it is thought that stress may act as a trigger to bring on the illness.

It is not exactly clear what goes wrong when a person develops schizophrenia, but it seems that chemicals in the brain are affected. This produces the symptoms of hallucinations, delusions and thinking difficulties.

We also know that taking certain types of medication improves the symptoms of schizophrenia. The medication is of course made up of

chemicals. It is thought that these help to balance the chemicals in the brain.

Schizophrenia is a disorder of the brain that may be brought on by stress.

But, many scientists have studied the problem and they have not found the exact cause. At present, we still do not know what exactly causes schizophrenia. Nor do we have a total cure. We do, however, have treatment that can help people to get better.

What exactly goes wrong with the chemicals in the brain is not clear.

Is Schizophrenia a Family Illness?

Schizophrenia is an illness, that can be inherited. That does not mean that if somebody in your family has the illness everybody else will get it. Nor does it mean that a person with schizophrenia should not marry and have children. We said before that people in general have about a 1 in 100 chance of getting the illness, but, if a close relative like a parent or brother or sister suffers from schizophrenia then your chances of getting the illness are higher.

It is not the illness itself that is inherited but the tendency to get it. This tendency may only develop into schizophrenia when the person is under stress. But the amount of stress it takes to bring on the illness seems to vary.

The risk of developing schizophrenia is greater if you have a parent or a brother or sister who has had the illness.

Stress and Schizophrenia

One of the greatest periods of stress, especially for young men, is in early adult life. At this time they are striving to get a good job, make friends and become independent. This is the most common time for schizophrenia to begin in men. In women, major life stress often starts later, when they have children. We find that the age at which schizophrenia tends to start is later in women.

Major stressful events such as a death in the family, loss of a job or breakup of a relationship can make schizophrenia worse or trigger off a relapse of symptoms.

Once a person has schizophrenia, the environment in which he or she lives – his family, work and so on, can help him a lot. People can support him by encouraging him to slowly regain his former skills. If they tend to push him, or nag and criticise him this may make things worse. On the other hand, if too much is done for him and he does nothing, this too can make him worse. Of course, it is impossible to totally avoid stress. But family members can help one another to cope with difficulties by taking things step by step.

Relapses may be triggered by:

1. Stressful events
2. Tension at home and work

It is clear that the family can be very helpful. But occasionally they can make things more stressful. However, there is no evidence that families cause schizophrenia.

A few years ago, many psychiatrists believed that schizophrenia was entirely caused by the way the parents brought up their children. While we all know how important this is, there is no scientific evidence that poor child care or an unhappy childhood causes schizophrenia.

Families do not cause schizophrenia.

MEDICATION

Medication was introduced for the treatment of schizophrenia about 30 years ago. It is the main form of treatment. There are several different types of drugs used in the treatment of schizophrenia, with different brand names. Medication may be given in the form of tablets or injections. Injections are often helpful as they are less likely to be forgotten. All the different types of medication have the same helpful effects.

There are two ways in which medication is used in the treatment of schizophrenia.

1. To reduce the symptoms of an attack of the illness.
2. Once the symptoms have improved, the same medication is used to prevent further attacks or the symptoms getting worse.

If the person with schizophrenia stops taking his or her medication against the doctor's advice the chances of them having a further attack of schizophrenia are more than doubled. This is why it is important to take the medication that the doctor prescribes even when the person feels completely well.

Taking medication helps to prevent relapse

Unfortunately the medication used for the treatment of schizophrenia can sometimes produce unwanted side effects. These are not usually serious and should be discussed with your doctor. Some of these side effects include drowsiness, shakiness, restlessness, and muscle stiffness. Others are sensitivity to sunburn, increased appetite, and dizziness especially when standing up suddenly.

Some of these effects the person can avoid him or herself. For example, by avoiding too much sun, by standing up slowly and watching their diet. But if your relative is worried about anything to do with the medication, go and see your doctor.

Discuss any medication worries with your doctor.

HOW CAN RELATIVES OR THE FAMILY HELP?

1. Relatives can encourage the person to take the medication that your doctor or psychiatrist has prescribed.

Often people feel they do not need medication, especially if they are feeling well again. But it is important to take the tablets or go for the injections as they have been prescribed. The relatives can play an important role here in encouraging the patient to do this. Sometimes when the person is feeling better, he or she does not see the need to take further tablets or injections. But, if medication is stopped, a relapse may occur sooner or later. Sometimes the medication will produce side effects, these should be discussed with the doctor.

Encourage your relative to take the medication.

2. The person with schizophrenia can be very sensitive to stress or change. Relatives can help the patient by trying to reduce stressful events or by helping the person cope with stress.
 - (a) The person can be stressed by dramatic changes in routine or lifestyle, eg., moving house, or a member of the family leaving home. Where such events cannot be avoided, try to give the person advance notice. Explain the situation clearly so that any problems can be solved. Try to make any changes as gradual as possible.
 - (b) If the person becomes anxious or worried, even by trivial things, encourage him/her to relax. Be patient with them and try to calm the situation down. Try not to get over concerned or upset yourself.

You can best help the person with schizophrenia if you are calm and relaxed yourself.

- (c) Sometimes the person may become depressed and fed up. This is always difficult to cope with. Try to be sympathetic and give support. Do not blame the person, it is not their fault. Try to be encouraging and positive so that you build up a person's confidence. This can be very tiring so you both may need time away from each other. Fortunately, depression is usually only short lived.
3. Living with a person with schizophrenia can be very difficult.
 - (a) They may behave in a strange way. They may spend all day in bed or take hours to get things done. They may seem not to care about themselves or others.

It is very easy to get angry or impatient especially if the person appears lazy or unhelpful. This is not surprising but it is not helpful to the person. Try to be patient and encourage gradual change. Try not to criticise or punish the person for doing things you disapprove of. This is being negative. Encourage the patient to try and praise his or her efforts. This is being positive.

Try to praise and encourage and avoid criticism and arguments.

- (b) You may feel very worried. You may find you are always wondering what will happen next and how you will cope. The best thing is not to spend too much time together. Try not to be too fussy or over protective. It is important that the person is encouraged to lead an independent life and gain confidence in him or herself.

Encourage the person to gradually become more independent and confident.

- (c) You may find that you become anxious or depressed yourself. Try to relax. It is often helpful to talk over your feelings with someone else. Try to keep your own interest and hobbies going. You need time for yourself and this will take your mind off things. Getting very worried and overconcerned can make things worse.

If a crisis occurs, do not feel guilty or blame yourself. You cannot anticipate everything. Try to cope with situations as calmly as possible as they arise. Try not to over-react and try to stay relaxed. Sometimes there are no right answers, but learning comes from experience.

Make time for yourself. This will help everyone.

4. Family Problem Solving

Living with someone who suffers from schizophrenia can cause tensions at home. It can increase the impact of other problems.

Sometimes it may be useful to get the family together to talk things out. Be clear about what the problem is. Allow everyone to express their views and feelings. Listen to one another but try not to argue or criticise. Try to find different ways of dealing with the problem. Agree together on the best thing to do and how to carry it out. This is a positive approach to solving problems. It stops wasting time arguing and being negative.

Talk things over. Try to find solutions together.

FAMILIES DO NOT CAUSE SCHIZOPHRENIA

Information about schizophrenia

SUMMARY

1. Schizophrenia is a major mental illness that affects 1 in 100 people.
2. The symptoms include delusions—false beliefs; hallucinations—false perceptions, usually voices; difficulties of thinking, feelings and behaviour.
3. The exact cause is not known but there appears to be an imbalance of the brain chemistry.
4. Stress and tension make the symptoms worse and possibly trigger the illness.
5. People who develop schizophrenia possibly have a tendency which may run in families. This increases their risk of getting schizophrenia.
6. Some people recover from schizophrenia completely, but most have some difficulties and may suffer relapses.
7. Although there are no complete cures available, relapses can be prevented and life difficulties overcome.
8. It is VERY important to take the medication prescribed.
9. Family members and friends can be most helpful by:
 - Encouraging the person to take the medication
 - Staying calm and relaxed themselves
 - Being encouraging and positive
 - Solving family problems in a calm way

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