50

AN EVALUATION OF A BRIEF MULTIPLE FAMILY GROUP PSYCHOEDUCATION PROGRAMME WITH FAMILIES IN WHICH A MEMBER HAS SCHIZOPHRENIA

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Lunacy, like the rain, falls upon the evil and the good; and although it must forever remain a fearful misfortune, yet there may be no more sin or shame in it than there is in an ague fit or fever.

Inmate of the Glasgow Royal Asylum, 1860

(Torrey, E. 1988:273).

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER ONE

INTRODUCTION TO THE STUDY

1.1 INTRODUCTION

According to the American Psychiatric Association (A.P.A.) in the Fourth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV), there is a lifetime prevalence of schizophrenia estimated to be between 0,5% and 1,0% (1994:282). The incidence rates are estimated to be about one in ten thousand per year. For the person affected and the family concerned such an illness raises such issues as loss of expected aspirations, confusion, anger, guilt, shame and frustration. It is against this background that effective intervention should assist and challenge families to develop their inherent capacities to cope with the difficulties that chronic illness presents.

1.2 STATEMENT OF THE PROBLEM

Schizophrenia is a mental illness characterised by symptoms that include hallucinations, delusions, disorganised speech, grossly disorganised behaviour, affective flattening, alogia and avolition. There is a marked impairment in social and occupational functioning and there are continuous signs of the disturbance for at least six months (American Psychiatric Association,1994:285-286).

According to Kaplan and Sadock (1985:631) schizophrenia is a "syndrome that is heterogeneous in its cause, pathogenesis, presenting picture, course, response to treatment, and outcome" and should be understood as an "effort to adapt to a highly altered experience of inner and outer reality". Increasing understanding of schizophrenia has led to changes in treatment and management.

In 1955 the deinstitutionalisation movement began in the United States of America and reached its peak between 1965 and 1980 (Torrey,1988:232). This was facilitated by the advent of psychotropic medication and it was believed that such a movement would

promote rehabilitation and reintegration into society, provide a more effective patient care service and be more economical (Kaplan & Sadock,1985:2024). However, the results have not been entirely successful (Kaplan & Sadock,1985:2025). In reality, the community support networks have been scarce and many patients have been discharged into environmental circumstances that seriously threaten their recovery and mental health. Some are discharged into the care of their families who frequently feel unprepared and ill-equipped to cope with and help such a family member (Iodice in Turner,1995:499). There is a recognition that the family is an essential element in the successful integration of a person with schizophrenia. There is also a need to preserve and enhance the family as the primary support system and not regard it merely as the "dumping ground" for such patients (Iodice in Turner,1995:500).

The major problems encountered by families in which a member has schizophrenia are as follows:

i) Lack of knowledge which may contribute to stress in the family increasing the potential for disharmony.

ii) There may be evidence of high levels of expressed emotion (E.E.), which refer to the degree of criticism, hostility and emotional overinvolvement (Nichols & Schwartz,1991:487).

iii) Communication within a family that is ambiguous and complex may result in uncomfortable levels of arousal and confusion (Anderson et al,1980:493; McFarlane in Gurman & Kniskern,1991:471).

iv) Boundaries within family systems may become blurred and also lead to confusion (McFarlane in Gurman & Kniskern,1991:368; Nichols & Schwartz,1991:491).

v) Role expectations by the family may need to be reassessed in order to allow the person with schizophrenia to attain a degree of self-worth (Spaniol et al,1992:369).

vi) When a member of the family has schizophrenia, high levels of stress may be generated. It is essential that the family develop adequate problem-solving skills in order to avoid an escalation of stress (McFarlane in Gurman & Kniskern, 1991:369-371).

vii) Clear limits on behaviour also need to be established in order to create a sense of predictability (Anderson et al,1980:493; McFarlane in Gurman & Kniskern,1991:370).

viii) When families are inflexible in their capacity to adapt to the illness, stress in the family may also escalate (McFarlane in Gurman & Kniskern,1991:371).

ix) When a family is not able to accept the illness, unrealistic expectations can be made, creating undue stress (Nichols & Schwartz,1991:490).

x) In the past there has been much blame accorded to families in which a member develops schizophrenia. It is understandable that such families will withdraw socially in order to avoid such a judgment. The symptoms of the patient may cause embarrassment and thus the family becomes isolated. Further, schizophrenia is still widely regarded as an evil and families in which this illness is present may feel stigmatised and alone. Such families may need assistance in accepting support from a wide range of resources in order to avoid relapses (McFarlane in Gurman & Kniskern,1991:365).

In circumstances where adaptive family functioning is undermined there is a potential for recurring readmissions. It has been shown by Kreissman in Turner (Iodice in Turner,1995:500) that 60% of admissions are readmissions.

Psychoeducation (McFarlane in Gurman & Kniskern,1991:363-395; Nichols & Schwartz, 1991:486-494) as a model was developed by Anderson, Hogerty and Reiss in the 1980's (McFarlane in Gurman & Kniskern,1991:363; Nichols & Schwartz,1991:487). In collaboration with family caregivers they began to address these problems from an educational perspective. This entailed a move away from family therapy which focused on ventilation of feelings and which inevitably raised issues of blame and defensiveness in highly charged emotional sessions (Dreier & Lewis,1991:16; Nichols & Schwartz, 1991:487). Psychoeducation as a model of family therapy is a collaborative information-sharing partnership with a family in which people feel "empathised with, supported and also empowered to deal with the patient" (Nichols & Schwartz,1991:489).

The multiple family group format has been bound to be more successful than the single family group format "in extending remission, especially in patients at higher risk for relapse, with a cost benefit ration of 1:34" (McFarlane et al,1995b:679).

The duration of psychoeducation programmes range from two years to several weeks (Dixon & Lehman,1995:634-635).

This study then seeks to evaluate the impact of a brief multiple family group psychoeducation programme with families in which a member has schizophrenia.

1.3 AIMS OF THE STUDY

1.3.1 OVERALL AIM

To evaluate the effectiveness of a brief multiple family group psychoeducation programme with families, who have a family member with schizophrenia, currently being treated as patients of Valkenberg Hospital.

1.3.2 PARTIAL AIMS

i) To assess families' knowledge about schizophrenia

ii) To assess their present levels of functioning.

iii) To assess their support systems.

iv) To assess objectives i), ii) and iii) via a pre-test questionnaire in which the sample group of families give their responses in personally conducted interviews.

v) To undertake action research whereby a psychoeducation model is introduced and families are exposed to a one day educational skills workshop followed up by six weekly family sessions.

vi) To administer a post-test questionnaire to assess the impact of psychoeducation on families.

1.4 SPECIFIC RESEARCH QUESTIONS

i) To what extent will a psychoeducation programme, consisting of a one day skills workshop and six weekly family care-giver sessions,

- increase knowledge about schizophrenia,
- improve family functioning and
- improve support?

ii) What would be the feasibility of conducting future psychoeducation programmes?

1.5 THE SIGNIFICANCE OF THE STUDY FOR SOCIAL WORK PRACTICE

When family therapy began to receive recognition as a specific means of intervention in the 1950's, the relationship between the family and schizophrenia received much attention. It was the generally held view that schizophrenia was the consequence of disturbed family functioning. To date none of these allegations have been able to withstand the rigours f research inquiry (McFarlane in Gurman & Kniskern,1991:364).

In recent years there has been the suggestion that schizophrenia brings about "nearly devastating effects on families when faced with a mentally ill member in their midst for long periods of time" (McFarlane in Gurman & Kniskern,1991:367). With increasing numbers of people with schizophrenia being discharged into family care it has become increasingly difficult for social workers to assist these individuals and their families in isolation. It is envisaged that the use of a multiple family educational therapy approach would be more cost effective and the participants would be linked to community resources. They will also be grouped together with those who have had "first hand" knowledge of living with schizophrenia. Hence, they could use their own experiences to assist one another and provide support. When families are confronted with having to live with a chronically mentally ill person there is little preparation for the difficulties that lie ahead. Such a study could determine the importance of giving families the necessary information, so that uncertainties and unrealistic expectations can be dealt with. Such a psychoeducation programme could also minimise the development of dysfunctional patterns.

1.6 ETHICAL CONSIDERATIONS

One of the major considerations pertained to the inclusion or not of the index patient. The following ethical issues were considered:

i) Anderson et al (1986:74-75), McFarlane in Gurman & Kniskern (1991:374) and Solomon et al (1996:42) recommend that patients are not included in the workshop as the patient may not be able to tolerate the stimulation.

ii) Families may find it easier to talk about their concerns without the ill member present, especially those concerns that could impact negatively on the patients. Further, relatives are more likely to attend a workshop in which the patient was absent (Reilly et al,1988:431; O'Shea et al,1991:41-42; Solomon et al,1996:42).

iii) Excluding the patients may result in their becoming suspicious of what is being talked about.

iv) During the Pilot Study (Appendix G:154), the index patient was not able sustain attention during the five out of eight sessions he attended.

Informed by the above, the writer decided to exclude the patients from the workshop. The parents were asked to invite their family members with schizophrenia to attend the group sessions, if they felt that this would benefit the families and patients concerned.

Confidentiality in terms of family names of participants has been assured.

The writer took on the dual role of therapist and researcher. At all times the interests of the participants were paramount.

1.7 REFLEXIVITY

The following issues were considered:

i) The writer has worked in the field of mental health for eight years and during this time, it had become increasingly clear that chronic mental illness and specifically, schizophrenia,

had a debilitating effect on families in terms of their relationships and ongoing family functioning.

ii) The writer had a strong conviction that not sufficient work was being done with the family caregivers of schizophrenic patients (McFarlane in Gurman and Kiskern,1991:385).

iii) The writer believes that an essential aspect of therapy is respect for the family as a whole and each of its individual members. This value was expressed in a collaborative attempt to share the unique knowledge of all concerned. In this way, families were enabled to believe that they had an important and positive role to play and that they were not victims of schizophrenia but active participants in promoting a more satisfying family life.

iv) Part of the hesitation of the writer involved in the process, was directly linked to her own level of anxiety about the proposed programme. The psychoeducation model which the writer proposed to undertake was not one with which she was familiar.

v) Another area of concern was related to whether she would obtain a sufficient sample and that this sample would remain in the study.

1.8 PERMISSION TO CONDUCT THE STUDY AND ACCOUNTABILITY

In order to conduct research at Valkenberg Hospital, the writer was granted permission from Professor Brian Robertson of the Department of Psychiatry at the University of Cape Town. In negotiating entry into the hospital community, the writer met with the chief social worker to gain an orientation into the personnel structure of the hospital, the process of admission, rehabilitation and general administrative procedures. Contact was made with four of the consultants, who were able to provide possible candidates for the study. One of the consultants invited the writer to participate in two ward rounds per week with his team, in order to facilitate staff co-operation and enable the writer to develop a sense of the hospital process. This took place for the duration of the selection process and throughout the study.

The names of eighteen families were made available. Only five met the criteria and were available. One of these failed to attend. Contact was made with the speakers for the day workshop. A venue was negotiated with staff of one of the wards and the consultant in

charge. Six sessions were held at weekly intervals except for one, where it was agreed to postpone a meeting, until the following Saturday as the hospital was having an Open Day.

1.9 DEFINITION OF TERMS

SCHIZOPHRENIA, according to the American Psychiatric Association (1994:273), is a disturbance that lasts for at least six months and includes at least one month of active-phase symptoms. These include the presence of at least two or more of the following:

i) Delusions which are false beliefs based on incorrect references about external reality that are "firmly sustained despite what almost everyone believes and despite what constitutes incontrovertible and obvious proof or evidence to the contrary" (American Psychiatric Association,1994:765). They may be characterised by grandiosity, persecution or reference and are usually bizarre

ii) Hallucinations which are sensory perceptions that have the compelling sense of reality of true perceptions but that take place in the absence of external stimulation of the relevant sensory organs (American Psychiatric Association,1994:767). In schizophrenia they are usually of an auditory nature and are experienced as a voice of an individual or as multiple voices

iii) Disorganised speech which is based on inferences about the organisation of thought processes. These processes are considered to be disordered based on the presence of loosening of associations, tangentiality and in severe cases, the person may be incoherent, making up words that only he / she understands (American Psychiatric Association,1994:276)

iv) Grossly disorganised or catatonic behaviour in which there is a marked decrease of reactivity to and awareness of the environment. There may be prolonged holding of a postural position which may be quite bizarre, resistant to alteration, purposeless or resemble unstimulated excessive motor activity (American Psychiatric Association,1994:276).

v) Negative symptoms in which the affect may be blunted or inappropriate, alogia (reduction in quality and quantity of speech which reflects a poverty of ideation) and avolition.

Schizophrenia can be subdivided into subtypes depending on the predominant symptomology. They are as follows:

i) the Paranoid type in which the delusions and hallucinations are of a persecutory nature,

ii) the Disorganised type in which there is disorganised speech, behaviour and inappropriate affect,

iii) the Catatonic type in which there is marked behavioural disturbances,

iv) the Undifferentiated type in which there are sufficient symptoms for a diagnosis of schizophrenia but symptoms do not meet the criteria for those types mentioned above and

v) the Residual type in which symptoms are present in an attenuated form (American Psychiatric Association,1994:286-290).

THE FAMILY is that group of related people who constitute the primary caregivers. The caregivers may be the parents, siblings, grandparents, aunts, uncles, others who are related within the immediate extended family and those who through bonds of kinship, care for the person with schizophrenia. For the purposes of this study those who will be included are family members residing within the same household or a family member who has been identified as having sufficient interest in and influence over the identified client.

FAMILY DYSFUNCTION may occur when there are maladaptive responses to chronic problems over which the family does not have direct control. Such dysfunction may be manifest in the following dimensions, extent of knowledge about schizophrenia, expressed emotion, communication, boundaries, roles, problem-solving, behaviour, flexibility, extent of acceptance of the illness and support networks. They may be described as a system's solution to an evolutionary impasse (Vostanis et al,1992:19).

PSYCHOEDUCATION as a model of family therapy is a collaborative partnership with therapist(s) and families in the context of an interactional environment in which families feel empathised with, supported, educated and empowered to cope more effectively with

a family member who has a chronic, disabling condition (Mc Farlane in Gurman & Kniskern,1991:364; Nichols & Schwartz, 1991:489).

The method of psychoeducation in this study involves four phases - namely,

i) a preparation phase,

ii) an assessment phase,

iii) a one day educational skills workshop and

iv) six weekly focus group sessions.

In this study the multiple family group format will be used in which a number of families meet together.

1.10 SUMMARY

This chapter introduced the research topic. The research questions were set out, the significance of the study outlined and ethical questions were raised. Reflexivity was addressed. The process of permission and accountability was outlined and key concepts were defined.

In the next two chapters the literature will be reviewed.

CHAPTER TWO

FAMILIES, SCHIZOPHRENIA AND THERAPEUTIC INTERVENTIONS

2.1 INTRODUCTION

In the past fifty years there have been many changes in the way in which schizophrenia has been understood in relation to the family. Concurrently, there have been significant advancements made in the treatment of schizophrenia while the family as an entity has also changed. Nichols & Schwartz (1991:ix) also point out that in 1962 there were just three journals devoted to family therapy and in 1991 there were nineteen in the United States of America plus a further seventeen in other parts of the world. This indicates an awareness of the importance of the family in a society that has undergone transformation.

2.2 FAMILIES IN A CHANGING SOCIETY

Since the Second World War there have been significant shifts in how families are constituted with developments in many other forms of committed relationships (Sprenkle & Bischof,1994:9). Changes in the family have occurred in the following ways:

i) There has been a trend towards single parent families and raising families outside of traditional marriage (Economist,1995:22; Kiely in Turner,1995:928).

ii) With longer life expectancy, great-grandparents are becoming a feature in extended family households. According to Jones in Gerdes et al (1981:304) between 1900 and 1970 there was a sevenfold increase in people over the age of 65 years.

iii) In South Africa past political and ongoing economic factors have impacted on families in which either one or both parents have had to live away from their families (Simkins in Burman & Reynolds, 1986:19). Parents may be absent from the home for long periods during the day in order to work. This has resulted in the caring of the children by grandmothers or female members of predominantly multigenerational households (Cock et al in Burman & Reynolds,1986:70, 81).

iv) The roles and status of women in the work force have also undergone changes. Women are no longer accorded "temporary and intermittent" status (Cock et al in Burman & Reynolds,1986:76). With the revival of the feminist movement in the 1960's, there has been an increasing diversity of choices and there have been opportunities for advancement (World Book Encyclopaedia. Vol 7, 1981:73). However within the family system, in general, women are still expected to fulfill roles according to traditional gender constructions. This has led to unresolved power relationships between parents which impact on the family as a whole (Goldner,1985:36-37; Altschuler,1993:282-284).

These changing circumstances have contributed to changes in the ways in which schizophrenia has been understood and treated. This has impacted on the families' capacities to cope with their various crises. In particular, families with a mentally ill member are under a great deal of stress. Therefore other innovative ways have been sought to assist families in which a member has schizophrenia.

2.3 MENTAL ILLNESS AND SCHIZOPHRENIA

2.3.1 EARLY DEVELOPMENTS

The earliest records of mental illness go back to the times of Babylon and Ancient Egypt. In A.D. 490 the first recorded hospital established for people with a mental illness was established in Jerusalem (Kaplan & Sadock,1985:1576-1577). Throughout history there have been accounts of how a few have tried to alleviate the suffering of the mentally ill. However, there was much misunderstanding and the records show notorious cruelty to those with a mental illness. Dorothea Dix in 1843 decried "the state of insane persons confined within this Commonwealth in cages, closets, cellars, stalls, pens, naked, beaten with rods, and lashed into obedience" (Torrey, 1988:1).

In 1896 Emil Kraeplin grouped together paranoid psychosis, hebephrenia and catatonia and coined the term dementia praecox (Torrey,1988:77). The term schizophrenia was used by Bleuler in 1911 who in his search for common symptoms, identified the splitting of the mental functions of cognition and affect (Kaplan & Sadock,1985:63;

Torrey,1988:31). He changed the name dementia praecox to schizophrenia and added simple schizophrenia to Kraeplin's definition.

The treatment of schizophrenia until the turn of this century in South Africa and more specifically the Western Cape, was "within the bounds of a very limited knowledge and in often abysmal conditions" such as overcrowding and poor accommodation (Valkenberg Hospital Centenary Newsletter, 1991:7). In referring to Valkenberg Hospital in the Western Cape, du Toit (1991) states, "It is a history, not only of Valkenberg Hospital, but well nigh of the treatment of mental illness in South Africa".

2.3.2 DEVELOPMENTS IN THE CAPE

People with mental illness were isolated from others and our own history testifies to such treatment. In 1818 Somerset Hospital was opened in Green Point and one of the four wings of the hospital was a "lunatic asylum" (Louw, 1969:34). The buildings of the original Somerset Hospital were poorly built. During the middle of the 1800's Robben Island, which had been used for prisoners since 1658 was used to incarcerate the "extremely sick, the mentally ill (known as lunatics), the very poor and the lepers" (Hutton,1994:20-24). Here they experienced much degradation. In 1862 the New Somerset Hospital was opened to accommodate the mentally ill and the original Somerset Hospital was reopened to take those who could not be accommodated on Robben Island (Louw,1969:38). The Grahamstown Asylum was opened in 1875 and the Port Alfred Asylum was opened in 1888 (Swartz,1995:399). Black patients were admitted to Fort Beaufort Asylum in 1894 (Valkenberg 100 Years of Devoted Care,1991). Valkenberg Hospital began treating White patients with a mental illness in 1891 (Valkenberg Hospital Centenary Newsletter,1991:7). It was not until 1921 that all patients with mental illness were removed from Robben Island.

With the advent of psychotropic medication in the 1950's many more people with schizophrenia were able to return to the community (Kaplan & Sadock,1985:714-715; Torrey,1988:186; Valkenberg Hospital Centenary Newsletter,1991:8).

2.3.3 THE DEINSTITUTIONALISATION MOVEMENT

During the past three decades growing numbers of patients have been discharged from psychiatric institutions as the deinstitutionalisation movement has gathered momentum. The process of deinstitutionalisation has been further advanced by reductions in state funding to psychiatric hospitals. This movement has received both widespread acclaim and criticism. Deinstitutionalisation provides opportunities for formally incarcerated patients to return to a potentially more fulfilling life in the community. It would appear, however, that community support systems have been inadequate in promoting the quality of life of the discharged patient and the community itself has been opposed to mentally ill people living among them (Kaplan & Sadock,1985:1882; Iodice in Turner,1995:499). In the only controlled study conducted it was found that over a five year period rehabilitation gains had been the same for those in the hospital compared with those in home care (Kaplan & Sadock,1985:2025).

Being discharged into the community usually means sending the patient back to the family. Approximately 65% of patients discharged from a mental hospital are accommodated by the family (Simon et al,1991:323). Families are expected to take care of the disabled individual frequently without the required preparation, knowledge, skills, training, resources and support (McFarlane in Gurman & Kniskern,1991:364; Simon et al,1991:323; Spaniol et al,1992:343; Keefler,1994:370-371; Winefield & Harvey,1994:557; Solomon et al,1996:42). The families feel abandoned and resentful because of limited financial support from the state and relatively little support from the mental health system in general. They find themselves having to cope with bizarre behaviour, medication non-compliance and educational and career deficits (Spaniol et al,1992:343). In a study by Winefield & Harvey (1994:561) it was shown that 45,7% of caregivers regarded the benefits of living together were to avoid "worse outcomes, such as being able to keep an eye on the patient's drinking, reminding the patient about medication, or because the patient was unhappy living elsewhere". It was reported that some of the difficulties of living with someone with a mental illness, were that there was a

tendency for such a person to be self-centered, physically destructive, demanding and irritating.

Thus, on the one hand, deinstitutionalisation does have its merits in that the mentally ill are being returned and potentially reintegrated into normal society. On the other hand, very few services exist to facilitate their reintegration. Some mental health professionals have tried to assist families of patients with schizophrenia.

2.4 PSYCHOTHERAPEUTIC APPROACHES TO THE MANAGEMENT OF SCHIZOPHRENIA

Therapeutic services aimed at rehabilitation and integration of people with schizophrenia have included a range of psychotherapies. People with schizophrenia change over time and the method of intervention should be appropriate to meet their specific therapeutic needs (Bellack & Meuser,1993:319). The more recent approaches to the treatment of schizophrenia have recognised the influences of biochemical imbalances in the brain. Therefore pharmacotherapy is important in the treatment regime (Kaplan & Sadock,1985:714; Torrey,1988:186; Simon et al,1991:326). However, some side effects present other problems (Kaplan & Sadock,1985:721-723; Torrey,1988:194-201).

Additional to pharmacotherapy, the following psychotherapeutic interventions have been used:

i) **Individual therapy** which focuses on support and education is recommended (Torrey,1988:259). In studies of case management which includes support, education and advocacy it has been shown, however, that there are inconsistent improvements in symptoms or functioning (Liberman,1994:108).

ii) **Groupwork** is effective in enabling those in similar situations to share the burden of their problems and may serve to affirm those who are achieving some measure of success. The group is a powerful learning environment which can provide a safe space for the acquisition of knowledge and the practice of new skills. Liberman (1994:108) states that there is little evidence from controlled studies to determine the efficacy of different types

of groupwork. Social skills training, however, is well documented and has shown to be very effective.

(iii) **Community work** has enabled social workers to treat those with schizophrenia in a group context, while providing education to the community. It is relatively inexpensive and serves social, support, and educational functions as well as vocational training. The emergence of Fountain House, (Kaplan & Sadock,1985:732) based on the clubhouse model "has achieved wider acclaim than any other approach for meeting the needs of persons with schizophrenia living in the community" (Torrey,1988:265). At Fountain House , "members" are able to "gather, socialize, feel comfortable, and be with friends" (Torrey,1988:266).

(iv) According to Bellack & Meuser (1993:324), research into the efficacy of **interventions with families** in which a member has schizophrenia, prior to 1980, have not been published. More recent research has suggested that patients and families do benefit, especially with long term intervention. Falloon et al (1993a: first page of the Preface) states that "family care is the greatest natural resource for the clinical management of all health problems".

In order to assist families more effectively, the psychoeducation model of family therapy aims to educate families. There is a move away from attempting to cure the family but rather to educate the family (Nichols & Schwartz,1991:488-489).

2.5 CRITIQUE OF FAMILY THERAPY IN WHICH A MEMBER OF THE FAMILY HAS SCHIZOPHRENIA

Anna Freud, according to Johnson (Johnson,1995:53), was influential in her assertions that parents and their disturbed offspring be separated as the parents had been instrumental in causing the problems. This way of thinking influenced some of the forerunners of family therapy. Fromm-Reichman, in 1948 coined the term the "schizophrenigenic mother" who lacked warmth, was overpowering, overprotective and denied the child the opportunity to develop a separate identity (Kisker,1985:273; Simon et al,1991:324). Theodore Lidz, according to Torrey (1988:163-164), McFarlane in Gurman & Kniskern

(1991:364), and Simon et al(1991:324), attributed the development of schizophrenia to destructive relationships between parents which Lidz termed "marital skew" and "marital schism". Murray Bowen, according to Nichols & Schwartz (1991:65) and Simon et al (1991:324), put forward the psychodynamic concept of the "pursuer-distancer" dynamic in which relationships between mothers and those with schizophrenia were characterised by cycles of separation and incorporation anxiety. In order to treat what Bowen termed an "undifferentiated family ego mass", he hospitalised whole families over a five year period. Lyman Wynne, according to Nichols & Schwartz, (1991:65-66) concluded that thought disorders in schizophrenia were the result of communication problems in families. Bateson and the Palo Alto group, according to Torrey (1988:164), Nichols & Schwartz (1991:65) and Simon et al (1991:324), claimed that bizarre behaviour in schizophrenia reflected a family's dysfunctional communication. In a paper by Bateson, "Towards a theory of schizophrenia" (1956) the concept of the double bind as a critical determinant of schizophrenia was introduced. Bateson and the Palo Alto group initiated conjoint sessions with the families of schizophrenia sufferers. The Milan school contributed to the discussion in suggesting the concept of "schizophrenic transaction" (McFarlane in Gurman & Kniskern,1991:364) which means a uniquely destructive means of communication. Hayley, according to Nichols & Schwartz (1991:490) "encouraged families to expect normal behaviour from schizophrenics", creating a potential for unrealistic expectations.

None of the above contributions have withstood empirical validation (Torrey,1988:164; Simon et al,1991:325-326). No study has been able to isolate consistent psychosocial factors that would predispose people to schizophrenia.

However, more recently, magnetic resonance imaging has shown that in people with schizophrenia cerebral ventricles have been enlarged and that there is a decrease in cortical grey matter (Simon et al,1991:326; Murray,1994:15). Murray suggests that such dysfunction could be genetic, supporting the genetic notion of neurodevelopmental abnormalities (1994:16). Despite this powerful argument in favour of more understanding

for the families in which a member has schizophrenia, these findings have not provided the basis for successful relief of symptoms, prevention of the illness or the enhancement of family functioning (McFarlane in Gurman & Kniskern,1991:364). The criticism or dismissal of families in which a member has schizophrenia has continued (Bellack & Meuser,1993:324). Spaniol et al (1992:342) found that 53% of graduate mental health programmes in California still blame families for mental illness.

It was out of a growing understanding that families needed more concrete and collaborative assistance that other approaches began to emerge. At this time families, as consumers, also began to express their dissatisfaction with the mental health system (Bellack & Meuser,1993:324). Among the newer approaches were the solution focused approach which grew out of the strategic model (Nichols & Schwartz,1991:481-486). The work of Michael White combined elements of the solution focused approach and the psychoeducational approach. He also promoted the concept of externalisation of the problem, namely, schizophrenia (White,1987:47-57; Nichols & Schwartz,1991:494-500). The psychoeducational approach of Anderson in Nichols & Schwartz (1991:488-489) was based on the assumption that schizophrenia created devastating problems for families and that education could serve as a powerful means of not only preventing family dysfunction but enhancing present effective functioning.

2.6 ASSUMPTIONS UNDERPINNING PSYCHOEDUCATION AS A MODEL OF FAMILY THERAPY

The assumptions underpinning the psychoeducation model are as follows:

i) The family is believed to be significant and valuable (Anderson in McFarlane et al,1995a:130). Further, the family is recognised as an important and constructive resource for the member with schizophrenia. However, the families' inner and external resources can become depleted and social isolation could perpetuate the above problems (Nichols & Schwartz,1991:488-489).

ii) There is an understanding that when a member of a family has a chronic debilitating mental illness the family may experience grief, stigma and traumatic role changes (Spaniol

et al,1992:341). These families may engage in counterproductive interactional patterns and family relationships as they "cycle through hope and then despair" (Spaniol et al,1992:342). The burdens as described by McFarlane in Gurman & Kniskern (1991:367) may be chronic tension, fear, depression, and financial problems.

iii) Education is empowering and where there is a sense of mastery, there could be a decrease of blame and guilt (Dreier & Lewis,1991:12, Nichols & Schwartz,1991:489). Anderson et al (1980:493) states that knowledge increases acceptance, support and tolerance of the patient and decreases conflict.

iv) There is a commitment to collaboration between the families and the therapist who is knowledgeable, empathic, supportive and non-judgmental. There is a basic understanding that families bring unique experiences to the process and together with the knowledge of the therapist, enriched learning and validation of families is made possible (McFarlane in Gurman & Kniskern,1991:377-378; Spaniol et al,1992:343; Durst,1994:37).

v) It is the task of the therapist to facilitate the emergence and expression of the families' powers and capacities (Mack,1994:192).

vi) There is a focus not only on the dynamics within the family but the family is viewed within the context of the broader community. Re-entry into the community and the building of social networks is an important objective (McFarlane in Gurman & Kniskern, 1991:473-375).

vii) Psychoeducation utilises behavioural and cognitive approaches (Dreier & Lewis,1991:16).

viii) Psychoeducation can be applied to single families or in a multiple family group format.

2.7 ASSUMPTIONS UNDERPINNING THE MULTIPLE FAMILY GROUP APPROACH TO PSYCHOEDUCATION

The assumptions underpinning the multiple family group approach are as follows:

i) Learning within a group for those who have experienced similar problems and successes is both supporting and validating (McFarlane in Gurman & Kniskern,1991:365; McFarlane et al,1995a:128). The group facilitates an "interplay of various guided human experiences"

which Yalom refers to as "curative factors" (1974:3). The successes of others instils hope in those still struggling. There is a sense of universality - that they are not alone. There is an opportunity to altruistically give "support, reassurance, suggestions, insight, and share similar problems". The multiple family group format enriches the imparting of information and the development of socialising techniques (Yalom,1974:6-17).

ii) Any messages of blame emanating from therapists, can be neutralised by a group of families more effectively than by one family (McFarlane in Gurman & Kniskern,1991:365).

iii) Because the presence of mental illness has a tendency to isolate families, such a format counters the effects of loneliness, abandonment and rejection (McFarlane in Gurman & Kniskern,1991:365). In the application of the single family or multiple family group format, the goals are similar.

2.8 THE GOALS OF PSYCHOEDUCATION

The **primary goal** is to support families to become effective, confident and constructive caregivers so that their family members with schizophrenia are enabled to become integrated into society, experience improved quality of life and do not relapse needing readmission to hospital (Anderson, et al 1980:492; McFarlane in Gurman & Kniskern,1991:372-373; Simon et al,1991:327).

The **secondary goals** include:

- educating families about schizophrenia and medication,
- facilitating increased understanding of the illness,
- giving information about community resources,
- encouraging the establishment of effective social networks,
- enhancing family functioning, thereby assisting the families to deal effectively with stress and frustration (Anderson et al,1980:492-494; Dreier& Lewis,1991:15; Gurman,1991:373; Simon,1991:326-327).

Winefield & Harvey (1994:565) stress that education of schizophrenia is insufficient to reduce caregiver stress and that knowledge and skills to cope with disturbed behaviour is

also highly indicated. In the multiple family format an added goal is to develop nurturing and support of members (Spaniol et al,1992:343).

2.9. SUMMARY

This chapter has addressed the issues of families in a changing society, the developments in understanding of the illness and the psychotherapeutic management of schizophrenia. Family therapy in families where a member has schizophrenia was critiqued. The assumptions underpinning the psychoeducation model and the multiple family group format were stated. The goals of psychoeducation were outlined.

In Chapter Three the psychoeducation model and factors impacting on its success will be reviewed.

CHAPTER THREE

THE PSYCHOEDUCATIONAL MODEL AND FACTORS IMPACTING ON ITS SUCCESS

3.1 CONTRIBUTIONS TO THE PSYCHOEDUCATION MODEL

Various therapists have taken different approaches to the psychoeducation model. The common elements that are present in these approaches include the importance of education about schizophrenia, the impact of expressed emotion and the reduction of stress (Simon et al,1991:327-330). Contributions to the psychoeducation model have been made by various therapists including the following:

i) **Anderson and colleagues** emphasise the importance of medication, having knowledge of the illness, maintaining effective social networks and developing skills to promote effective communication and reduce stress (Nichols & Schwartz,1991:488; Simon et al,1991:328). They outline a two year treatment programme consisting of four phases. Phase one begins as soon as the patient has been admitted and involves a meeting with the family, phase two is a one day survival workshop, phase three involves family sessions with the client and phase four prepares for termination (Simon et al,1991:328). Fox (1987:425) acknowledges that such a programme delays relapse but criticises both the lack of attention to disturbing side effects of medication and the costliness of such an intervention.

ii) **Falloon,** according to Bennun in Carpenter (1993:153) is influenced by behaviourist theory and this is reflected in his assessments of families. He also emphasises family problem-solving. Falloon outlines a home-based psychoeducation approach that has the benefit of keeping the index patient in the community at times of decompensation but this

is staff intensive and excludes supportive contact with other families (Falloon et al,1993b:147-161; Keefler,1994:371; Dixon & Lehman,1995:633-635).

iii) **Tarrier,** according to Bennun in Carpenter (1993:153) also uses a behavioural intervention, but focuses on goal-setting and the mechanisms to achieve this.

iv) **Leff,** according to Bennun in Carpenter focuses on communication patterns and the role of expressed emotion (1993:156). Leff in Keefler (1994:371) found that hospital based sessions were more effective than home based sessions.

v) Where these approaches are used with single families, **McFarlane** supports the multiple family approach and suggests from four to seven families being the optimal number (McFarlane in Gurman & Kniskern,1991:363-395). In two multiple family programmes, McFarlane showed that there were significant decreases in relapse rates, especially in families in which there had previously been high expressed emotion (Dixon & Lehman,1995:634).

vi) **Michael Goldstein and colleagues** focus on reducing stress and conflict through the use of brief intervention (six sessions) with families in which a family member has schizophrenia. In such a study these sessions were held straight after discharge and in this crisis phase it was found that the families were accessible and amenable to change (Nichols & Schwartz,1991:488; Simons et al,1991:327; Keefler,1994:371; Dixon & Lehman,1995:633).

v) In a study of brief family interventions by **Glick**, Bellack cites Goldstein, who claims that there were only modest changes in patient functioning and family attitudes (Bellack & Meuser,1993:326). This study was conducted over a five week period with family members attending an average of eight comma six (8,6) sessions.

vi) In another study by **O'Shea et al** (1991:33-44) a brief multiple family psychoeducation programme was used which was motivated by lack of feasibility of longer programmes in an economically deprived environment. In this study, O'Shea and colleagues continued screening families until there had been commitment from at least three families. However, the attendance at most of these programmes ranged from five to twelve participants representing four to six households (1991:38-39). Although O'Shea et al lacked hard data to draw significant conclusions from this study, they suggested that "psychoeducation is clearly and consistently superior to no family-focused services" (1991:43).

The South African context favours a cost-effective, brief intervention, psychoeducation programme.

3.2 CATEGORIES OF FAMILY FUNCTIONING UNDER INVESTIGATION

The goal of this programme is to determine the extent to which family functioning is influenced by families attending a brief multiple family group psychoeducation programme. Family functioning has been translated into certain categories as indicators that can be described and evaluated. In reality these categories do not exist as mutually exclusive entities. According to systems theory as it relates to the family (Kaplan & Sadock,1985:1427) these categories impact on one another and thereby influence one another. For purposes of clarity, these categories will be discussed separately:

3.2.1 KNOWLEDGE OF SCHIZOPHRENIA

Knowledge is empowering and will give families a sense of mastery over a situation that may seem chaotic and at times beyond their control (Nichols & Schwartz,1991:489). It facilitates tolerance, support and reduces conflict, blame and guilt (Anderson et al,1980:493; Dreier & Lewis,1991:12; Nichols & Schwartz,1991:489). According to McFarlane, the well functioning family possesses the available knowledge about schizophrenia and the skills to manage their situation (McFarlane inGurman & Kniskern,1991:370). Schizophrenia is a very difficult illness to understand and because it

is defined according to symptoms which can also be present in other illnesses, much confusion can arise (Torrey, 1988:73).

In the one day workshop, information is given about :

- the etiology of the illness as it is understood at present,
- the symptoms and how to detect these in the early stages,
- negative symptoms which can be misunderstood as laziness (Anderson,1980:493),
- the vital role of medication and side effects,
- available resources and
- how to cope with a crisis.

According to Leff, such knowledge, especially in respect of negative symptoms, could negate the potential for blaming the family member with schizophrenia for his condition It could also decrease impatience in the family (Bennett,1991:209).

In the multiple group format, families have the opportunity to learn from one another

Whilst knowledge of the illness is important, this alone is insufficient to reduce caregiver distress (Posner in Winefield,1994:565).

3.2.2 EXPRESSED EMOTION

Expressed emotion (E.E.) refers to the degree of criticism, hostility and emotional overinvolvement (Nichols & Schwartz, 1991:487) in families in association with "subjective stress, financial loss, and risks to their personal safety" (Bellack & Meuser,1993:325). McFarlane in quoting Hooley (Gurman & Kniskern,1991:371) states that EE can be understood as a "failure of adaption to a "chronic disaster". Leff & Vaughan (1985:87) state that overinvolvement tends to develop from the mothering role which is used beyond that which is age appropriate for the patient. Despite certain criticisms of the EE concept (Vostanis et al,1992:16), in a variety of studies done in Britain between 1962 and 1987, it has been shown consistently that when patients return to families in which there is high EE, the relapse rate is much higher than for those who return to families in which there is low EE (Leff & Vaughan,1985:95; Leff in

Bennett,1991:195-198; McFarlane in Gurman & Kniskern,1991:368; Nichols & Schwartz,1991:487-486). It appears that high EE induces arousal thereby rendering patients vulnerable to disabling levels of autonomic hyperactivity and ultimately emergence of symptoms (McFarlane in Gurman & Kniskern,1991:367, 370). Vaughn and Leff point out in a 1976 study that two thirds of critical comments were made about negative symptoms (McFarlane in Gurman & Kniskern,1991:370).

In the psychoeducation approach various therapists have dealt with EE in the following ways (Nichols & Schwartz,1991:202). Leff (1976) gave attention to negative symptoms, Falloon modeled low EE behaviour, Hogarty reinforced adaptive behaviour and Goldstein adopted a problem solving approach around areas of family conflict.

3.2.3 COMMUNICATION

According to the attention arousal hypothesis people with schizophrenia have an impaired capacity to control attention and filter and select information. When the communication is complex and ambiguous, arousal is induced with possible negative consequences. It is believed that where the family's feelings of "inadequacy, guilt, anger, and concern" are raised, there is a predisposition for "communication deviance" (Anderson et al,1980:483). Therefore it is suggested that communication be clear, concrete, moderately specific and simple especially in the post psychotic phase. It is also important that interactions between family members are relatively conflict free (McFarlane in Gurman & Kniskern,1991:369). According to Bennun in Carpenter (1993:152), Falloon introduced a sequential communication pattern that included "rehearsal, feedback, coaching, reinforcement and generalisation". Anderson also proposed a model for communication training that involved the following principles:

i) There should be a moderate level of specificity, in which detail and abstraction should be avoided,

ii) A distinction needs to be made between description and evaluation,

iii) Each member of the family needs to own his communication

iv) Communication should be positive (Bennun in Carpenter,1993:153).

3.2.4 BOUNDARIES

Blurred boundaries between family systems create the potential for confusion and overstimulation which may render a person with schizophrenia vulnerable to decompensation (McFarlane in Gurman & Kniskern,1991:368; Nichols & Schwartz,1991:491). Leff in Bennett (1991:205) reports that overinvolvement is common in parents where their offspring has schizophrenia. Enmeshment may occur as a consequence of feelings of embarrassment and frustration (Nichols & Schwartz,1991:488). This is linked to the intrusive nature of interactions in high EE families (Keefler,1994:372). Generational and intergenerational boundaries need to be strengthened to prevent the possibility of conflict spilling over into the family system as a whole, especially where the patient has become the locus of family control (Nichols & Schwartz,1991:191). Clear boundaries also have the potential for creating structure and predictability (Anderson et al,1980:493). Minuchin (1974:106-107), however, cautions against setting up a rigid boundary between the patient and parental subsystem. Due attention should be given to the pain and suffering experienced by the patient who can best articulate this if the boundaries facilitate appropriate interaction and communication. However, attention also needs to be given to the well siblings. It has been shown that when the marital subsystem is strong the patient usually copes much better. This enables the parents to cope more effectively with the debilitating effects of living with a chronic illness in a family member (McFarlane in Gurman & Kniskern,1991:369). Further, the boundaries of the family to the outside world need to be sufficiently open to facilitate support. This will be discussed more fully in the section dealing with support.

3.2.5 ROLES

Not only are clear boundaries important but also clearly defined roles. Schizophrenia usually presents in late adolescence or early adulthood. In the United States the onset of the illness in 75% of cases occurs between the ages of seventeen and 25 years (Torrey, 1988:80). This is the time in the family life cycle that offspring are preparing to leave

home or have just done so and parents begin to look forward to a life in which old or new interests can be pursued. Schizophrenia changes this and the patient now once again becomes a dependent family member but is also an adult. The illness may bring about a change of roles for the patient and the family. These need to be calmly renegotiated and agreements reached that are clear to all family members. In an unsupportive social environment it can be difficult for families to separate from the caregiving role (Spaniol et al,1992:343). According to Altschuler (1993:399, 393) chronic mental illness challenges rigid gender constructions within families. Prolonged dependence of young men calls for an urgent reframing of traditional roles usually linked to gender identity.

3.2.6 PROBLEM SOLVING

Obtaining consensus on resolution of conflict and problems are "essential to surviving" when living with someone who has schizophrenia (McFarlane in Gurman & Kniskern,1991:369). Falloon (1993a:30-37) showed that family functioning was improved when families adopted efficient problem solving capacities. According to Bennun in Carpenter (1993:155) the assumptions that underpin the need for effective problem-solving are "that it provides relatives with a systematic sequence with which to address family difficulties, it improves their ability to cope and it reduces family stress." Falloon outlines a step by step approach that includes the following sequence, problem identification, generation of alternatives, alternatives discussed in terms of advantages and disadvantages, the best option chosen, a plan made of how to implement the chosen alternative and finally there is a review of the outcome (Leff in Bennett,1991:201). Anderson takes a different approach by focusing on solutions. The steps she outlines are defining the problem, operationalising it, listing possible solutions, evaluating solutions and then evaluating the outcome.

3.2.7 BEHAVIOUR

Clear limits on behaviour and adherence to family rules will alleviate uncertainty and conflict (Andersonet al,1980:493). McFarlane in Gurman & Kniskern (1991:369-370) states that when family rules are respected, and the parents are in charge, the home

environment is likely to be more calm and therapeutic. Disruptive or violent behaviour which has the propensity to perpetuate expressed emotion (Bellack & Meuser,1993:325), needs to be calmly and consistently disallowed in accordance with agreed upon norms of acceptable behaviour. A structured environment will facilitate compliance with family norms, viz. around personal daily living tasks such as washing, dressing thus reducing the potential for conflict. As the patient improves over time, increasing responsibility can be entrusted to him / her. This has the potential for building self esteem and thereby positively affecting family relationships.

3.2.8 FLEXIBILITY

When families are flexible they are able to cope with the changing demands placed upon them when a member has schizophrenia, without the family becoming dysfunctional or disintegrating. By enabling families to accept the person with the illness there may be less resistance to making further adjustments. Flexibility of a family system can be determined from the first interview using the circular questioning technique as outlined by Penn (1982:271-274). This will help to track how the illness may have changed relationships, how coalitions have changed over time. Comparisons of and between subsystems can be made and families who have experienced difficulties in trying to manage their circumstances, can be better understood.

3.2.9 EXTENT OF ACCEPTANCE OF THE ILLNESS

As stated above schizophrenia usually presents at a time when the individual and the family look towards the future especially in terms of growing independence. The expectations the family and the patient had for him / herself may never be realised. With this is the accompanying experience of the loss of a mentally healthy person. Families deal with this loss in a variety of ways and at different paces. It is useful, however to be aware of the grief process as described by Kubler-Ross (1970), namely, the stages of denial and isolation, anger, bargaining, depression, and finally acceptance. Some families or individuals may become locked into a particular stage which may have a negative impact on effective family functioning.

McGorry (1995:315) refers to the responses of the patient when the diagnosis of schizophrenia is first made as "potentially shattering" with denial as a defense. Family caregivers, may also share these responses.

3.2.10 SUPPORT

In a study done by Beels (McFarlane in Gurman and Kniskern,1991:365) social isolation was associated with morbidity in schizophrenia. Social isolation may be seen as a consequence of the withdrawal of contact by the family and friends who may experience shame, embarrassment and frustration in regard to the patient. According to McFarlane in Gurman & Kniskern (1991:367) the relationship between families in which a member has schizophrenia and the nature of their support networks has been extensively studied with one significant factor emerging - the family and particularly the patient are more isolated than their peers. Further it has been shown that there is a strong association between isolation and high EE. The families need to be helped to keep their boundaries to the outside world sufficiently open to be able to receive "support, information, guidance, recreation, and simple social contact" (McFarlane in Gurman & Kniskern,1991:369) and in turn communicate quite openly with their peers about the patient's condition without feeling a sense of guilt and blame.

In order to facilitate the extension of support networks, in psychoeducation groups involving multiple families, Leff , Falloon and Hogarty, showed a relapse rate at twelve months not exceeding 12% compared with a control group in which the relapse rate ranged from 41% to 53% (Leff in Bennett,1991:203).

3.3 FACTORS INFLUENCING FAMILY PARTICIPATION

Much of the literature promotes the benefits of multiple family group psychoeducation as a means of improving or enhancing family functioning. However, factors that encourage or prevent participation are not so well documented but these are important to bear in mind during the selection process. Attendance may vary from those families who stay with

the programme for the duration, those who attend partially, those who attend and then drop out and those who are selected and never attend at all. Wiedeman et al (1994:549) makes the distinction between assessment dropouts - those who were assessed but did not attend the treatment - and treatment dropouts - those who dropped out during the treatment period. In five multiple family group studies the rate of those who began the programme and dropped out was 22 percent for the Schulze-Monking and Stricker study in Buchremer (1989) , 45 percent for a study by Leff in 1989 and 45 percent for a study by Mc Creadie in 1991 (Wiedeman,1994:547-548). In a study by Mc Farlane 29 percent dropped out before the end of a two year programme (McFarlane,1995b:684). In a brief programme conducted by Solomon et al (1996:44) there was a 30 percent drop out. No reasons for the drop out phenomena were given. Factors that influence attendance will be looked at from the perspectives of the families, the psychoeducation programme, the multiple family group format and the therapist. Such a discrete explanation is made for clarity but these factors tend to overlap and influence one another.

3.3.1 FACTORS RELATING TO THE FAMILIES

Factors relating the families could be:

i) The loss of a mentally healthy family member can be devastating and require difficult adjustments (Spaniol et al,1992:342). During this grieving process (Kubler-Ross,1989), families may be emotionally unavailable for assistance. The family may defend against the pain of such a diagnosis and deny the illness (Torrey,1988:279; O'Shea et al,1991:36). Wolrond-Skinner refers to the fear of accepting mental illness by the family as this could result in the "ultimate separation" of the known person who then becomes lost (1981:35).

ii) Isolation is another defense that is manifest in the family closing ranks and rendering them unavailable for support (Anderson et al,1980:493; McFarlane in Gurman & Kniskern,1991:367). Part of this may be due to embarrassment about the illness (Spaniol et al ,1992:342) and feelings of blame and shame (Torrey,1988:274).

iii) At times when the family self esteem is under threat there can be a simultaneous challenge to the sense of power (Mack,1994:180). In engaging with a therapist who is perceived as being knowledgeable and powerful the family's feelings of powerlessness

(Durst,1994:37) can be aggravated. Thus, becoming involved in such therapy could be perceived as a threat.

iv) Families may experience anger (Anderson et al,1980:393; Torrey,1988:279) that becomes projected onto those who try to help. When the anger is turned inwards this manifests as depression (Torrey,1988:279) and Dreier & Lewis (1991:13) states that such parents would not find psychoeducation effective.

v) Wolrond-Skinner refers to the treatment barrier (1981:34) in which families and patients will avoid the pain and reality of mental illness by attributing to the doctor a pseudo-authority which then removes their responsibility and ultimately hinders effective treatment. This may be expressed as a lack of interest (O'Shea et al,1991:36). In an earlier publication Wolrond-Skinner (1979:25) draws attention to the fact that different family members may have differing perceptions of the problem and this could result in only certain members being available for therapy.

vi) The burden of caring for someone with a chronic mental illness may be a "profoundly distressing experience" (Spaniol et al,1992:343) and may sap the families' energy leaving them little over to commit themselves to a programme of several weeks.

vii) Some families may have been exposed to previous group experiences and are not keen to become involved in yet another group (O'Shea et al,1991:36). McFarlane in Gurman & Kniskern (1991:385) states that these families will be slower to change. For those who have already affiliated to a support group there is already a place for nurturing and being nurtured (Spaniol et al,1992:344).

viii) Families who have become more knowledgeable about schizophrenia, at times more so than the professionals (Spaniol et al,1992:344), may have been able to reframe the difficult situation and take on an advocacy role. In such cases families may not benefit much from a psychoeducation programme.

ix) As schizophrenia usually presents at an age when young people are preparing to leave home, the return to a dependent state by the patient may result in difficult adjustments for all concerned. This role, of the primary caregiver, is often not by choice and attending a programme of psychoeducation may be perceived as another unwanted expectation.

x) Some families may feel uneasy or distrustful about attending family therapy in which there is an expectation that they should divulge emotional concerns which according to some cultures, are only done in certain relationships (Durst,1994:33). According to O'Shea et al (1991:37) families may experience ambivalence about being asked to join such a programme in that they both welcome and resent this which could result in attendance drop out.

xi) Families may also be reluctant to join a research programme which may be perceived as perpetuating "the many myths about families and mental illness" (O'Shea et al,1992:345).

3.3.2 FACTORS RELATING TO THE PROGRAMME

Factors relating to the programme could be:

i) The programme is designed to combine the knowledge of the therapist and the experience of the families and through a collaborative effort to help families to cope more effectively. However, the programme may appear "oversimplified and authoritative" (Anderson et al,1980:494) and may be too educational at the expense of meeting more immediate family concerns.

ii) Joining with the family should take place in the assessment interview ideally at the home but in reality, due to lack of resources, this may have to be done on the telephone or at the hospital (O'Shea et al,1991:38). This is not always satisfactory.

iii) Wherever the programme is conducted, there may be those who rely on public transport and this may prove an obstacle to regular attendance.

iv) According to Simon et al (1991:330) a major problem with this programme is that while the family is not considered part of the cause of schizophrenia, there is a shift to a belief that they perpetuate it and this can be experienced as punitive.

3.3.3 FACTORS RELATING TO THE MULTIPLE FAMILY GROUP FORMAT

Factors relating to the multiple group format could be:

i) While the multiple family group could be experienced by some as supportive and validating, other families may find them intimidating (O'Shea et al,1991:42).

ii) This group format may offer a more economic use of professional expertise (O'Shea et al,1991:42) but some families may need more individualised intervention.

iii) Nichols & Schwartz (1991:554) caution that bringing families together in a group may be effective if their initial difficulties have been overcome. The psychoeducation group format does not make provision for working through initial problems.

iv) The multiple family group format brings with it both the weaknesses and strengths of family therapy and group therapy. According to Carol Phillips, lecturer in family therapy at the University of Cape Town, the issues to be considered are that :

- families bring a past, present and future to therapy whereas group therapy brings the present
- in family therapy the process is faster and in group therapy the process is slower
- in family therapy the therapist can be scapegoated but in group therapy it may be anyone in the group.

Such factors could result in tensions that family members, already burdened, may find intolerable and drop out.

3.3.4 FACTORS RELATING TO THE THERAPIST

Factors relating to the therapist could be:

i) The lack of therapist's experience in running such groups can undermine confidence in the process. According to Weber et al (1985:357) the therapist should take a leadership role. In striving for collaboration and openness the therapist should inform families that she / he does not have all the answers and is also striving to help (O'Shea et al,1992:346). This could be interpreted as incompetence and undermine the therapist's position. Simon et al (1991:331) highlights the need for social workers to receive more training in the field of teaching and coaching new skills.

ii) With the dynamics of both families and groups operating, working alone without a co-therapist is a threat to objectivity, balance and an understanding of complex interactions (Nichols & Schwartz,1991:554). A feeling of helplessness can be experienced by the therapist (Spaniol et al,1992:341) which may impact negatively on the families.

3.4 SUMMARY

Psychoeducation as an means of enhancing or improving family functioning in families in which a member has schizophrenia has been reviewed. Categories of family functioning under investigation, have been discussed. Factors influencing family participation have been explored.

In the Chapter Four the research methodology will be set out.

CHAPTER FOUR

RESEARCH METHODOLOGY

4.1 INTRODUCTION

In this chapter the research design is introduced and the research process is discussed in detail.

4.2 RESEARCH DESIGN

This is a hybrid study with features of **exploratory** and **evaluative** components. The study also used a combination of both **qualitative** and **quantitative** approaches.

The study was **exploratory,** in that it explored the feasibility of undertaking a psychoeducation programme with family caregivers (Grinnell,1988:30; Rubin & Babbie,1993:107; Sells et al,1993:201). This study attempted to develop some insight and understanding into brief multiple family group psychoeducation for the South African context.

The study was **evaluative,** in that it sought to assess the effectiveness of such a programme by incorporating elements of a pre-test - post-test design (Grinnell,1988:402; Rubin & Babbie,1993:537).

This research study, however, also combined both **quantitative** and **qualitative** dimensions in its methodological approach.

The **quantitative** dimension was evident in those sections of the questionnaires which sought to extrapolate numerical hard data (Robson,1996:307) via the Likert scales (Grinnell,1985:199-202; Robson,1996:256-259). At the same time the Wilcoxon matched

pairs test was used to ascertain statistical significance between the pre- and post-test questionnaires (Runyon & Haber,1991:500-501).

The **qualitative** dimension was evident in those sections of the questionnaires which allowed for the respondents' richness of meaning to be conveyed (Robson,1996:307). The focus group approach used in this study was another example of the qualitative dimension. In the focus group discussions participants shared "their thoughts and experiences on a set of topics selected by the researcher" (Morgan & Spanish,1984:253). Combining quantitative and qualitative approaches assists "to enrich our understanding of the problem studied" (Rosnow & Rosenthal, 1976:74).

4.3 SAMPLING

4.3.1 THE POPULATION

The designated population contained both nuclear and extended families of patients of Valkenberg Hospital, with a known diagnosis of schizophrenia, and living at home with nuclear or extended family.

4.3.2 THE SAMPLE

In this study an availability or accidental sampling procedure was used (Grinnell,1985:143). A sampling frame of eighteen families was targeted. Five families, that is, ten participants, committed themselves to the research study. However, one family, consisting of both parents, "dropped out" after the assessment. Two families, that is, four participants and the husband of one family, "dropped out" after attending the one day workshop and one focus group session. Three participants remained in the study.

4.3.3 SELECTION OF FAMILIES

The families who were selected met the following criteria:

i) The index patient and family had been given the diagnosis of schizophrenia;

ii) At the time of selection the index patient was residing with his/her nuclear or extended family; and

iii) The families needed to be comfortable conversing in English.

4.3.4 PROCESS OF SELECTION

Of the names of eighteen families, five families met the criteria and were available.

Thirteen families did not meet the criteria for the following reasons:

* Four did not have a diagnosis of schizophrenia
* Four were not available
* Two families were already attending a support group
* One mother reported that she was coping well.
* In one family the index patient had moved away from home
* One family was excluded as the index patient at the time still strongly rejected the diagnosis.

Prior to this selection process, a pilot study was conducted with one family (Appendix G:154). A questionnaire was developed and refined.

4.4 PROGRAMME DEVELOPMENT AND CONTENT

4.4.1 PILOT STUDY

The purpose of the pilot study was to refine the programme and questionnaire for further research. This pilot study was conducted with a single family (mother, father and son who has schizophrenia). It consisted of eight, weekly family sessions. At the beginning of each session those attending were asked to complete a questionnaire consisting of open ended questions and a rating scale. In the final interview, which was used for evaluation, the family were asked to complete another questionnaire consisting of the same questions that they had answered on a weekly basis (Appendix G:154-156). In this study there was not an initial day workshop. Instead, the eight psychoeducation sessions were preceded by a total of eleven individual contacts with the family members which included individual family sessions, sessions with the parents alone and the son alone.

Having concluded this study, the writer introduced some changes, and the Four Phase programme was developed which will be discussed in the following sections.

4.4.2 PHASES OF THE MULTIPLE FAMILY GROUP STUDY

Broadly the intervention consisted of four phases.

4.4.2.1 PHASE ONE

This was a **preparation phase.** The purpose was to negotiate entry into the hospital community (Henderson & Thomas,1984:35-39). This phase consisted of the following:

* Permission was granted to conduct the study at Valkenberg Hospital.

* The chief social worker assisted in identifying a target population.

* Contact was made with four consultants. An outline of the programme and selection criteria were given. The possible benefits to the families were discussed. Permission was requested to recruit patients from their wards. This process was then repeated with the social workers, nursing staff, registrars, medical students, occupational therapists and a clinical psychologist who were involved in the admission wards.

* Access to the patients' files was obtained and discussions with the relevant therapists were undertaken to ascertain suitability.

* The questionnaires were developed.

* Speakers for the one day workshop were approached to negotiate their input on that day.

4.4.2.2 PHASE TWO

This was an **assessment phase** in which the sampling took place. It consisted of the following:

* Contact with the families was established. Ideally contact should have involved a family interview but, due to the difficulty in having families together for an interview, this was not possible. Parents of two families and the mother of one family were interviewed at the

hospital. Parents of another family were contacted separately by telephone only. A mother and maternal grandmother were interviewed at the maternal grandmother's home. The grandmother was close to the patient with schizophrenia and the father was not able to attend any of the programme due to work commitments. It was agreed with Families A and C, that the siblings, who were under twelve years of age, would not attend (O'Shea et al,1991:39) the programme. All those contacted who were available then provided information about the family.

* Permission was granted by the participants for the use of an audiotape.

* Confidentiality was ensured as families would remain anonymous.

4.4.2.3 PHASE THREE

This was a **one day workshop** and consisted of the following:

* Information which was given on the illness (McFarlane in Gurman & Kniskern,1991:374), resources (Simon et al,1991:327; Winefield & Harvey,1994:558) and how to cope in a crisis (Iodice in Turner,1995:508). A consumer gave input on her experiences in terms of living with her family.

* Questions from the families and discussions took place.

* Informal discussions at the lunch break were held with presenters and family members (McFarlane in Gurman & Kniskern,1991:375).

4.4.2.4 PHASE FOUR

This was the **focus group session phase** and consisted of the following:

* According to Folch-Lyon & Trost (1981:444) a focus group can be defined as "a discussion in which a small number (usually six to 12) of respondents, under the guidance of a moderator, talk about topics that are believed to be of special importance to the investigation".

* Six focus group sessions each lasting about 75 minutes, in accordance with a programme outlined by O'Shea et al (1991:39-41). Each session consisted of a socialisation phase and a work phase. The work phase began with input around the topic for the day, during which members were encouraged to ask questions and make

comments. This was followed by a discussion which focused on where families felt they were coping.

* In keeping with the purpose of the focus groups, there were opportunities to share knowledge, affirm families, challenge them to become more effective and to develop a core support network (McFarlane in Gurman & Kniskern,1991:373; Spaniol et al,1992:345). In a focus group, members are better able to share behaviours and attitudes with those who they feel share the same concerns (Folch-Lyon & Trost,1981:445).

* Some homework assignments were given to facilitate the practising of skills and the inclusion of the absent family members (Solomon et al,1996:45).

* The introduction of a new theme for each session. The themes were as follows:

- Session 1. Support
- Session 2. Communication
- Session 3. Roles and Boundaries
- Session 4. Problem solving
- Session 5. Contracting desired behaviours
- Session 6. Summary of sessions and evaluation.

4.5 DATA COLLECTION

Data was collected as follows:

* Biographical data of the patients and their families was obtained from the patients' files and semi-structured interviews with the families (Grinnell,1985:313-316) in order to present a profile of the families (Appendix A:81). The semi-structured interviews allowed for the development of a working relationship with the families (McFarlane in Gurman & Knniskern,1991:374). This data was collected in Phases One and Two of the study.

* Before the workshop commenced, in Phase Three of the study, participants were requested to complete the pre-test questionnaire (Appendix B:83) in order to obtain biographical details of the participants (Section A:81) Data concerning their knowledge of schizophrenia, their family functioning and support networks were recorded qualitatively in Section B:81 and quantitatively in Section C:86. Section D:88 recorded suggestions families wanted to discuss.

* Data from the workshop was obtained from transcripts of the presenters' talks (Appendix D:97). This took place in Phase Three of the study.

* Data from audiotapes and written material of the six focus group sessions were recorded according to the themes for the sessions (Appendix E:113). This took place in Phase Four of the study.

* After the final focus group session, participants were requested to complete the post-test questionnaires even if they have not attended the whole programme (Appendix C:89). This formed part of Phase Four of the study.

4.6 DATA ANALYSIS

The analysis of the data included the classifying of data and then manipulating this for the purpose of answering the research question (Rubin & Babbie,1993:92).

The data was analysed as follows:

* Biographical data from the files and data from the semi-structured interviews were tabulated and discussed.

* Biographical data from Section A of the pre- and post-test questionnaires were tabulated and discussed.

* The inputs from the one day workshop have been transcribed and discussed in relation to the literature.

* Data from the audiotapes and written material have been selected to highlight certain contributions. This has been discussed and interpreted in light of theory.

* The group process itself has been evaluated in relation to the literature.

* Attention has been given to "drop out" rate in light of available theories.

* Data from Sections B and C of the pre- and post-test questionnaires has been compared to determine what changes have taken place. The qualitative material has been tabulated and discussed in light of the literature. The quantitative material has been tabulated and statistical tests for significance have been applied. This material was grouped according to the themes that constitute family functioning (See ChapterThree:25-31).

* Data from Section D of the pre- and post-test questionnaires have been discussed.

* The major findings of the one day workshop, the six focus group sessions and the questionnaires were triangulated in order to evaluate the extent to which the psychoeducation programme was effective.

4.7 LIMITATIONS OF THE STUDY

Limitations may be present in the following areas:

a) The study sample.

i) An availability sampling procedure was used which meant that a final suitable sample could not be guaranteed. Initially the sample size was adequate (O'Shea et al,1991:39) but due to a "drop out" the sample size was small, rendering generalisation difficult.

ii) Commitment of the participants needed to be sustained over a seven week period. In this time the participants' circumstances changed and impacted on their ability to attend the whole programme. This affected the internal validity of the study.

iii) The families had vastly different experiences which rendered the group too heterogeneous. The ages and genders of those with schizophrenia varied which could have negatively impacted on the way in which families were able to benefit from sharing experiences.

iv) The study was conducted in English and those who could not understand English were excluded. This study, therefore, could not be generalised to other language groups.

v) Only White and Coloured people were available to be selected. Therefore, the study could not be generalised to people of other races.

b) The research design.

i) The one day workshop. In this early stage participants may not have felt comfortable asking questions and benefit may have been difficult to ascertain.

ii) In the focus group sessions there was not a co-facilitator and the writer felt that her inexperience in conducting focus groups may have negatively impacted on the group.

iii) The pre- and post-test questionnaires provided for a wide range of information to be gathered in both a qualitative and quantitative way. However, the questionnaires were long and some fatigue could have set in, thereby giving rise to "faulty" responses.

iv) The questionnaires did not permit for changes that might have been accounted for by:

- unique events that could have taken place concurrently with the programme, such as, a television programme on schizophrenia (Huyshamen,1981b:96).
- the Hawthorne effect in which participants, knowing they were part of a study, wanted to give the best performance (Huyshamen,1981b:97)
- a Halo effect which might have been present in those rating scales that could not be verified by the descriptive component (Rosnow & rosenthal,1996:407).

In this respect, internal validity might have been compromised.

v) Through the test-retest method there was an attempt to establish reliability.

4.8 SUMMARY

This chapter has laid out the research design, the sampling, the programme development and content, the method of data collection, data analysis and the limitations of the study.

In the following chapter the research findings will be presented and analysed.

CHAPTER FIVE

PRESENTATION AND DISCUSSION OF FINDINGS

5.1 INTRODUCTION

The presentation of findings focuses on five major, inter-related components of this study.

For purposes of clarity the findings are be presented as follows:

i) Biographical details of the families and participants

ii) Observations and discussions of the One Day Workshop

iii) Results of the six Focus Group Sessions

iv) Results of the pre- and post-test Questionnaires

v) Triangulation and discussion of major findings

5.2 PRESENTATION OF FINDINGS

5.2.1 BIOGRAPHICAL DETAILS OF THE FAMILIES AND PARTICIPANTS

The biographical details of the families were obtained from the questionnaire in Appendix A:81. The biographical details of the participants were gathered from Section A of the pre- and post-test questionnaires (Appendices B:83 and C:89). This has been presented here in order to familiarise the reader with the participants.

Five families agreed to participate in the study. Initial data was gathered from the hospital staff and patient's files and then verified with the parents.

5.2.1.1 BIOGRAPHICAL DETAILS OF THE FAMILIES

Table 1. Family Profiles of the Sample

Identifying data	Family A	Family B	Family C	Family D	Family E
Family Composition	Mother, father, index patient and two younger sisters	Mother, father index patient and two younger brothers	Mother, father older brother and sister and index patient	Mother, father, index patient and younger sister and brother	Mother and father. Three half brothers and three half sisters. Index patient is the youngest
Members of the Household	As above	Mother, father, index patient and three unmarried paternal uncles	Mother, father and index patient	Mother, father, index patient and brother	Mother and index patient. Father lives on his own
The Index Patient	17 years of age. In Std 9. Male. First breakdown 1995. Three admissions.	29 years of age. Female. First breakdown 1985. Eight admissions	27 years of age. Female. First breakdown 1995. One admission	25 years of age. Female. First breakdown 1996. One admission	32 years of age. Male. First breakdown 1987. Numerous admissions
Factors Precipitating Most Recent Breakdown	Father shot in PAGAD rally	Non-compliance with medication	Unknown	Unknown	Cannabis use
Effects of Illness on Family	Concerned about future	Concerned about future	Fear to leave her alone	Worried and confused	Angry
Attempts by Family to Cope	Helped to resume school	Try to reason with patient	Read about the illness. Joined a support group	Obtain information from the Internet	Try to dissuade from cannabis use
Needs of Family	Learn more	Compliance with medication	Learn more	Establish prognosis	Learn more about effect of cannabis
General Assessment of Family	Close family	Concerned	Concerned	Distressed	Fragmented

DISCUSSION

From Table 1, it can be shown that:

* Of the five families, four parents have been married once only and were still living together. In Family E both parents were married previously and have separated from each other.

* Two index patients were first children in families of three children. Two index patients were the youngest of three children. One index patient was the youngest of both parents' marriages and the only child of their present marriage. The average age of the index patients was 26 years and the average age of first breakdowns was nineteen years. The number of breakdowns varied from one to "numerous" over an eleven year period.

* Factors precipitating the most recent breakdowns varied from stressful events to cannabis use and non-compliance with medication.

* The effects of the illness on the families suggested concern, fear, anxiety, confusion and anger.

* The families all reported constructive attempts to cope.

* There was a general need for the families to learn more.

* The general assessment of families indicated that there was concern about their family members. In the family where the diagnosis had just been made, there was distress. In the family where the marriage had broken up, the index patient had had numerous admissions, there had been cannabis use and the family was fragmented.

* In terms of gender distribution of the index patients, there were three females and two males.

5.2.1.2 BIOGRAPHICAL DETAILS OF THE PARTICIPANTS

Table 2. Families' assigned reference letter, Individuals' assigned number, Nature of relationships to index patient, Age, Source of income and nature of work and Religion.

Families' assigned reference letter	Individuals' assigned number	Nature of relationships to index patient	Age	Source of income and nature of work	Religion
Family A	1	Mother	38	Clerk	Muslim
	2	Father	38	Builder	Muslim
Family B	3	Mother	65	Pension	Christian
	4	Father	66	Pension	Christian
Family C	5	Mother	51	Doctor's receptionist	Anglican
	6	Father	54	Researcher	Congregational
Family D	7	Mother	45	Hotel receptionist	Catholic
	8	Grandmother	68	Pension	Church of England

DISCUSSION

From Table 2, it can be shown that:

* Family E did not attend the programme and therefore, did not complete the questionnaires.

* There were more female caregivers that male caregivers
* The average age of the participating parents (excluding the maternal grandmother) was 51 years.
* Three participants (37,5%) were in receipt of a pension and five (62,5%) were employed.
* Two participants (25%) were of the Muslim faith and six (75%) were Christian.

5.2.2 OBSERVATIONS AND DISCUSSION OF THE DAY WORKSHOP

The transcript of the talks given at the Day Workshop is given in Appendix D:97

Families A, B, C and D attended the Workshop. The brother of the Index Patient in Family C and his girlfriend requested to join the workshop only. As they lived out of Cape Town they were not able to attend the Focus Group Sessions.

OBSERVATIONS

The following **observations** were made:

* The psychiatric registrar pre-empted questions about the causes of schizophrenia and so was able to address parents' feelings of responsibility for the illness. She did not give a list of symptoms but described these in everyday language (Dreier & Lewis,1991:12). She stressed the importance of medication and this created the opportunity for a lively discussion about medication and other forms of treatment (McFarlane in Gurman & Kniskern,1991:374).
* The Valkenberg social worker gave input on resources and stressed the role of the families as a resource. In this way their efforts were affirmed and their important role in keeping their family member mentally healthy, was supported.
* The input by the community sister was intended to help families when faced with a crisis. In trying to make her point she informed the group that in the future, the patients will be seen in the community and no longer at Valkenberg Hospital. Prior to this the families had had no idea about these developments and this seemed to create uncertainties for them.
* A member of Fountain House, as a consumer of mental health services, gave input on her expectations of her family. Participants asked her questions. She made the point that

although she has schizophrenia, she does not like her family to take over from her and do every day activities for her.

* During the lunch break participants met informally with hospital staff which helped to "solidify their social relationships" (McFarlane in Gurman & Kniskern,1991:380).

DISCUSSION

The workshop provided the opportunity for families to engage in discussion with each other, hospital staff and a consumer. This was a beginning of reducing isolation and building group cohesion (McFarlane in Gurman & Kniskern,1991:380). There was an attempt to enable families to experience "compassion and understanding" (Nichols & Schwartz,1991:490).

McFarlane in Gurman & Kniskern (1991:374) suggests that the treating clinicians meet with the families. In this programme, this was not possible due to staff commitments elsewhere. This may have hampered the families' sense of connectedness and commitment to the programme.

5.2.3 PRESENTATION AND EVALUATION OF THE SIX FOCUS GROUP SESSIONS

There were six focus group sessions that were held on a Saturday at Valkenberg Hospital. Attendance at the sessions was as follows -

Table 3. Attendance of respondents at the psychoeducation programme

Number of Respondent	Attendance at Day Workshop	The Actual Group Session attended	Total Number of Focus Group Sessions Attended
1	1	1, 2 ,3, 4, 5, 6	6
2	1	2	1
3	1	3, 4 ,5, 6	4
4	1	3, 4, 5, 6	4
5	1	1	1
6	1	1	1
7	1	2	1
8	1	2	1

DISCUSSION

Of the eight participants who joined the programme, only three participants (37,4%) attended more that the one day workshop and one focus group session.

5.2.3.1 FOCUS GROUP SESSION ONE

Present: The mother of Family A (respondent One) attended. Her husband was not able to attend due to work. Family B (respondents Three and Four) had given their apologies due to a prior church commitment. Both parents of Family C (respondents Five and Six) attended. No one from Family D (respondents Seven and Eight) attended. On follow up of absenteeism, Family D had gone away for the weekend.

Content theme: Support

Highlights of the session were as follows:

* The mothers asked after each one's adult child with schizophrenia.

> "How is you daughter today.....is she coping nicely?" (Respondent One)
> "She seems a bit better today.....she doesn't lead a normal life but copes up to a point and your son" (Respondent Five)?
> "To me he is fine.....he is so different" (Respondent One).

* Respondent Six required clarity about the role of the writer and the purpose of the programme.

* The parents expressed a need to talk about medication.

* The inclusion of the index patients was discussed.

> "I did not think that it would be appropriate for him to be here.." (Respondent One).
> "My daughter was resentful that she was not invited.....I said that she could have come today" (Respondent Five).
> "She could certainly have come" (Writer).
> "If they feel that they are well enough" (Respondent One).

* An outline of the programme was given.

* The theme for this session was introduced. One parent talked about her daughter's isolation:

"There are a few friends that she will go and visit. She doesn't go out in crowds. She doesn't like going to the shops. She won't go to the cinema" (Respondent Five).

* After the mothers exchanged their experiences the writer affirmed the families' efforts to assist their adult children to experience being supported (McFarlane in Gurman & Kniskern,1991:376).

* There was an attempt to facilitate the group being experienced as a place, where people who have had similar experiences might have been able to draw support (McFarlane in Gurman & Kniskern,1991:365). Comments from the mothers were as follows:

"Families have spoken about friends who have let them down, [friends] who are embarrassed" (Respondent Five).
"They [friends] know about it [schizophrenia] but then often they don't say anything" (Respondent One).

* The writer quoted from an article written by a clinical psychologist about his feelings about support when his own son was diagnosed with schizophrenia (Johnson.1995:47-48).

"Nothing in my training prepared me to cope with psychosis in a family member.....Most [families] have suffered their bewilderment and grief in isolation as they have realized that their family member has a serious mental disorder".

The writer then added

"How very isolating this illness can make people become because there is sometimes so much focus on trying to care for this person that one's own interests, parents' interests, connections to friends get put onto hold."

* Parents talked about the difficulties about continuing with leading ordinary lives. This led to a discussion on how the member of the family could begin to separate from the family in terms of accommodation and employment.

* The difficulties facing families were acknowledged and it was suggested that the following session would be focused at looking at the practical issues of daily family life (Liberman,1994:112).

Evaluation: There was a need for parents to just talk with each other and so the programme for the day was shortened. This was done to facilitate support and information sharing within the group (McFarlane in Gurman & Kniskern,1991:367). The

family of respondent One tended to keep the diagnosis a secret and they seemed somewhat emotionally isolated as described by Leff in Bennett (1991:203) and McFarlane in Gurman & Kniskern (1991:367). The other couple had an older daughter and were well connected to empathic community resources.

Although the communication was still fairly restricted in keeping with the beginning phase of a group there was already some member sharing of concerns (Yalom,1975:305). Although the constellation of life experiences were quite different in the two families represented, sharing experiences of living with their own adult children with schizophrenia, created a sense of universality and support (Gurman & Kniskern,1991:365). This is an important curative factor of a group experience (Yalom,1975:9).

5.2.3.2 FOCUS GROUP SESSION TWO

Present: Both parents of Family A attended. The mother and maternal grandmother of Family D attended. Parents of Family B and C failed to attend.

On follow up Family B needed to walk two kilometers to a bus stop on a Saturday. Due to heavy rain, they were not able to attend. They were sad to miss this session and had tried to contact the hospital to give apologies but had forgotten in which ward the sessions were being held. Family C said that as they were about to start a new business venture they would not be able to attend. No family members with schizophrenia attended.

Content theme: Communication.

Highlights of the session were as follows:

* The members were welcomed and reintroduced to each other.

*. There was a summary of the previous session.

* The topic for the day was introduced. It was pointed out how this session would become an integral part of future sessions.

* Respondent Seven needed to talk about her feelings about her daughter's new diagnosis of schizophrenia. She talked about how her daughter had changed slowly and had become "antisocial". Respondent Two talked about his son.

> "We watch him every day..we know his ways... your case is different."
> (Respondent Two)
> "We can't watch her.....we mustn't worry too much about it"
> (Respondent Seven).

* The input followed the programme as outlined in Appendix E:114.

* An explanation was given of what communication is (McFarlane in Gurman, & Kniskern1991:369) . The importance of effective communication and the relationship between attention and arousal was explained (McFarlane in Gurman & Kniskern, 1991:367-368).

* Communication difficulties for a person with schizophrenia were related to quantity of information, complexity, intensity and negativity (Leff in Bennett,1991:202; McFarlane in Gurman & Kniskern,1991:368). The members contributed to these concepts with practical examples and this led to some discussion. Non-verbal communication as a means of communicating was stressed. The parents of Family A talked about how they communicate. The mother is more involved with the children and the father who

> "....doesn't bother as much" (Respondent One).

* Members were then invited to share examples where they were managing in this regard or where they felt that they needed to change. The mother of Family A said,

> "I just shout.....I have to watch myself.....The tone of voice - that is absolutely the nagging for him" (Respondent One)

* The members then felt that they could become more effective if the message was positive and they showed respect in their communication. Added to this were suggestions of specific, clear, concrete and relatively emotion free communication (McFarlane in Gurman & Kniskern,1991:369).

* This was followed by a short discussion initiated by the maternal grandmother of Family D (Respondent Eight) who was amazed that despite all the problems people with schizophrenia have

> "you would not think that there was anything wrong with them"
> (Respondent Eight)

* There was an attempt by the members to reframe the devastation that schizophrenia can create.

Evaluation: The mother of Family D seemed anxious and at times intimidated by the forceful way in which the father of Family A talked (O'Shea et al,1991:42). There was a sense that there were differing needs. This session challenged the ways in which members communicated in their families and there appeared to be a development of insight. Interaction was at times restricted. Family A wanted to need to talk about a range of issues while Family D seemed anxious, hesitant and puzzled (Yalom,1975:304). The atmosphere however was generally congenial.

5.2.3.3 FOCUS GROUP SESSION THREE

Present: Mother of Family A, the parents of Family B. The other two families were absent. In follow up, the parents of Family C had decided that due to their new business commitments they would not be able to attend the remainder of the programme. The writer suggested that they already had support and were quite knowledgeable. The mother of Family C agreed. The maternal grandmother in Family D reported that her daughter (Mother of Family D) was experiencing much hardship at that time. She seemed to have taken all the worries of the daughter with schizophrenia on her shoulders. The maternal grandmother had tried to persuade her daughter to continue but she did not think that she would. The maternal grandmother in such an event, reported that she would drop out also. She was reassured that she would be welcome should she wish to return. The mother of Family D confirmed that she was too stressed at the time, although did not elaborate. She added that she had felt quite depressed listening to the other family and she could not face that her daughter could become so disabled. Her need for time to process the implications of a diagnosis of schizophrenia were acknowledged. She was assured that she would be welcome to return should she feel able to do so. A suggestion was also made for her to consider consulting with someone to help her over this difficult time and that her husband may also benefit. Both families did not return although they agreed to complete the post-test questionnaires. The mother of Family C however, did not do this.

Theme content: Roles and boundaries

Highlights of the session were as follows:

* The members were welcomed and Family B talked about their difficulty getting to the group if it was raining. The mother of Family A offered to provide transport in future.

* The content of the previous week's session was summarised. The mother of Family A reported trying not to nag.

* The topic for the day was introduced. The input was given according to guidelines in Appendix E:117.

* Roles were talked about in terms of how they change over time and the expected, permitted and prohibited behaviours of each role (Kisker,1984:124-129; Spaniol et al,1992:345). Problems with clarity of roles were linked to stress and how this is communicated.

* Attention was given to the family as a system and how the subsystems are divided by boundaries (Minuchin,1985:51-60; McFarlane in Gurman & Kniskern,1991:368-369). These should be clear but become problematic when rigid or too open. This was illustrated on newsprint. The role of stress was highlighted again.

* Members were then encouraged to contribute what they thought that they were doing to ensure clear roles and boundaries. They suggested the following -

> "Tone of voice, expression, respect, space and no nagging"
>
> (Respondents One, Three and Four).

* The members shared that their adult children needed to be alone sometimes. This was linked to the need to not create too much stimulation / arousal. Emotional space was talked about and due recognition given to mother of Family A who was trying to improve on this.

* The members talked about how time consuming the ill member could be and recognised the need to give the other family members time as well as the spouse. Respondent One said that it had been so long since she and her husband had been to the movies. Family B said that they go to church together. There was a linking of the issue of support from outside of the family.

Evaluation: The mention of no nagging which had also been referred to in the previous session was a positive development in terms of reducing expressed emotion (McFarlane in Gurman & Kniskern,1991:369). Respondent One assumed a leadership role in the group. She contributed well and by this stage was prepared to really work. She became supportive of Family B and she seemed to take role of ensuring the group's survival. Family B seemed to connect well with this member. This group was active and participatory. There was an experience of a close bond forming (Douglas:1979:69-70)

5.2.3.4 FOCUS GROUP SESSION FOUR

Present: The mother of Family A and parents of Family B

Theme content: Problem solving

Highlights of the session were as follows

* The issue of absentees was addressed. Information was given for the reasons that the members had given for not being able to return..

* The previous sessions were briefly summarised. Members were requested to make comments or ask any questions about these sessions. Mother of Family B (respondent Three) said that she had tried not to nag and that

> "Debbie is 100% better off" (Respondent Three)

The mother of Family A (respondent One) reported,

> "I think about this all the time. This past week I've been very calm - it actually helped a lot. Because I spoke a lot to my husband.....On Thursday we went to the movies to be together. We have neglected our love life because of [son's] illness" (Respondent One).

* These efforts were acknowledged. The issue of stress in the family was raised again and the positive effects of being calm.

* The theme for the day was introduced (Leff in Bennett,1991:201; O'Shea et al,1991:40). Effective problem solving was linked to remaining calm and thereby reducing stress. The input was based on the programme outline in Appendix E:120.

* During this session the mother of Family A (Respondent One) stated

> "In the beginning I didn't know that this is the kind of things that also affect people with schizophrenia. But since I was coming here it also taught me that maybe that's why he [son] lands up in hospital" (Respondent One).

Family B were able to relate their own experiences of problem solving at times effective and at times not.

* During the generation of alternatives another alternate was added to those in Appendix E:122-123 by the group members. There was a suggestion that the family member is asked how he/she is feeling when parents notice that he/she is not well . The advantage of this would be that they could demonstrate

> "understanding, support and love" (Respondent One)

* The group agreed to take a homework assignment on problem solving to do with their families. Added to the format outlined was an added point - "What opportunities for growth do you think there are?" In this way those attending were able to impart their new knowledge to the family as a whole.

Evaluation: Respondent One indicated an improvement in the parental subsystem which can suffer when a family member has a chronic illness (McFarlane in Gurman & Kniskern,1991:369). Respondent Three also indicated her attempt to reduce expressed emotion. In this group, members began to share areas of where they would like to improve. The trust in the group seemed to be growing in keeping with the problem-solving stage of group development (Northen, 1969:192). Insight into the effects of communication was demonstrated.

5.2.3.5 FOCUS GROUP SESSION FIVE

Present: Mother of Family A and parents of Family B.

Theme Content: Contracting desired behaviours

Highlights of the session were as follows:

* The members began by reporting on what this group had meant to them.

> "We should have more of these groups" (Respondent Four).
> "You learn a lot about the illness....if you don't go to a group you won't learn" (Respondent Three).
> "I'm now so aware..... I've really learnt a lot" (Respondent One).

* The homework assignments were discussed. Family B struggled with the strategy for problem solving but raised the issue that sometimes problem solving required negotiation. Family A had come together as a family and their son with schizophrenia had identified a problem that the family jointly tried to resolve. The problem was one of communication. It was felt that this could be resolved by feeling free to express himself. The opportunities for growth that successful resolution could facilitate, would be success in business and human relations.

* The theme for the session was introduced and followed the format in Appendix E:124 . Members felt that ensuring that rules are adhered to, is a family responsibility. Coercion was decided against, and the distinction between bribing and reward was discussed in the group. There was input on the difference between punishment and discipline. This was followed by a discussion on the role of parents setting an example.

* In the general guidelines for negotiation mother in Family B stressed how important it was for her to listen to her daughter (Dougan et al,1986:90). In so doing she was processing the loss of a mentally healthy child.

> "I've learnt to understand, to listen to her. I must answer her. It is very hard sometimes to answer her back.....The way she was.....They say that God has a purpose for everything" (Respondent Three).

* There was an important discussion on what to do when the situation cannot be changed. Parents explored ways in which they could accept difficulties without a sense of defeat (Leff in Bennett,1991:202).

* Handouts were given to the members (Appendix E:128-129).

* A homework assignment concerning negotiation was agreed upon.

Evaluation: The members worked well in this session The programme for the day was too full and the concepts were quite difficult. This session should have been spread over at least two sessions. The problem was raised about what would happen to the adult child

when the parents have passed away There was not sufficient time to deal with this very pertinent concern (O'Shea et al,1991:43). However, there seemed to be a sense of hope emerging - another curative factor of groupwork (Yalom,1974:6-7). There was a realisation that the group was to come to an end.

5.2.3.6 FOCUS GROUP SESSION SIX

Present: The mother of Family A and the parents of Family B.

Theme content: summarisation and evaluation

Highlights of the session were as follows:

* The parents of Family B had not understood the homework assignment and had decided to reflect on their experiences using one of the pamphlets as a guide (Appendix E:129). In response to "recovery takes time" they wrote

> "Its so really sad but we as parents must accept things as they come our way" (Respondents Three and Four).

In response to "Create space. Stay calm" they commented on how staying calm had made a difference. The father said

> "That I also learnt now.. Before I used to shout at her. But nowadays I just see it doesn't help....I talk to her nicely. Then she understand me" (Respondent Four).

They commented on the difficulties they encountered when their daughter needed to be readmitted. They felt that the person with schizophrenia should be treated as a normal person. There was further discussion on stress. They needed to talk about the difficulties they experience in gaining access to the doctors.

* The mother of Family A said that she had also not done the homework assignment but had written a letter instead that she said could be read to the group. She commented thus:

> "I can truly say that these 8 weeks have left me with a remarkable sense of hope and self discovery.....I have learnt that one cannot always control what happens in your life or your families but you can surely control how to deal with it" (Respondent One).

This mother talked about some of her concerns as her son tries to adjust to every day life.

* The sheets of newsprint from all the sessions were put up about the room and briefly referred to.

* The questionnaires were given to each member.

Evaluation: There was a sadness that the group was ending. Because of the fairly structured nature of the programme, there was too little time to deal with personal concerns as described by O'Shea et al (1991:43). This was evident in the material that the parents needed to talk about in this session. However, there was a feeling of hope.

5.2.3.7 DISCUSSION OF THE FOCUS GROUPS

* **THE GENERAL FORMAT** for each meeting was to provide an opportunity for families to talk about their experiences and then link their inputs to the topic of the day. This then stimulated discussion and was intended to serve the purpose of affirming families where they were being effective and also challenging them to rethink where they could become more effective. This was in keeping with the purpose of the focus group sessions (See Chapter Four:41). The homework assignments were intended to involve the family members who were not actually attending the groups. This was an indirect means of reaching them and could have been used more extensively.

* **THE DROPOUT RATE** was a striking feature of this programme. Of ten people who agreed to enter the programme, only eight started and three attended four or more focus group sessions (Table 3:49). This represents a 62.5% dropout rate. This is much higher than the comparable, brief psychoeducation programme conducted by Solomon et al who reported a 30% drop out (1996:44). The factors that could account for this are as follows:

a) Factors that relate to the families were as follows:

i) The daughter of Family D had just been given the diagnosis of schizophrenia. They all needed time to process this diagnosis it seemed that they were not yet emotionally available to engage in such a programme. This is in contradiction to the work by Goldstein

who favours intervention as soon as the diagnosis is made (Nichols & Schwartz,1991:488). However O'Shea et al (1991:36) describes this "resistance" and attributes this to denial. This would be more in keeping with the stage of denial in the process of loss (Kubler-Ross,1993). This is used as a defense against the pain of such a reality (Torrey,1988:279; O'Shea et al, 1991:36) which would signify the "ultimate separation" (Wolrond-Skinner,1981:35).

ii) In Family D only the mother and maternal grandmother were available as the father worked on a Saturday. During the programme period, the father of Family A needed to put business concerns ahead of such a programme and the parents of Family C began their own home industry.

iii) The parents who did not attend were separated and the mother insisted that the father attend on his own. The mother had been the primary caregiver and was angry with her son, her husband and the mental health system. She had attended groups previously and seemed to lack hope that any further intervention could help them. This concurs with O'Shea et al (1991:36) who cautions about those who have attended previous groups and have become disillusioned. Ambivalence to attend such a programme may have accounted for the difficulties to attend regularly and the "drop out" (O'Shea et al,1991:37).

iv) The parents of Family C seemed to be well supported and knowledgeable. Possibly they did not need such a programme. Their association with the Cape Support for Mental Health Group which also has an advocacy function, is an indication of this (McFarlane in Gurman & Kniskern,1991:387).

v) The parents of Family C had a problem leaving their daughter on her own and Spaniol et al (1992:343) refers to the draining effects of caring for someone with a chronic illness.

b) Factors that relate to the programme were as follows.

i) The programme as designed by the writer, was intended to meet a need of families to learn more about coping with the illness. However a major shortcoming was that there was not sufficient time to deal with specific issues that trouble families. There was inadequate processing of unresolved emotions around the meaning of schizophrenia and its impact on the lives of the families concerned. This was evident in the last session when

there seemed to be a need to talk about a range of problems and concerns. Anderson et al (1980:495) cautions that this could be a problem for some.

ii) In terms of the process, the joining phase should have occurred over time and been characterised by support and empathic listening (McFarlane in Gurman & Kniskern,1991:374). The parents of Family E, who did not attend, and the parents in Family B were interviewed face to face. Only the wife of Family A was interviewed and so an alliance was not created with the father before the beginning of the programme. In Family C contact was only telephonic to the mother and father separately due to lack of time. O'Shea et al (1991:38) made telephonic contacts and he points out that about 60% to 75% of people contacted telephonically and who agree to attend, drop out during the programme. The essential relationship building was not done at this stage. In Family D the father was not available and it seemed that the burden for the family was being carried by the mother, who required more support than the group was able to give her at the time.

iii) Access to Valkenberg Hospital was difficult for those who relied on public transport. Access was made more difficult due to the rain, which can be expected from in Cape Town during September and November.

c) Factors that relate to the multiple family group format were as follows:

i) While the group format was experienced as supportive by the two families who remained in the programme, the mother in Family D felt intimidated and she reported feeling depressed listening to how disabled others had become (O'Shea et al,1991:42).

ii) There were different levels of understanding and coping with schizophrenia that may have rendered the group too heterogeneous for effective intervention and member satisfaction. According to Northen (1988:95) "groups should be homogenous in enough ways to insure their stability and heterogeneous in enough ways to insure their vitality".

d) Factors relating to the therapist were as follows:

i) The writer (as therapist) felt that her inexperience in both family therapy and groupwork may have played a factor in reducing member confidence, especially in the family who were already very knowledgeable. This lack of experience resulted in the writer relying too

much on the educational aspect of the designed programme leaving too little room for spontaneity.

5.2.4 PRESENTATION AND DISCUSSION OF THE PRE- AND POST-TEST QUESTIONNAIRES

The **purpose** of the pre-test questionnaire was to obtain a baseline of data relating to the level of knowledge of schizophrenia and family functioning in families in which a member had schizophrenia . This questionnaire was completed by eight respondents.

The **purpose** of the post-test questionnaire was to determine the differences in the above data after the completion of the day workshop and six focus group sessions (Grinnell,1985:250). This questionnaire was completed by seven respondents.
The results of the questionnaires have been presented in Appendix F:132.

The presentation and discussion of the findings have been made in accordance with the families' knowledge of schizophrenia and the main areas of family functioning that the psychoeducation programme focused on.

5.2.4.1 KNOWLEDGE OF SCHIZOPHRENIA

There was some increase in the knowledge of schizophrenia (Table 4:132). However the inability of 37,5% of respondents to give more detail about their knowledge is in keeping with the difficulties people have in really understanding this illness (Torrey,1988:73).
The increase in the understanding of the family members of respondents Three and Four may be accounted for in the work they took home to do with the family (Table 5:133).
According to the rating scale, there appeared to be a general shift in respondents to having a better knowledge, although this was not statistically significant (Table 26:147; Table 43:152 and Table 44:153)

5.2.4.2 EXPRESSED EMOTION

In this section the expression of anger, criticism and emotional overinvolvement were explored According to such writers as Leff & Vaughan (1985a:95), Leff in Bennett (1991:195-198) and Nichols & Schwartz (1991:487-486) the level of expressed emotion is an indicator of relapse rates. In this study there was an improvement in **managing and expressing anger** for those who remained in the programme (Table 12:137; Table 13:138). Respondents Three and Four indicated that they had become more calm. The reports of inappropriate expressions of anger in respondents Two and Eight may have been due to increased self awareness. In terms of the mean scores for respondents' **attempts to communicate anger in a healthy way,** there was a trend to a perception that this had improved. However, these results were not statistically significant (Table 31:148; Table 43:152 and Table 44:153).

In terms of **managing criticism** and **communication of criticism** there was no indication of high expressed emotion before or after the programme. Respondents Three and Four did not respond initially but at the end, said that they communicated criticism with calm and quietness (Table 14:138 and Table 15:139). Although there were no significant changes, the two questions dealing with criticism were answered by all the respondents in the Post-test questionnaires. This may be an indication that there was an increase in the level of knowledge and insight. According to the rating scales, there was no change in the mean scores and this was not statistically significant (Table 32:148; Table 43:152 and Table 44:153).

There was a small improvement in emotional **overinvolvement** and this was supported by the trend in the rating scales (Table 16:140; Table 33:149; Table 43:152 and Table 44:153). The findings in terms of **over concern** and **over protection,** suggest an improvement in the participants. Respondents Three and Four both shifted from being over concerned to less concerned and attributed this to their attendance at the group sessions (Table 17:140; Table 18:141). According to the mean difference on the rating scales there was a decrease in over concern and over protectiveness and both these results

were statistically significant (Table 34:149; Table 35:149; Table 43:152 and Table 44:153). These factors may have been strongly influenced by Elaine who has schizophrenia and spoke at the workshop about her need to become independent and not to be treated as an invalid (Appendix B:110). Over concern and over protection may also be more eloquently expressed by parents of daughters and adolescents. Keefler (1994:372) points out that overinvolvement is more resistant to change than criticism and hostility.

5.2.4.3 COMMUNICATION

In the respondents' **descriptions of communication** in the families, there was some positive development by the end of the programme. (Table 10:136). Respondents Three and Four who had initially reported that their communication was "very close" and "good", at the end stated that this was "calm". For them this was an improvement.

Respondents One, Two, Three and Four referred to **improving communication** by becoming more constructively involved with each other in ways that facilitated relatively conflict free interaction (Table 11:136). This view is also supported by McFarlane in Gurman & Kniskern (1991:369). There was little mention by the respondents in this section, on communication being clear, concrete and simple, as discussed in the focus group session Two (See Chapter Five:53). However, these concepts were expressed elsewhere. For example, this was mentioned in respect of expressing criticism and this is an indication of the overlap of themes. In the rating scale the question looked at the families' **attempts to solve issues by discussing these together as a family** and here there was a shift to an improvement in this area. The responses, however, were not statistically significant (Table 29:148; Table 43:152 and Table 44:153).

5.2.4.4 BOUNDARIES

In order to understand the nature of boundaries in the families it was felt that it would be useful to explore this in terms of who the respondents **turn to in a crisis**. On the assumption that boundaries may become diffuse in a family in which a member has schizophrenia (Nichols & Schwartz,1991:488) it was felt that crisis situations would

provide insight into subsystem structures. It would appear that the psychoeducation programme has the potential for strengthening the marital subsystem, which enables the index patient to cope better (McFarlane in Gurman & Kniskern,1991:369). Respondent One reported that it had been a long time since she and her husband had been to the movies (See Chapter Five:55). In the following session she reported that they had been to the movies during the week. Respondent Seven reported relying on herself initially and later reported that she talked to a friend as she was the strongest in the family. She was quite isolated and seemed to be struggling emotionally. She reported feeling depressed. (Table 19:142). In the rating scale the respondents' **openness with each other** was explored. This was an attempt to elucidate the quality of the boundaries. Although there was a shift to more openness, this question was too vague for any significance to be attached to it. Further, there was no statistical significance (Tables 30:148; Table 43:152 and Table 44:153).

5.2.4.5 ROLES

At the end of the programme there seemed to be more clarity about the participants' **contributions / roles** within the family. (Table 20:143). The father who had been unclear about his role, reported that he was now head of the household. The programme may not have been able to assume a role in this change, as he left the programme after the first focus group session. Generally, the women seemed quite clear about their roles even before the programme. Three women had nurturing roles and one had an organisational role. In the focus group session attended by respondents One, Three and Four, the discussion of roles included the importance of communication in establishing roles. Respondent One also reviewed her role of wife and companion to her husband in light of the energy that her caregiving role had assumed. This is an important development in terms of McFarlane's assertion that marital needs become subverted for those of the ill child (McFarlane in Gurman & Kniskern,1991:369). The total mean scores before and after the programme indicated that there was a shift to a **greater clarity about their roles**. There was also a shift to increased **confidence about the contributions** the

respondents made to the families. Neither of these two results showed statistical significance (Table 38:150: Table 39:150; Table 43:152 and Table 44:153).

5.2.4.6 PROBLEM SOLVING

In focus group session Five, respondents One, Three and Four gave an indication (Table 8:134) that they had worked through the problem solving strategy as discussed at the focus group session Four (See Chapter Five:56-57). Such an input provided for a systematic sequence of addressing difficulties. Their understanding of effective problem solving was essential to survive schizophrenia (Leff in Bennett,1991:20; McFarlane in Gurman & Kniskern,1991:369; Falloon et al,1993a:30-37). Problem solving was reinforced when families A and B undertook to do a homework assignment. This provided an opportunity to include family members not able to attend the sessions. The difference of the mean scores for the statement that **all problems were openly discussed by the whole family** (Table 36:149; Table 43:152 and Table 44:153) suggests that after the programme there was a move not to discuss all problems by the whole family. This finding was also statistically significant and may point to the fact that boundaries between the subsystems were becoming more appropriately defined. The statement that **only some problems were openly discussed by the whole family** (Table 37:150; Table 43:152 and Table 44:153) suggests that after the programme there was a move to only discuss some problems with the whole family. This finding, however, was not statistically significant.

5.2.4.7 BEHAVIOUR

There was a shift to more parental control in terms of **who sets the rules** (Table 21:143) and this is in keeping with the establishment of a calm and therapeutic home environment (McFarlane in Gurman & Kniskern,1991:369-370). The **means to ensure that the rules are adhered to** showed some improvement in how parents co-operate with one another (Table 22:144). The couples who reported that the family or the parents were **responsible for ensuring that the rules are adhered to**, are married. This may indicate clearer agreements in parents (Table 23:145). In terms of **consistency in ensuring that the rules are adhered to**, there was also some improvement (Table 24:145 The difference of the

mean scores for establishing **difficulties agreeing on accepted standards of behaviour**, suggested that there was a shift to greater ease in this respect. Respondents Six and Seven, who only attended one focus group session, indicated a deterioration in this respect. This result was not statistically significant (Table 40:150; Table 43:152 and Table 44:153).

5.2.4.8 FLEXIBILITY

The three respondents who did not respond to this question (Table 25:146) had not attended the full programme. Respondent One added that they had now accepted their "son as a schizophrenic". She attributed this to increased knowledge of the illness. The differences in the total mean scores of **difficulties in accepting change most of the time** (Table 41:151; Table 43:152 and Table 44:153), indicated that there was some improvement but was not statistically significant. The differences in the total mean scores for **ease in adapting most of the time** also indicated some improvement but this was also not statistically significant (Table 42:151; Table 43:152 and Table 44:153).

5.2.4.9 EXTENT OF ACCEPTANCE OF THE ILLNESS

In this section the process of loss was explored in asking what respondents **felt when they thought of their family member with schizophrenia** (Table 6:133). There was limited movement in this process. Respondent Three seemed to indicate that she should accept the illness but this response seems to have been based on a rational decision. Respondent Seven seemed to move from being both angry and sad to being sad and respondent Eight moved from being shocked to shocked and saddened.. The difference between the total mean scores for exploring the respondents **acceptance of schizophrenia,** suggests that the families were coming to accept their situations and this finding was statistically significant (Table 27:147; Table 43:152 and Table 44:153).

Although the qualitative and quantitative results do not correlate, it may be, that on an emotional level there was still a process of loss to be resolved until there could be an emotional acceptance of the illness. However, on a rational level, families may have

realised that the illness was permanent and that they needed to accept this, in order to effectively help their family members and themselves. Such acceptance may have been facilitated by the improved levels of flexibility indicated in Chapter Five:58.

5.2.4.10 SUPPORT

Respondents were asked to indicate **peoples, groups or organisations that gave them support** (Table 7:134). Generally respondents, both before and after the programme, indicated satisfactory formal and informal support networks. Most families were in a position to receive support which facilitated coping (McFarlane in Gurman & Kinskern,1991:369). However, Respondent Seven seemed to derive her only support from the psychiatrist placing her in an isolated position. She may have experienced great difficulties as she was fairly isolated and did not turn to her husband for support. Such a scenario has been described by Anderson et al (1980:493). In exploring the **appreciation of support** (Table 8:134; Table 43:152 and 44:153) the difference in the total mean scores indicated a shift to greater appreciation but this was not statistically significant.

5.2.4.11 RESPONDENTS' EVALUATION OF THE PROGRAMME.

Data for this section has been obtained from the post-test questionnaire, Section D.

i) Number of group sessions attended

Refer to Table 3:49.

ii) Motivation for attendance

The motivation to attend was to learn more about the illness according to five respondents (71,4%). One of these respondents added that she wanted to learn more about what to expect after the patient had been discharged. One respondent (14,3%) stated that motivation was out of concern for the index patient and one respondent (14,3%) wanted to give support to her family. It seemed clear that there was a need for psychoeducation.

iii) Indicated reasons for not attending

Three respondents (42,9%) stated that business commitments had prevented them from attending the programme. Within this group, one person also had unexpected family commitments. Previous church commitments and the weather accounted for non-attendance by two respondents (28,6%) and one respondent (14,3%) went away on holiday. The full programme was attended by only one person (14,3%).

Business commitments were reported by the majority of respondents for non-attendance. Although a Saturday over lunch time was preferred by the majority of people initially, over time this was not so. It may have been difficult for families to commit themselves for seven consecutive Saturdays as clearly there were prior plans and circumstances changed. Conducting such a group in winter in the Western Cape posed problems for people who needed to use public transport which, over weekends, tended to be infrequent. Elderly family members may have had real difficulties moving about in the rain.

iv) Other possible reasons for non-attendance

All of the respondents (100%) reported that, had their circumstances been different, they would have attended all sessions.

The Post-test questionnaire did not gather the full explanation as other reasons had been given at other times. One mother did not only have business commitments. On a previous occasion she had talked of her difficulties accepting the diagnosis. This concurs with Kubler Ross (1989) and Spaniol et al (1992:342) who refer to the mourning process which would have left her unavailable at this time for psychoeducation (Anderson et al,1989:493; McFarlane in Gurman & Kniskern,1991:367). She had also told the writer that she felt depressed at the extent of possible disability.

v) The extent to which the programme met the respondents' expectations

In Section D of the pre-test Questionnaire (completed by eight respondents) respondents were asked to indicate what they would like to learn or share in the programme. A need to learn more, was expressed by four of the respondents (50%). Three respondents (37,5%) did not answer this item and one respondent (12,5%) reported not needing to learn or share anything about schizophrenia. This question dealt with expectations in terms of learning or sharing only, and was too narrowly focused to ascertain any other expectations.

In the post-test questionnaire (completed by seven respondents) six people (85,7%) reported that the programme had met their expectations. Two added that it had exceeded their expectations, in that they had learnt more than expected and met "nice people". One respondent claimed that the programme had made her a more positive person who had learnt how to take control of some situations. Dreier & Lewis (1991:12) assert that when there is knowledge of the illness and techniques for management, mastery increases and guilt decreases. One person (14,3%) reported that his expectations had not been met, as he had hoped for more individual counselling. This highlights the importance of the initial family interview in which joining with the family should take place and such issues discussed. Due to time constraints this interview was conducted on the telephone on two separate occasions with the mother and the father. Although O'Shea et al (1991:38) indicate that this is a reality, it was not entirely effective.

vi) Opinions of the content of the programme as a whole.

Five respondents (71,4%) gave positive responses, with such comments as, "excellent", "very interesting", "informative", "learnt about schizophrenia in more detail" and that out of a broader knowledge of schizophrenia there was a better understanding of how to deal with a person with schizophrenia. The importance of encouragement was mentioned. One respondent (14,3%) reported that the content was satisfactory and one respondent (14,3%) felt he could not respond as he had not attended the whole programme.

vii) Opinions of the presentation of the programme

Six respondents (85,7%) gave comments such as, "wonderful", "exciting" "there should be more groups" and with attending the programme and increasing knowledge, the parents could contribute to keeping their family member well. One respondent (14,3%) reported that the presentation was "O.K.".

viii) Opinions of the group participation

There was a recognition by five respondents (71,4%) that meeting in a group was beneficial. One person added that it was a programme that every one in a similar situation should attend. One person added that she valued meeting others. One respondent (14,3%) said that it "tended to be taken over". At the only group session he attended, he was quite withdrawn and this may have reflected his need for more individual counselling. One respondent (14,3%) commented that through the group, she had realised how dramatically the life of the family members with schizophrenia had been changed by the illness. As the diagnosis had recently been made, this suggested that group participation may be premature for families in similar situations. However, for some participants, the group provided peer support (O'Shea et al,1991:42; McFarlane et al,1995a:128).

ix) Reported benefit from attending this programme

Two respondents (28,6%) developed a clearer understanding of the illness. One respondent (14,3%) reported a realisation that there were effective ways of managing their situations, such as encouragement, and avoiding shouting and pushing. One respondent (14,3%) developed a sense of calmness about the illness and was feeling less stressed. One respondent (14,3%) had become more confident in relating to his son. One respondent (14,3%) said the programme enabled a parent to take more positive steps and one respondent (14,3%) commented that she realised that she was not alone. This was important for someone who seemed fairly isolated.

All these responses were in keeping with the primary and secondary goals of psychoeducation (See Chapter Two:20) and have also highlighted the unique needs that each family had.

x) Aspects of the programme enjoyed the most

Two participants (28,6%) enjoyed everything. Two respondents (28,6) enjoyed the workshop the most. These two only attended one group session. One respondent (14,3%) singled out the session on communication. One respondent (14,3%) benefited from learning from others' experiences. One respondent (14,3%) commented that she did not find the programme enjoyable. This response needed to be understood against the background of a recent diagnosis. This person also seemed to be absorbing all the family stress on her own.

xi) Ways in which respondents may not have benefitted from the programme

Six people (85,7%) did not answer this question and one respondent (14,3%) said that she had lost some hope. O'Shea et al (1991:42) cautions that such a group can be intimidating. Again this highlights the possible difficulties parents may have after recently being given the diagnosis.

xii) Aspects of the programme enjoyed the least

Three people (42,9%) did not answer this. Two respondents (28,6%) were worried about transport. One respondent (14,3%) did not like the fact that people made "excuse" for not attending. This person had made the effort to come to every session. One respondent (14,3%) raised the issues of Valkenberg's long term plan to become a tertiary referral centre and the decentralisation of out patient services, not always staffed with doctors, to the community.

xiii) Recommendation of such a programme to other families

Six people (85,7%) said that they would recommend this programme to other families One respondent (14,3%) said that it needed to be developed into a programme. This person only attended one group session and unfortunately was not present for the entire time.

xiv) Recommendations for additions, omissions or changes in the programme

Three people (42,9%) did not answer this question. Two respondents (28,6%) said that they would liked to have "continued for good" and one added that in all the years his daughter had

been ill, this was the first time they had had such a group. One respondent (14,3%) said that she would like to have brought anybody to the group. One respondent (14,3%) felt that the time scheduled to conduct the sessions, was not suitable and therefore, could not attend more.

xv) Further comments

Three respondents (42,9%) concluded by thanking the author for the "good work she's doing for the community" and her interest. One respondent (14,3%) wished he could have attended more. One respondent (14,3%) said that he then understood so much more. One respondent (14,3%) requested closer contact between the hospital and the family. This programme was experienced as a reaching out to families. One person (14,3%) felt that the objectives were not clear enough. This highlights the importance of making the time to conduct face to face interviews with potential members to ensure that such an issue is conveyed and clearly understood (McFarlane in Gurman & Kniskern,1991:374). One parent in a letter to the author said that she had been "left with a remarkable message of hope and self discovery" and that in life one is not always able to control what happens but one can control how to deal with it.

5.2.5 TRIANGULATION AND DISCUSSION OF THE MAJOR FINDINGS

The participating families represented very different circumstances and needs. The impact of the psychoeducation programme varied for each family and individual. Added to this the rich variety of data has enabled the writer to address areas of strengths, deficits and contradictions as this applies to the major themes.

The workshop provided an opportunity for members to increase their **knowledge of schizophrenia** by obtaining input on schizophrenia and medication. The participants were able to ask questions and discuss areas of concern. Further input was given in the focus group sessions. However, the questionnaire results were contradictory with the rating scales indicating some improvement but the descriptive aspect did not support this. The questionnaire was lengthy and respondents may have been reluctant to give longer answers.

The concepts of **communication and expressed emotion** were introduced in the workshop by the Valkenberg social worker. Elaine from Fountain House urged parents to acknowledge that their adult children with schizophrenia were able to become independent. The second focus group session focused on this and became a theme throughout the sessions. Its importance was derived from the notion that high expressed emotion was a significant indicator of relapse as mentioned previously (See Chapter Five:53) and which was also evident in a variety of cultural settings (Leff in Bennett,1991:196). The questionnaire showed improvements in expressed emotion, especially in terms of over concern and over protectiveness which were statistically significant. The knowledge and insight gained in this respect was transferred to other aspects of family functioning, such as roles (See Chapter Five:55).

The notions of **boundaries and roles** were also introduced in the workshop when the Valkenberg social worker urged families to strive for balance between caring for the ill family member and taking care of themselves. The concepts were more formally explained and discussed in the focus group sessions. It became clear during the process of the focus group sessions that respondent One was realigning her boundaries and so strengthening the parental subsystem. In this area respondent Three was applying her insights of effective communication to decrease intrusiveness, thereby strengthening her boundary with her daughter (See Chapter Five:58).

Effective **problem solving** was introduced in the workshop when the nursing sister spoke about how to manage a crisis. This concept was also introduced more formally in the focus group sessions and this formed the basis for a homework assignment in which non-attending family members could participate. It was statistically significant that the families began to refrain from discussing all problems openly in the family. Such improvements were also supported by and support improvements in boundaries and roles.

Negotiating acceptable standards of **behaviour** was suggested by the Valkenberg social worker in the workshop. She talked about encouraging the ill family member to become

involved at his / her own pace. She urged a balance between acceptable behaviour and understanding the limitations of the illness. In the focus group session the concept was introduced in terms of who sets the rules and how. Added to this there was a discussion on how families could cope when the situation could not be changed. In the questionnaire, the view was expressed that the parents set the rules and the family takes responsibility for maintaining them. There was also an indication of more consistency in adhering to the rules. Once again there was an indication that clearer roles and boundaries were supporting changes in this area.

In the workshop the families were urged to be **flexible** and compromise within their changed circumstances. Flexibility was a theme that recurred throughout the programme, for example, in the expectations for behaviour and the change of roles and boundaries as circumstances change. It appeared that knowledge of schizophrenia also helped a member to become flexible. Overall, the responses to the questionnaire indicated that there was an improvement in being able to cope with change.

In terms of **acceptance,** as an aspect of family functioning, Kubler-Ross asserts that acceptance is not giving up but more a state of peace. She implies that at this stage the emotional work is done (1989:99-100). The process of the programme may have helped families intellectually, to partly come to terms with the illness. However, as indicated in the questionnaire, much work on an emotional level still needed to be done. The duration of the programme may have been too short to have helped members in this respect.

Support was a theme throughout the process. It was mentioned several times in the workshop. Members in the focus group sessions began to support one another. After the third session respondent One gave transport to respondents Three and Four. In the participants' evaluations of the programme, five respondents reported that meeting in a group was beneficial.

5.3 CONCLUSION

The questionnaires were very lengthy and fatigue may have influenced the responses reflecting a weakness in the data capturing.

The strengths of this programme lay in the building of themes and the fact that there was a transfer of knowledge from one theme to others. This phenomenon is supported by systems theory as outlined by Kaplan & Sadock (1985:1427). The workshop enabled all the themes to be introduced and they were then highlighted or integrated into the focus group sessions.

According to McFarlane in Gurman & Kniskern (1991:390) the multiple family group psychoeducation programme is successful when the families report:

- a feeling of decreased burden
- increased knowledge in schizophrenia
- increased coping skills
- increased social network and
- improved morale and hope.

In this respect the programme under investigation showed some measure of success.

5.4 SUMMARY

The biographical details of the families and participants, the one day workshop, the six focus group session and the questionnaires were presented and discussed. Triangulation of the major findings was undertaken.

In the following chapter the main conclusions will be presented and recommendations made.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 MAIN CONCLUSIONS OF THE STUDY

The following conclusions have been reached:

* It was a difficult and long process to secure a sample of families who met the specified criteria.

* The significant "drop out" impacted on the study and may have significantly skewed the results.

* The success of the model depended on too many factors, which could not be controlled for. These factors relate to the following aspects of the study:

  i) The one day workshop would have been enhanced by the presence of the consulting clinicians (McFarlane in Gurman & Kniskern,1991:372).

  ii) The brief intervention model tends to focus more on education and there was insufficient time to deal with more spontaneous or emotive issues.

  iii) The multiple group format facilitated support, but, because of the diversity of participants, heterogeneity may also have inhibited this development.

* Despite the brief nature of the programme, there were some significant gains, especially in the areas of expressed emotion and the realigning of subsystems. Acceptance of the illness seemed to have occurred on an intellectual level, with the emotional acceptance lagging behind.

* An interesting development was the way in which the themes interlinked and supported each other. In this regard an awareness of reducing expressed emotion influenced all other themes and in turn was influenced by the other themes

* There was an expectation that schizophrenia would be understood in terms of symptoms. In spite of input of this nature the families were not able to give this after the programme. This raises the question of how exactly the illness is understood and the moral issue of whose explanation is the most valid.

* There was some emphasis placed on reducing stress and surviving that which cannot be changed. These issues were not addressed in the questionnaire. Some valuable insights might have been gained by the families and such data could have contributed to this study.

6. 2 RECOMMENDATIONS

Based on the results of the programme the following recommendations could be made:

* The therapist who conducts the psychoeducation programme should be a staff member of the facility providing the programme (O'Shea et al,1991:35).

* Such a programme could be conducted not only in the hospital but in the families' communities rendering it more accessible. This would be in keeping with the move to decentralise psychiatric services (O'Shea et al,1991:34).

* The present programme format of the day workshop and six focus group sessions could be retained as this may go some way to balancing the needs of families and conducting that which is feasible. However, such a programme challenges established patterns of family functioning and may need to be conducted over a longer period. This would facilitate development of support networks and the practicing of new skills.

* Such programmes need not only include the family but any members of the household involved in a caregiving function.

* The exclusion of the index patients leaves valuable family members out of the programme. They could be invited to attend some sessions or a parallel psychoeducation programme (O'Shea et al,1991:24).

* In order for the joining phase to be more effective this should take place over a longer time that one interview (McFarlane in Gurman & Kniskern,1991:374).

* The day workshop should also include members of the clinical team or those with whom the family are familiar (McFarlane in Gurman & Kniskern,1991:375). Further, a consumer is able to give families valuable insights (Appendix D:110).

* A co-therapist could be included during the focus group sessions. Such a person would be able to keep track of the process and tune into other needs of the families that may require further attention. Dreier & Lewis (1991:16) suggests the holding of support sessions between the psychoeducation sessions.

* Homework assignments are useful in that they could include other members of the family who are not able to attend.

* The questionnaire was very long. It needs some refinement and should be shortened to obtain more in depth answers instead of many answers.

* Further research could be conducted into the following:

i) The programme could be analysed from the perspective of group development.

ii) The impact that such a programme has on individual families over time could be explored. Keefler (1994:371) suggests that brief psychoeducation programmes lack long term benefits.

iii) Selection criteria could be developed that could predict who would benefit from a brief multiple family group psychoeducation programme. This cost effective means of intervention may become costly if the "drop out" rate is too high.

6.3 CONCLUSION

In conclusion it could be stated that the brief multiple family group psychoeducation programme could be an effective model in improving knowledge, family functioning and support.

Presently there are dwindling financial resources for psychiatric care. The challenge to the psychiatric community is how to use such a programme in a creative way so that the family will be strengthened and relapse rates reduced. This will make a significant contribution to enhancing the quality of life for those with schizophrenia and their families.

APPENDIX A

IDENTIFYING DATA

NAME

D.O.B.

FILE NO WARD

ADDRESS

TEL NO

NAME OF THERAPIST

LEVEL OF EDUCATION

DATE OF FIRST ADMISSION

ADMISSIONS

FAMILY COMPOSITION

MEMBERS OF HOUSEHOLD

FACTORS PRECIPITATING MOST RECENT BREAKDOWN

OTHER POSSIBLE FACTORS CAUSING STRESS / RECENT CHANGES

EFFECT OF ILLNESS ON FAMILY

ATTEMPTS BY FAMILY TO COPE

NEEDS OF FAMILY TO BE ADDRESSED IN THERAPY

PREFERRED DATES / TIMES

APPENDIX B

PSYCHOEDUCATION PRE-TEST QUESTIONNAIRE

Date of Administration: 28 September 1996.

Thank you for agreeing to complete this questionnaire. Your input will give valuable information that will help in the planning of future services.

Please bear in mind that there are not right or wrong answers.

SECTION A

Please provide the following information -

1. Relationship to patient (e.g. mother, father)

2. Age

3. Source of income

4. Religion

5. Is your family member currently in hospital?

6. What is his / her present condition (e.g. recovering at home, improving)?

SECTION B

1.1 How would you explain the term schizophrenia?

1.2 How do other members of the family understand this term?

2. When you think of your family member having schizophrenia, what do you feel?

3. List people / groups / organisations that give you support

4.1 When faced with a problem, how does the family attempt to solve it?

4.2 Could you think of a different way?

5.1 How would you describe communication in the family?

5.2 How could communication be improved upon?

6.1 What happens to you when you feel angry?

6.2 How do you communicate this?

6.3 What happens to you when you need to convey criticism?

6.4 How do you communicate this?

7.1 Do you feel that you are overly involved (e.g. take too much responsibility) with your family member who has schizophrenia?

If this is so, please give an example from your own experience

7.2 Do you feel that you are over concerned (e.g. become very worried, anxious) about your family member with schizophrenia?

If this is so, please give an example from your own experience.

7.3 Do you feel that you are overprotective (e.g. worry about safety) towards your family member with schizophrenia?

If this is so, please give an example from your own experience.

8.1 When you have a problem, which family member do you turn to?

Please explain why.

9. Each one of us has a unique place in the family. What contribution do you bring to the family?

10.1 Every family has its own way of operating (do's and don'ts).
Who sets the rules in your family?

10.2 How does the family ensure that the rules are adhered to?

10.3 Who ensures that they are carried out?

10.4 Is this done consistently?

11.1 Change is not always easy. How does your family cope with change?
Please qualify your answer by giving an example

SECTION C

Please circle your response and add any other comment you wish to make.

1. I have a good knowledge of schizophrenia

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree

2. I have accepted that my family member has schizophrenia

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree

3. I appreciate the importance of feeling supported by others

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree

4. We try to solve problems in the family by discussing issues together

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

5. We are open with each other

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

6.1 I am able to communicate my anger in a healthy way

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

6.2 I am able to communicate criticism in a healthy way

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

7.1 Most of the time I am overly involved with my family member who has schizophrenia

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

7.2 Most of the time I am over concerned about my family member with schizophrenia

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

7.3 Most of the time I am over protective about my family member with schizophrenia

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

8.1 All problems are discussed openly by the entire family

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

8.2 Only some problems are openly discussed by all family members

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

9.1 I still need clarity on the kind of role I could play in the family

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

9.2 I am quite confident about the contribution I make in the family

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

10. We find difficulty agreeing on accepted standards of behaviour

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

11.1 Most of the time we have difficulty accepting change

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

11.2 Most of the time we find it easy to adapt

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

SECTION D

Is there anything else that you would like to share of learn about the issue of having a person with schizophrenia in the family?

APPENDIX C

PSYCHOEDUCATION POST-TEST QUESTIONNAIRE

Date of administration: 16 November to 22 November 1996.

Thank you for agreeing to complete this questionnaire. Your input will give valuable information that will help in the planning of future services.

Please bear in mind that there are not right or wrong answers.

SECTION A

Please provide the following information -

1. Relationship to patient (e.g. mother, father)

2. Age

3. Source of income

4. Religion

5. Is your family member currently in hospital?

6. What is his / her present condition (e.g. recovering at home, improving)?

SECTION B

1.1 How would you explain the term schizophrenia?

1.2 How do other members of the family understand this term?

2. When you think of your family member having schizophrenia, what do you feel?

3. List people / groups / organisations that give you support

4.1 When faced with a problem, how does the family attempt to solve it?

4.2 Could you think of a different way?

5.1 How would you describe communication in the family?

5.2 How could communication be improved upon?

6.1 What happens to you when you feel angry?

6.2 How do you communicate this?

6.3 What happens to you when you need to convey criticism?

6.4 How do you communicate this?

7.1 Do you feel that you are overly involved (e.g. take too much responsibility) with your family member who has schizophrenia?

If this is so, please give an example from your own experience

7.2 Do you feel that you are over concerned (e.g. become very worried, anxious) about your family member with schizophrenia?

If this is so, please give an example from your own experience.

7.3 Do you feel that you are overprotective (e.g. worry about safety) towards your family member with schizophrenia?

If this is so, please give an example from your own experience.

8.1 When you have a problem, which family member do you turn to?

Please explain why.

9. Each one of us has a unique place in the family. What contribution do you bring to the family?

10.1 Every family has its own way of operating (do's and don'ts).
Who sets the rules in your family?

10.2 How does the family ensure that the rules are adhered to?

10.3 Who ensures that they are carried out?

10.4 Is this done consistently?

11.1 Change is not always easy. How does your family cope with change?
Please qualify your answer by giving an example

SECTION C

Please circle your response and add any other comment you wish to make.

1. I have a good knowledge of schizophrenia

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree

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Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree

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Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

8.2 Only some problems are openly discussed by all family members

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11.1 Most of the time we have difficulty accepting change

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

11.2 Most of the time we find it easy to adapt

Strongly agree. Agree. Neither agree nor disagree. Disagree. Strongly disagree.

SECTION D

i) Number of group sessions attended.

ii) What motivated you to attend?

iii) Please indicate your reasons for not attending.

iv) Would you have attended if your situation had been different?

If your answer is NO please explain

v) Did the programme meet your expectations?

Please explain your answer.

vi) What is your opinion of the content of the programme as a whole?

vii) What is your opinion of the presentation of the programme?

viii) What is your opinion of the group participation?

ix) In what way have you benefited from attending the programme?

x) What did you enjoy the most?

xi) In what way have you not benefited from attending the programme?

xii) What did you enjoy the least?

xiii) Would you recommend such a programme to other families?

xiv) What else would you like added, omitted or changed?

xv) Any further comments.

APPENDIX D

SUMMARY OF TALKS GIVEN AT THE DAY WORKSHOP ON 26 SEPTEMBER 1996

INTRODUCTION BY WRITER

Thank you all for being here today and for completing the questionnaires.

What brings us together is the fact that you all have a family member with schizophrenia.

When a family member has schizophrenia, this presents new challenges to families and it is my hope that during the course of today, and over the next six sessions we together, are going to work out how to creatively and effectively meet those challenges in order to facilitate happy family life which could help to keep your family member well.

The programme for the day will be as follows -

* Dr Jane Saunders will be talking on what schizophrenia is and the role of medication. You will then be able to ask questions and make comments.

* Then Adina Surdut who is a social worker at Valkenberg Hospital will talk to you about community resources. Unfortunately the occupational therapist is not able to be with us today and Adina has kindly agreed to address some of the issues that the occupational therapist would have done on "How to assist you family member on a day to day basis." You will then be able to ask questions and make comment. If anyone has suggestions of your own please feel free to share these with us.

* This will take us to about 12H45 when lunch will be served. We will then reconvene at quarter to two.

* Sister Brown of the Community Psychiatric Services will talk about what families can do to help when they notice changes in their family member and how to cope with a crisis. Again there will be time for questions and comments.

* Finally, Elaine, who is a member of Fountain House and has schizophrenia, will talk about her experiences of living with her family and what her expectations of her family are. Your are welcome to ask Elaine any questions.

* We should then complete the day's proceedings at three o'clock.

Do you have anything you want to ask or say before we begin.

There were no questions or comments and Dr Saunders was introduced.

SCHIZOPHRENIA AND THE ROLE OF MEDICATION - DR JANE SAUNDERS - REGISTRAR IN THE DEPARTMENT OF PSYCHIATRY, PRESENTLY AT WILLIAM SLATER ADOLESCENT UNIT.

Before I begin I would like to ask each family how long their family member has had schizophrenia.

The first family reported that their daughter has had schizophrenia for one year with one breakdown and has been well since February 1996. The second family said that their son who is sixteen years has had three admissions with the first one having been about eighteen months ago. He is currently in hospital. The third family said that their daughter has had schizophrenia for the past eleven years and has been in hospital many times. She has just been discharged. The fourth parent said that her daughter has just been diagnosed and is currently in hospital.

There seems to be quite a range and I will take this into account. I am not going to give you a text book description of schizophrenia, but rather I would like to give you some ideas and you can ask what you want to know.

If I could tell you what the cause of schizophrenia is I would have the Nobel Prize. However, there are some indications that in some people there is a genetic component. In other words, if a parent has schizophrenia, there is more of a chance that one of their offspring will develop the illness than from the general population. There is also a suggestion that there may be some indication of damage to the developing brain of the child. There is evidence of structural changes that effect certain parts of the brain that could have happened before or just after the baby was born. You may ask, "Why does the

illness not present earlier?" The answer to this may lie in the fact that we lose brain cells all the time from the beginning of adolescence and this process is triggered by hormones. From then on the brain cells are decreasingly unable to compensate. If we look at causes, we know what does not cause schizophrenia, such parenting, what we as parents may have done or not done for the child, vaccinations, something that the mother took in pregnancy. Parents frequently take the blame but it is important to know that they are not to blame.

It has been shown that among those with schizophrenia, one third will recover sufficiently to lead a normal life, one third will lead a relatively normal life but will not go to university, and one third will not be able to work.

Schizophrenia does not mean split personality. It means split from reality. This is indicated by strange thoughts, hallucinations (usually auditory), some changes in personality in that the person becomes apathetic (but this could also be due to the medication). The person may become aggressive or very frightened. Just imagine what it would be like to believe that there is a huge monster in this room who is trying to hurt you and no one believes you. This can be very frightening and you may resort to aggression as a means of defending yourself. The presentation of these symptoms may be very slow and you may notice gradual changes over a period of time.

Medication. Without medication one could get better. This would take a long time and one could expect a relapse within a year. Medication does not cure schizophrenia but it halts the psychosis. It does not help with the negative symptoms, such as lack of motivation, fairly flat mood which can also pose problems. Medication can be taken by injection once a month which is helpful if people are likely to forget. Or else they are taken in tablet form. Whatever form is prescribed, medication must be taken. They do have their problems. Most mediations are designed to control the thought problems, hallucinations and delusions but they may accentuate the negative symptoms by increasing lethargy. It must be remembered that even when a person is compliant with medication they can, as in

asthma and diabetes, break through and in schizophrenia this happens when the patient is under stress. Medication invariably has side effects but there are newer drugs on the market such as Clozipine and Respiridone which have relatively few side-effects but they are expensive and available in the hospital only in special circumstances. The most serious of the side effects is an oculargyro crisis in which the patient rolls back his or her eyes and can be very frightening. There is medication frequently prescribed to alleviate some side effects such as stiffness like Disipil or Orphenidrine.

At this point would you like to ask questions?

A father: Does shock treatment help with schizophrenia?

Dr S: Electroconvulsive therapy is never used for schizophrenia alone. It is used when there is a depression that is resistant to any other conventional form of treatment.

Brother: These thought processes, do they vary from one person to another?

Dr S: Yes they do.

Brother: My sister has some fear of dogs and so she will not visit. I find this very difficult as I would like her to visit but I cannot just get rid of my dogs.

There was a brief discussion about the thought processes that seemed strange to us but often had some symbolic meaning for the patient who may be reluctant to talk about such things.

Dr S: One of the problems with schizophrenia is that the messages that are sent to and from the brain via neurotransmitters, is faulty and the result can be a strange interpretation of reality.

Mother: What do you do with a person who wants you to confirm their illusions?

Dr S: One should acknowledge their experience, be respectful and simply say that you do not see or hear it.

Father: My son needs to go back to school but I want to know if he will be able to take the pressure.

Dr S: Stress can trigger a breakdown. You can try to predict what stresses him, you can liaise with the teachers and if necessary during times of stress we could increase the dose

of medication by a little. You need to know that your son may not absorb information at school as well as he did before his illness and medication also slows him down.

Mother: Can people become used to the medication so that it is no longer effective?

Dr S: This does not happen with the antipsychotic medication and as a rule of thumb, if a medication worked in the past it should continue to do so. The thing about medication that one medicine may be good for one person and not good for another.

Mother: Can this medication become addictive?

Dr S: It is not addictive. There is a question about Disipil used for side effects though. The benzodiazepines, such as Valium and Serapax can be addictive but we tend to use this to settle someone who is psychotic, enabling us to use less antipsychotic medication which has more side effects. Once settled we withdraw the benzodiazepine.

Mother: Can antibiotics be taken with antipsychotics?

Dr S: The vast majority of medicines are safe with antipsychotics but it is a good idea for you to take the antipsychotic to the pharmacist to show him or her what is being taken when any other medicines are prescribed.

Mother: My son has just started smoking and I notice so many patients smoke. What is it that makes smoking attractive?

Dr S: It is felt that nicotine may help to make people feel more calm but smoking may also be a way to cope with boredom.

Mother: I have also heard of so many people taking dagga.

Dr S: Dagga can cause a psychosis and it is a problem.

Mother: You hear that there is dagga in the hospital.

Dr S: Friends bring it in. It helps people to feel disinhibited and they are able to escape, temporarily, from chronic illness.

Mother: I was wondering about suicide. My son has never said anything but he gets so down.

Dr S: This is a good point to raise. In schizophrenia there is a higher incidence of suicide than in the general population. There seems to be a crisis point at the beginning of the illness. It is important that the person is supported thorough this stage of terror. He or she needs reassurance that no one will hurt the patient.

Mother: My child was so afraid of what was being "said" to him.

Dr S: That is very frightening. And even when the patient is not hearing the voice or voices there may be a fear of the return of the voice. You could encourage your family member to tell you when the voice returns.

Mother: What should we do when the voice says, "Don't tell anyone"?

Dr S: Even then patients will generally tell people who they trust.

Mother: My son has said that I am the good voice that he hears instructing him. How do I handle this?

Dr S: Encourage him to take responsibility for himself and so try to lessen your part in the delusional process.

Father: How can we tell when our child is becoming ill again?

Dr S: Go back to just before the relapse period and see the changes and ask yourself, "What were the cues I overlooked?" Write them down and so the next time you will have a reference point. Some have the same delusions and others have different delusions for each breakdown. It is important to accept that in a person who has had two or three breakdowns, this will become a life pattern.

Mother: I was reading the other day that there is a relationship between gluten allergies and schizophrenia.

Dr S: There have been many substances associated with schizophrenia such as toothpaste, the mother - the so-called schizophrenigenic mother, which we know is nonsense, where the person is, in order of the family. There has been no scientific evidence to support any of these factors.

Mother: I suppose it is a good idea to have a balanced diet.

Dr S: Exactly. Exercise is also important. The healthier the body the more resilient it is. In fact we encourage people to explore what they feel comfortable with, provided it does not compromise the patient in any way. Many of our patients consult with traditional healers and we are beginning to work more closely with them. In fact a holistic approach to helping someone with schizophrenia has the greater chance of success.

Mother: My son has been on tablets and now he has asked to go onto the injection. I am not so sure about this.

Dr S: The best thing if you have queries about medication is to talk with the doctor.

Mother: When my son became ill this last time, he said that all the forks had numbers on them. Now he is so much better and he says that the numbers have gone but at that time they were definitely there.

Dr S: This is a delusion which you cannot change and is what we would call a fixed delusion. Sometimes people will hang onto what they said in the past as a way of saving face even though they may now realise that that was not real.

Brother: I know of someone who believed that he needed to commit suicide.

Father: My son also said this to me and I asked him, "Why do you want to do this?" and he said that he was a failure in life. I am worried - will this depression come back again?

Dr S: The chances are that it will. If you think about it he is a young man who may be feeling that he is losing who he is. He needs to know that there is support and that he has options.

Writer: He also needs to feel affirmed - to feel valued as a person.

Dr S: Yes, that he is a decent person who is kind. This is far more important in the long run than becoming a professor. I think that schizophrenia really makes us think about what is really important in life - being able to relate to one another and to be able to support one another.

Dr Saunders was thanked for her valuable input and for answering the questions participants had put to her.

RESOURCES - MS ADINA SURDUT - SOCIAL WORKER IN THE MALE ADMISSION AND REHABILITATION WARDS AT VALKENBERG HOSPITAL.

There are many community resources which can be beneficial to a person who has a mental illness and the family. Different problems will require different resources, for example, accommodation, drug counseling and support.

Often we forget a really crucial and most obvious resource and this is the family unit. Be it parents, siblings or an extended family. One often undermines the impact of the family during the patient's admission and most notably when he or she is back home. I will first focus on the issue of the family as a resource. Taking care of a family member with schizophrenia, at home, may make you feel quite anxious. You may be thinking , "How must I be treating him/her?, should I ask her to help me with household chores, should I let them see their friends, should we ever mention their stay in hospital, can they ever return to work?" These are all normal questions and one wants to do the best of making the adjustment of having one's family member back home as easy as possible.

The patient also experiences difficulties. He or she has been isolated from the outside. We don't always realise how incredibly structured a hospital is and in some ways easier than the big wide world.

For the family to be a positive resource one needs to establish and maintain a supportive environment for the patient. I would also like to advise a structured home environment. By this I mean a compromise between a disorganised, lax type atmosphere and a rigid home full of strict rules and high expectations. Often families have set expectations of the member returning home, such as, that things must continue just as they had in the past. Family members often feel pressurised to make the person who has been in hospital get back to their previous level of functioning. But we need to understand this takes time. It doesn't mean that they cannot be involved in household routine, and decision making - in fact this can help them settle in. I would discourage you to plan or think about long term issues although I know that parents can't help worrying about their children's futures. You may need to focus on the present issues. You may be understandably worried about long term issues, like career, marriage and so on, but the more immediate things going on are actually more important. Dealing with current day to day issues effectively and in a supportive and caring climate will provide a foundation for the future. Activities that can help you to get through each day and help your family member to get back onto his or her

feet can range from household chores, to shopping, jogging or going to the movies. It is important that they do something that they find enjoyable.

I want to emphasise the importance of effective communication. This really means giving and receiving information effectively. Communication is not only words but tone of voice, speed, body language. The question, "Have you tidied your room?" will come across differently depending on how you say this and the accompanying gestures. I know that Trish will spend more time on communication at a later stage.

I think that for you to be an effective resource understanding of the illness is the most important. You being here today and in the future sessions, will no doubt help you achieve this. We must understand that the behaviour of the patient when ill has nothing to do with his or her character. The fact that he or she can't get up in the morning does not necessarily mean that they are lazy. Nor, if they begin shouting or accusing you that you are trying to harm them, does it mean that they are being nasty. If one believes such things, one tends to respond critically and with anger. Similarly, if we believe that a person is incurably ill and has no control over their behaviour, one may become overinvolved and too concerned wanting to rescue them and do everything for them. It is important to treat your family member as you would your other children or your other siblings. I feel this is easier for the person who is ill. You must achieve a balance between caring and supporting your family member and getting on with your own lives and caring for yourselves. A relaxed family atmosphere is really what one should strive for.

Taking this into consideration, you need to realise that additional resources do exist in the community to assist you with the challenging task of maintaining stability and dealing with issues around mental illness. I can't mention all the resources but I'll discuss ones I feel will be the most beneficial to you.

i) Cape Mental Health Society is a community based mental health organisation. It provides services to people with mental illness and mental handicap. Its main functions are - social workers provide supportive and counseling services to both families and people

with mental illness and their families. They also assist with the administration of disability grants. They have six community based psychosocial rehabilitation groups, also known as clubs, in Brooklyn, Elsies River, Fish Hoek, Guguletu and Khayelitsha. They are more of a recreational nature and some have a work orientation.

ii) There is also Fountain House. This club was started by Cape Mental Health as it was felt that few services were available to patients when they left hospital, besides out patient clinics. It was established in 1983 as s psychosocial rehabilitation centre based on the clubhouse concept initially developed in New York. People who become members are men and women of all ages and cultures who have suffered from a mental illness. They join Fountain House as a member of the club, not as clients or patients. No treatment or therapy is directly provided. The work the members do are the tasks that need to be done to keep the club house running, such as, catering, clerical work. In the afternoons there is emphasis on recreation such as sport, chess and outings. Linked to this, is the Transitional Employment Programme. This involves members working at places where Fountain House has secured jobs, such as Pick 'n Pay. For example, they will train two members for the job one to do the job and the other as a replacement. They remain in that placement for six months. In this time self-confidence and work skills will be increased. It also helps to build a work history. I would encourage you to visit Fountain House. Attached to Fountain House is a group home for members.

iii) In terms of accommodation outside of the family the Cape Support Group have groups homes mostly in the Observatory area. This is referred to as Comcare. The Cape Support Group is a support group for relatives who have a family member with schizophrenia. This was founded in 1981 and they meet once a month. There is usually a speaker. One meeting that I attended they had a lawyer talk about how to set up a trust fund.

iv) Another organisation that also provides accommodation is the Abri Foundation where Lisa Wolters is in charge. Attached to these homes is a day programme in which people can do some sports, crafts and pottery. People living here are fairly independent but there is supervision in terms of medication and going to the hospital for checkups.

v) Then there are the local community clinics, where some of our patients go for checkups instead of coming to Valkenberg. These are in the Wynberg area, Athlone, Fish Hoek and so on.

vi) In some cases where people are not able to work, the State provides a Disability Grant of R410 per month. This should be regarded as a last resort but a temporary grant could be considered initially. The Provincial Administration Western Cape have regional offices at Wynberg, Athlone, Goodwood, Cape Town.

vii) Careers counsellors can also be consulted and the Department of Educational Psychology under Patrick Normand at Stellenbosch University will do assessments. The Department of Manpower will also assess people for certain types of work as well as the Work Assessment Unit at Groote Schuur Hospital.

viii) The Drug Counselling Centre offers counselling at Observatory if there are issues around substance abuse. There is also the Avalon treatment centre in Athlone.

ix) FAMSA offers services to families who may need further counselling.

I have pamphlets and telephone numbers should you wish to make use of any of these resources.

Are there any questions you would like to ask

Mother: What is the difference in the group homes?

Adina: Essentially they are very similar. The group home attached to Fountain House, Kimber House, does not have a house mother, members are expected to attend Fountain House or work during the week. A staff member comes to the house everyday to check that everyone is all right. At Abri although Lisa is the "house mother" she stays at only the one house and there is an expectation that people will attend a day programme. At the Comcare houses which can be more expensive, the residents are expected to go out every day but what they do is up to them.

Mother: I think that it would be very helpful to see an educational psychologist as you worry how your child will cope at school. Do you know how much this will cost?

Adina: At the university it is not expensive as it would be in private which is about R700. Interns would do the assessments under supervision.

Father: My experience of such things is a waste of money, we were charged about R700 for five minutes.

Adina: This seems quite irregular and I would urge you to exercise your consumer rights to obtain a more satisfactory service.

Father: That is in the past now. We got the account and I just paid it.

Adina: Are there any more questions or ideas you would like to raise?

There were no more questions or comments. Adina was thanked for her input and she made herself available to the families for further details.

WHAT FAMILIES ARE ABLE TO DO WHEN THEIR FAMILY MEMBER SHOWS SIGNS OF BECOMING ILL AND HOW TO MANAGE A CRISIS – SISTER MOSEEDA BROWN – COMMUNITY PSYCHIATRIC SISTER IN THE WOODSTOCK AND MAITLAND AREAS

What do you understand by a family crisis?

There were no verbal responses but a few non-verbal responses indicated that they did not have an answer.

Well, all families face a crisis at some time. In order to decrease the possibility of a family crisis you need to know more about schizophrenia. Don't be over-concerned about the diagnosis. You need to regard this person as a person who is a member of the family. It is not a sin to have a mental illness – plenty of people do and plenty of professional people also. It is important that the person with a mental illness accepts this and so does the family as this will help to be realistic about what he or she is able to do. Do you accept the illness?

Mother: Yes. . . . though it has not been easy.

Sister Brown: When the illness is accepted you are able to give support, see the family member as a normal human being, who is capable of making solutions and who happens to be on treatment. When your family member begins to change what do you do?

Mother: I get very worried because I don't understand what my child is thinking. I asked

him if his body was also feeling different.

Brother: My sister becomes restless and we get anxious about her.

Mother: We contact and make an appointment to see the doctor.

Sister Brown: Do any of you go to the community clinic?

Mother and Father: Our daughter does.

Mother: We did go to the Dr Abdurahman Clinic for a while but when we had problems we contacted the hospital directly.

Sister Brown: In the future with the new hospital system you will not be seen at Valkenberg as an out-patient but you will be seen in the community. So if you notice that your family member is becoming ill you can contact the clinic directly.

Writer: Does that mean that there will be 24 hour cover at the community psychiatric hospitals?

Sister Brown: If we are not available then you can go to Groote Schuur Hospital.

Mother: But we have just contacted the doctor directly at Valkenberg. . .

Adina: When you are known to us you can contact us directly.

Writer: Are you saying that Valkenberg will no longer have an out-patient service?

Sister Brown: Yes.

Writer: In short, when families are concerned about their family member they can at present, contact the hospital. In the future, if they are known to the hospital they can either contact the clinic as an initial measure or the doctor at Valkenberg. Could you please let us know what families can do after hours, the procedure at Groote Schuur Hospital.

Sister Brown: The emergency admission ward is C23. You need to go through general casualty and they will then admit a patient at C23.

Writer: It has been my experience that if you do have a psychiatric crisis it is worthwhile to contact C23 directly before coming to the hospital and they at least can expect the patient. This is quite important when the patient is very agitated. You can also inform the ward that the patient is known to Valkenberg.

Adina: There is a doctor on duty at Valkenberg at night and if the person has been in Valkenberg in the past eighteen months, the person can be admitted directly to

Valkenberg.

Mother: So you are telling us that there will be no more out-patients at Valkenberg?

Sister Brown: In accordance with the new health plan it is envisaged that this OPD will be closed.

Writer: Would anyone like to ask Sister Brown anything?

There were nods indicating that there were no further questions.

Writer: In summary then for the present if families have concerns these can be addressed at OPD. More urgent matters can be discussed with the doctor on the phone. In the event of an emergency at night or the weekend, either the duty doctor can be contacted at Valkenberg or the person can go to C23 at Groote Schuur. In the future it appears that the community clinics will take the place of OPD.

Sister Brown was thanked. Elaine, a member of Fountain House, a resident of Kimber House and who also has schizophrenia, was introduced to the group.

A PERSONAL EXPERIENCE: WHAT I EXPECT FROM MY FAMILY – ELAINE – A MEMBER OF FOUNTAIN HOUSE WHO HAS SCHIZOPHRENIA

Elaine: Thank you for asking me to join you today and for letting me share some of my ideas.

Sometimes our families do not understand us when we are mentally ill. We try to explain to them how we feel when we have this problem, but it does not help at all. While I was staying with my family I had a lot of problems because of many misunderstandings. They could not understand me when I was sick. They were shouting at me, telling [me] to come right. At that time they accused me of all kinds of things that they felt that I had done wrong in the past and this did not please them. They hit me, tied my hands and feet with rope, until they got help from the police station. The police had to take me to the hospital. That is where I got help. My therapist decided to call my mother to explain to her my illness. My therapist had to open a book and explain in details, the illness. Everything went

well after that. The week before I was discharged from the hospital I was allowed to spend nights at home. I felt welcomed, happy and had no problems. When I was out of the hospital and staying with my family things changed again. They did everything for me as if I could not do anything for myself. However, I felt that I was in control of everything. What I needed most was to stand on my own two feet. I wanted to show them that I could cope, but they could not see that. That is why I decided to move out.

I feel happy now and my family too. My family tell me everyday that they are happy for me. I hope that we will understand each other better.

Writer: Thank you very much Elaine for sharing your experience with us. Would you answer any questions?

Elaine: Yes.

Mother: What do you do at Fountain House?

Elaine: I work in the clerical unit on the computer.

Mother: Do you type?

Elaine: Yes, I try. I am still learning the computer.

Mother: In your spare time what do you do?

Elaine: I go with Fountain House to the Nico or the Baxter. Sometimes to the beach.

Mother: Do you get to see your family much?

Elaine: Yes, quite a lot.

Mother: Do they live close by?

Elaine: Yes, they live in Guguletu.

Writer: Elaine, I think you raised such an important point about being given the opportunity by the family to do things for yourself.

Elaine: Yes. I had to do things for myself and now they can see that I am able.

Mother: You must have felt quite frustrated.

Elaine: Yes I was but they were able to see that I could manage.

Writer: Any more questions or comments.

There were no further questions or comments. Elaine was thanked again.

The families were thanked for attending and participating. The families were reminded that the group would be meeting the following week from 12H30 until 13H45 for the following six Saturdays. The participants were informed that in the groups the focus would be on families who were in the important position of creating and optimal environment to keep their family members well. There would be an exploration of certain aspects of family functioning and how the effectiveness of families could be maximised to benefit all concerned.

APPENDIX E

OUTLINE OF THE FOCUS GROUP SESSIONS

SESSION ONE. SUPPORT

Purpose: Clarify use of tape recorder

Engage the families

Outline psychoeducation programme

Introduce the concept of effective support networks

Explore obstacles to support in order to facilitate issues of stigma and loss.

Programme for the day-

Tape and confidentiality

Introductions and expectations

Summarise last session

Psychoeducation rationale

Outline of further programmes -

5 October 1996	Support networks
12 October 1996	No group session - Valkenberg Open Day
19 October 1996	Communication
26 October 1996	Roles and boundaries
2 November 1996	Problem-solving
9 November 1996	Reaching agreements on family expectations
16 November 1996	Unfinished issues and evaluation

Outline of today's programme

Read article by Dale Johnson

Refer to literature that stresses the importance of families being supported

We will look at three areas of support

- support for the person with schizophrenia
- support within the family
- support from outside the family

Who gives you support

What are the obstacles to you being supported by others

Explore guilt / shame / stigma

Process of loss - denial / isolation, anger, bargaining, depression and acceptance

SESSION 2. COMMUNICATION

Purpose - Address the concept of communication, what it is, why it is so important and what aspects of communication can be difficult.

Explore how families communicate at present in order to affirm positive communication and enhance any areas that need working on.

Programme for the day

Welcome - especially any family members who have schizophrenia

Summarise last week's programme on support and illicit assistance from those who attended

- importance of support as a means of staying well
- support for the member with schizophrenia
- support for family members
- Student prepared to talk this over with families who missed this at another time
- future programmes - 26 October - Roles an Boundaries
  - 2 November - Problem-solving
  - 9 November - Reaching agreements on family expectations
  - 16 November - Unfinished issues and evaluation

Introduce the topic for today -

Today we are going to work on the subject of communication.

We will address - 1) what communication is

- 2) why it is so important in your particular situations
- 3) what aspects of communication can be difficult and
- 4) we will look at what families are already doing and can possibly do to enhance effective communication

Any questions or comments?

What is communication?

Communication is the way in which we connect to the world

It is a transfer of information in an interpersonal context.

What constitutes communication is language, gestures, tone of voice, speed, pauses, laughing and not saying anything at all.

Why is communication so important?

To explain this more fully I need to explain how information is actually processed in our heads using what is known as the arousal - attention hypothesis.

We're all aware of the world around us and this is determined to a large extent by two important states of mind, that is arousal and attention.

Arousal describes our states of wakefulness and ranges from being in a state of sleep to a state of being so wide awake that we are in a state of panic or euphoria.

Arousal helps us to take in information and attend to it. It is also influenced by the level of stress and emotion that is being experienced

With attention at an optimal level we are able to link incoming information with existing memory, assign meaning to this information, make decisions and prepare for response.

With reasonable attention, arousal can remain functional. So it can be shown that there is a strong relationship between arousal and attention, the one needing the other and so a feedback loop is maintained.

To illustrate this, with moderate levels of arousal and what we call eustress, we are able to process information which is frequently in the form of communication.
When the arousal level is too low , like when we are feeling tired, it is difficult to process information and it is at times like these that we can misinterpret the intentions of others
When the arousal level is too high and we experience distress, the attention level also drops off and again we are not able to process information effectively. Use example of child not being able to function at school.

It has been found that in schizophrenia there may be problems with this arousal - attention feedback loop. So with moderate levels of arousal attention may be impaired. Under conditions of mild stress there is too much arousal or there is too little response even when arousal is appropriate.

Bearing in mind that there may be problems with attention and arousal which is influenced in part by the experience of stress, let us look at **aspects of communication that may complicate the giving and receiving of information**.

The first point is the quantity of information. Can you think how this point could be illustrated? (movies,
The second point is complexity, (double bind)
The third point is intensity (over-involvement)
And the fourth point is negativity (hostility, criticism)

Break into two groups to discuss **what you are doing at present** that is helpful in terms of these points or **what you feel would be helpful to your family and others**. And as a fifth issue to indicate how you as receiver of information can communicate to your family member positively .

Attributes of effective communication:
The sender: Clear Concrete Simple Relatively free of emotion

The receiver: Listen Clarify Express genuine interest.

SESSION 3. ROLES AND BOUNDARIES

Purpose: Summarise what had been presented in the two previous sessions

Understand the importance of clear role definition

Understand the importance of clear boundaries

Explore with families where they are functioning effectively and where they feel they need to improve

Programme for the day

Welcome family members

Summarise the main points of last session

- What is communication
- Why it is so important
- Some of the problems in communication, namely quantity, complexity, intensity and negativity
- Important input from families - where they are having success and any other suggestions

Introduce the topic for today

Today we are going to focus on the roles we take in the family and the importance of how we determine the types of contacts we make with one another. And what is known as boundaries.

What is a role?

A role defines what you are and this determines and is determined by the tasks you need to fulfill. For example a person who takes the role of a mother usually becomes the primary caregiver of the children. But the person who is the mother may also be a sister and the tasks here may involve taking care of her younger siblings. Common to all roles is that

they signify behaviours that are expected, permitted or prohibited. They change over time and may vary in different cultures.

When does the issue of role become a problem in a family?

When there is role **conflict** (expect child to be employed but person not able to do this)

Role **inflexibility** (as mother need to resort to more nurturing but not able to do this)

Role **diffusion** (taking over the daily living activities like shopping of the patient - refer to Elaine)

Let's refer back to communication

Problems with roles are around the way we communicate our understanding of what those roles mean and if the messages are complex or ambiguous as in role diffusion, we can see that this creates uncertainty and stress.

If we go back to the example of Elaine we can see that in the family taking over her roles the implicit message was that she was not able and this can be very damaging for an already diminished self esteem and confidence.

On the other hand where the role evokes intensity of emotion, stress can escalate.

Lets take some examples, role of mother, father and grandmother. How are these played out in your families. *Use newsprint and go around the room.*

If we view the family as a **system**, we see that it usually consists of what we call **subsystems**. The parental subsystem and the sibling subsystem. This changes as the family changes. Adolescent subsystem. Position of grandparents.

Show this on newsprint.

Separating these subsystems we have what we call **boundaries**. A boundary could be described as an invisible line that regulates contact between the subsystem and determines the quantity of communication between subsystems.

Research has shown that when the boundaries are **clear,** contact is appropriate and each subsystem is able to function without interference, for example, parents can only be

effective if the children understand that the parents do the punishing and that it is not for other siblings to punish the youngest.

There are two other types of boundaries and the one is referred to as being rigid and the other diffuse or too open. If we consider that boundaries determine the quantity and quality of communication, we can then see that when they are **too rigid**, communication is limited and cold potentially leaving people feeling isolated, abandoned or rejected . If we think of a person with schizophrenia in such an environment, feelings of lack of self-worth can be reinforced and this creates stress.

When the boundaries are **too open**, there is too much communication and any small issue effects one family member or subsystem, the whole family becomes involved. When this relates to a problem, the potential for criticism, hostility or being overprotective can be allowed to overwhelm the family and where a member has schizophrenia this again leads to much stress.

So what is important is to have clear boundaries. When the parental subsystem is sufficiently intact, conflict does not spill over to the children Research has shown that when the parental roles are clearly understood and boundaries are clear, This creates an environment that is calmer and less stressful.

Bearing in mind that a person with schizophrenia may be easily overstimulated with reduced ability to filter and select information, **what can families do to create an environment in which roles and boundaries are clear?**

Use newsprint for families to write down their suggestions.

Involve the patient in family activities but respect his / her need to withdraw (regulate stimulation)

Need for "barriers to overstimulation" greatest in post psychotic phase (McFarlane in Gurman & Kniskern,1991:368)

Emotional space - reduce nagging, criticism, over concern

Be cool, controlled and concerned but not hostile, critical or over concerned

Direct attention and concern to well siblings also

Attend to marital needs, go to the movies together

Family needs, and at times this requires special effort, to keep their outer boundary open to support, information, guidance, recreation and simple social contact.

SESSION FOUR - PROBLEM - SOLVING

Purpose: Summarise previous sessions

Give input on problem solving and encourage participation

Families to do a problem solving exercise of their own

Welcome family members and talk about the absentees

Summarise the process thus far- **First session** -importance of support

Second session -importance of effective communication

Third session - what is a role, when does it become a problem, how roles change and the need for these to be clearly understood by the family.

- boundaries and the problems when they are too open or too closed, the importance of appropriate subsystems

- ways to create an environment in which roles and boundaries are clear.

Any comments to share or questions

Why talk about problem solving?

Firstly, it has been shown that when families solve problems efficiently, relationships in the family improve.

Secondly, learning the techniques of problem solving provides families with "a systematic sequence with which to address family difficulties, it improves their ability to cope and reduces family stress (Bennun in Carpenter & Treacher, 1993:155).

Any comments?

The importance of problem solving (Dougan et al, 1986:164)

*As we go through life we continue to grow and change and this requires us to tackle different situations in different ways and we could call this problem solving.

* Everyone has problems everyday, it doesn't matter who you are or what your circumstances are. Some problems may be small and some may be big.

*Unless we solve as they arise they can become bigger and distorted creating more problems and stress.

*Problems can also be seen as challenges and instead of viewing them as troubles or disasters we can turn them into opportunities for growth and development.

Is this making sense to you? Would you like to add anything, ask a question?

How do we solve problems?

Illicit suggestions

Solving problems is something that is such an everyday activity that we seldom think about how we actually do this. What we will do is unpack the various steps which may help you if you find yourselves getting stuck when trying to overcome a problem. To make things clear problems solving can be seen as an activity that has six steps (Leff in Bennett & Freeman,1991:201).

***Step one. Identify the problem.**

That may sound easier said than done but it is important that one has a clear idea of what the actual problem is. For example parents may be hassled by a child who has an untidy bedroom.

At this stage the problem which is real is too vague to do anything constructive with. It is important to be specific, such as the bed is not made and clothes

are just scattered in the wardrobe.

When a problem seems very big, it is important to break it up into smaller more manageable pieces, for example if a gets up early to complete some chores before going to work she may feel that she will be late when a whole lot of unpredictable problems present themselves, such as, finding that the electricity went off during the night, the fridge has defrosted, she had planned to bake a cake to send to school with one child and another child is sick.

This will involve seeing each problem individually and it will be important to prioritise what needs to be resolved right away and what can wait for later.

When this is done the mother may not feel so overwhelmed and may even still get to work on time.

Step 2. List alternate solutions.

This is the point at which one may do some brainstorming. That is coming up with as many ideas as possible without judging them - this will come later.For example, parents may notice that their child seems to be behaving differently. This is a problem and still quite vague. Could you become more specific about the problem? Could you think of something to resolve this problem?

The parents may think of the following -

- ignore the behaviour
- go to the hospital
- contact the hospital by phone
- check if medication has been taken

Step 3. Work out the pros and the cons.

It is useful to list pros and cons under two headings - more often this is done in one's head

	Pros	Cons
Ignore the behaviour	Keep the peace	Could be dangerous
Go to the hospital	Could be seen right away	May have to wait for hours and this could disrupt the family

Contact hospital by phone	Could get to doctor	The doctor may be Unavailable
Check if medication has taken	Could ascertain if this is the source of the problem	May be experienced as interfering

Step 4. Choose the best solution

There are two important issues here.

Firstly balance the pro with the con and decide if you will possibly adopt that alternative.

If there are a few that could be suitable, prioritise.

Let's go back to the example. To ignore the behaviour is too risky. The other Three are all possibilities but in order of priority one may decide to ask the person first about medication, the contact the hospital as this is the least disruptive to the family and then go to the hospital as a third option.

Step 5. Plan how to implement the solution.

This is where one becomes committed to the solution.

One needs to work out what the obstacles are and how to get around these as well as having some time frame.

To ask about the medication is going to require some sensitivity, done in a way that does not undermine integrity. And the parents may decide that this needs to be done before two in the afternoon so that the other plans can be implemented if needed.

It may be decided that instead of the parents contacting the doctor the person with the problem will want to do this. Again creating opportunities for taking control over their lives and responsibility. Going to the hospital may require that someone with a car needs to be contacted to assist with transport.

Step 6. Review the outcome.

This is the point at which the parents may look back after the event and agree that the way they approached the problem was effective, that this had given the person with the problem a chance to solve it also and that this strategy

could be used again if necessary.

In other words what was a problem turned into opportunity.

On the other hand it may be decided that it does not help to contact the hospital by phone and that to go straight there would have been better.

Any questions? Does this make sense to you?

It is the ideal and something that I'm sure you do all the time but when in a fix This strategy may be useful.

As an exercise I would like to think about a problem you have solved or one that you are having difficulty with. Put it through the six step test and see what you come up with. Please choose a problem that you feel you want to share. We will also look at how this can be turned into a challenge and opportunity for growth.

SESSION 5. CONTRACTING DESIRED BEHAVIOURS

Purpose: Share ideas generated by homework assignment

Summarise previous session

Give input on theme for the day and encourage participation

Give handouts at the end of the session so that this information can be shared with family members who could not attend.

Programme for the day

Welcome family members

Homework assignments

Summarise last session and remind that next week will be the last session

Any further questions or comments?

Introduce topic for today

Why introduce this topic?

Like many aspects of living in a family, such as communication and problem solving, ensuring that family members adhere to the family rules is also important. It is just such a process that can be stressful for all concerned and yet it need not be.

Once again it has been shown in research that when there are clear limits on behaviour uncertainty and conflict is reduced. Stress is reduced and families can then provide a mentally healthy environment.

Generally families adopt a code of behaviour in which there are rules which are understood by all because they are either talked about or these rules have evolved over time and may not actually be talked about.

For example a spoken rule may be the time for meals or adolescents to come home.

An unspoken rule may be about who sleeps where.

In healthy families rules serve as a means to ensure survival of the family so that each person can perform his appropriate role effectively. For example school going children may need to get up at a certain time so that they are able to prepare themselves adequately for school.

Rules may change over time (bed times change as children get older)

Some rules are the same for all family members (tidying the bathroom after use)

How do we ensure that the rules are adhered to?

There may be several ways -

Coercion

Bribing

Discussion

Agreement

Discipline - example, encouragement, enforcement.

We will focus on discussion and agreement.

How does this topic relate to your particular circumstances?

When a person has schizophrenia, usually he or she is no longer a child and is related to like an adolescent or an adult. However, we may notice behaviours that are not appropriate and as family members we need to step in to correct the behaviour - please note it is the behaviour and not the person - to ensure that it is in accordance with family expectations. If the behaviour continues or the behaviour illicits criticism and hostility, conflict and stress escalate and by now we know that that is what we need to avoid.
We could think of the person who refuses to come to the table for meals and how this impacts on the family.

How do we ensure that family expectations are met in terms of appropriate behaviour?

1. Parents need to be in control (which is different from controlling) - refer to boundaries
2. Set limits that are clear, simple and specific (refer to communication)
3. Families need to be consistent yet flexible. That is they need to adapt to changing circumstances without compromising their values.
4. When there is a possibility of a conflict of ideas one needs to negotiate and compromise and this is probably the most difficult.

How do we negotiate and compromise? (Dougan et al, 1986:90) (Example: Someone who will not come for meals)

1. State your observations
2. Ask the other person to state his or her position and listen
3. State your understanding of the other person's position
4. State your desired solution

5. Request the other person's desired solution and listen

6. Present the differences in ideas, calmly and without emotion

7. Propose a compromise and work around this until agreement is reached.

Illicit ideas, comments or questions from families

General guidelines for negotiation

Listen

Express support and understanding

Focus on the behaviour

Be constructive

Keep emotion - hostility, criticism, over protection, over concern or over involvement out of the discussion.

Illicit ideas from families

What can we do if the situation cannot be changed? (Example: Someone who will not leave the house)

Acknowledge the difficulty as experienced by the other person but state gently your point of view.

Always be respectful

Continue to be encouraging

Give yourselves time out making sure that the other person is in safe keeping.

Illicit ideas, comments and questions from the families

Ask the families to do an exercise as a homework assignment to see fro themselves where they are on track or where they can think of ensuring desired behaviour in a different way.

Acknowledge the stress that the unchangeable presents

What can you or any of the family do when you feel stressed?

Give handout from the book Stress Matters by Sue Musikanth (1996:53-61).
Give handout based on Mc Farlane in Gurman & Kniskern on Family Guidelines (1991:375).
Give hand out from Life Skills for Self Development by Dougan et al (1986:90).

FAMILY GUIDELINES

1. ***GO SLOW.*** Recovery takes time. Rest is important. Things will get better in their own time.
2. ***KEEP IT COOL.*** Enthusiasm is normal. Tone it down. Disagreement is normal. Tone it down, too.
3. ***CREATE SPACE.*** Stay calm. There may be a need to withdraw. Offer contact and feel comfortable with refusal.
4. ***SET LIMITS.*** Everyone needs to know what the rules are. A few clear, simple rules keep things calmer.
5. ***IGNORE WHAT YOU CAN'T CHANGE.*** Let some things go. Do not ignore the use of street drugs or violence.
6. ***KEEP IT SIMPLE.*** Say what you have to say clearly, calmly and positively. Do not insult.
7. ***FOLLOW DOCTOR'S ORDERS.*** Take medications as they are prescribed. Take *only* medications that are prescribed.
8. ***CARRY ON BUSINESS AS USUAL.*** Re-establish family routines as quickly as possible. Stay in touch with family and friends.
9. ***NO STREET DRUGS.*** They make symptoms worse.
10. ***PICK UP ON EARLY SIGNS.*** Note changes. Contact doctor, hospital or clinic.
11. ***SOLVE PROBLEMS STEP BY STEP.*** Make changes gradually. Work on one thing at a time.
12. ***LOWER EXPECTATIONS TEMPORARILY.*** Use a personal yardstick. Compare this month with last month rather with last year or next year.

Extracted from **Handbook of Family Therapy** (1991) edited by A. Gurman and T. Kniskern, p.375.

How do we negotiate and compromise? (Dougan et al, 1986:90)

1. State your observations
2. Ask the other person to state his or her position and listen
3. State your understanding of the other person's position
4. State your desired solution
5. Request the other person's desired solution and listen
6. Present the differences in ideas, calmly and without emotion
7. Propose a compromise and work around this until agreement is reached.

SESSION 6. SUMMARISATION AND EVALUATION

Purpose: Complete unfinished business

Summarise what had been presented and discussed

Evaluate

Programme for the day - outline to the families

Homework assignment

Summarise whole programme with the families and invite members to ask any further questions or give further ideas.

Workshop - What is schizophrenia and importance of medication

Resources with emphasis on the family as a resource

How to manage in the community

A personal account by a consumer

Session 1. Support

Importance of support to family member, to other individuals and to the family as a whole. We seemed to talk a lot about what our family member does and some ideas of the future.

Session 2. Communication

More than just the verbal which can also have different meanings depending on how the words are spoken.

Quantity, complexity, intensity and negativity

Guidelines for effective communication

Session 3. Roles and Boundaries

Roles need to be clear and yet there should be flexibility depending on the situation.

Boundaries need to be clear to allow for appropriate contact. They should not be too open allowing too much emotion (criticism, hostility, over protection, over involvement or over concern) to be expressed and felt. They should not be too closed as this leads to isolation or a feeling of rejection.

Guidelines for clear roles and boundaries

Session 4. Problem Solving

Six steps to effective problem solving -

1. Problem identification,
2. List alternatives,
3. Work out the pros and cons,
4. Choose the best solution,
5. Plan how to implement the solution and
6. Review the outcome.

Homework assignment.

Session 5. Contracting Desired Behaviours

Different ways to ensure that rules are adhered to.

Steps in negotiating and compromising -

General guidelines for negotiation

How to cope with situations that cannot be changed

Literature on stress management and guidelines for coping effectively at home when a family member has schizophrenia.

Request families to present the questions or comments that they have decided to bring to the final group session.

Discussion.

Talk about termination

Request families to complete Psychoeducation Questionnaire.

APPENDIX F

PRESENTATION OF FINDINGS FROM SECTIONS B AND C OF THE PRE- AND POST-TEST QUESTIONNAIRES

SECTION B

All responses in the tables are verbatim. Where there was no response this is indicated as such. Eight respondents completed the pre-test questionnaire and seven respondents completed the post-test questionnaire. Respondent Five did not complete the post-test questionnaire.

Table 4. Respondents' explanations of the term schizophrenia

Number of Respondent	Before the Programme	After the Programme
1	A thought disorder	Thought disorder
2	A thought disorder/chemical imbalance	Thought disorder
3	Impossible to explain	Split from the brain
4	Could not explain	Someone who talks to herself/strange behaviour, very changeable
5	Mental disorder	No response to questionnaire
6	Chemical imbalance leading to psychological disabling disorder. Likely to be long term. No quick recovery – medication control to be established	Mental disorder where sufferer has different perceptions of reality e.g. hears voices
7	Mental illness causing irrational thinking	Inability to think rationally
8	Does not know	Mental disorders involving thought processes

Before the programme, two respondents (25%) stated that schizophrenia was a mental disorder and were able to elaborate with symptoms, three respondents (37,5%) said that schizophrenia was only a mental disorder and three respondents (37,5%) could not explain. After the programme, four respondents (57,1%) were able to elaborate on the term, two respondents (28,6%) said that schizophrenia was a mental disorder and one respondents (14,3%) could not explain.

Table 5. Understanding of other family members of the respondents of the term schizophrenia

Number of Respondent	Before the Programme	After the Programme
1	A thought disorder	Thought disorder
2	As a sickness	Thought disorder
3	No response	Illness of the brain
4	No response	Illness in the brain
5	A mental disorder	No response to the questionnaire
6	Chemical imbalance leading to psychological disabling disorder. Likely to be long term. No quick recovery – medication control to be established	Mental disorder where sufferer has different perceptions of reality e.g. hears voices
7	Still trying to come to terms with the illness	No response
8	No response	Reasonably well informed

Before the programme, one respondent (12,5%) felt that the family members had a detailed knowledge of the illness, three respondents (37,5%) knew that it was a mental disorder or a sickness and two respondents (50%) were not able to state. After the programme, one respondent (14,3%) was able to give symptoms, four respondents (57.1%) stated that the families thought that schizophrenia was a thought or mental disorder and two respondents (28,6%) could not explain.

Table 6. Feelings of respondents when they think of their family members with schizophrenia

Number of Respondent	Before the Programme	After the programme
1	Sad – always worry about the future	Sad
2	Worry about his future	Sad
3	Depressed	Stressful
4	No response	Very emotional. Need to accept but don't feel angry, sad, frustrated
5	Saddened, frustrated	No response to the questionnaire
6	Distraught, helpless, sad	Dismay, especially at long term prospect and no improvement/stabilisation
7	Very sad and angry	Sad
8	Shocked	Shocked → saddened by condition and prognosis

In the beginning, the feeling of sadness was expressed by four respondents (50%)with a range of other emotions having been expressed. At the end, sadness and dismay was expressed by five respondents (51,4%) with fewer other emotions having been expressed.

Table 7. People, groups or organisations that give support to the respondents

Number of Respondent	Before the Programme	After the Programme
1	Support group at hospital . Mother -in-law	Brothers & sisters-in-laws
2	Mother, brothers, sisters, wife	Mother, brothers, friends
3	Ministers, family, neighbours	Social worker, church
4	Family	Social Worker, doctor, family church, clinic
5	Support from Cape Support for Mental Health	No response to the questionnaire
6	Family, service club affiliation	Family, Cape Support for Mental Health, Rotary
7	No response	Psychiatrist
8	No response	Cape Mental Health, Fountain House

There were a range of sources of support. These included informal sources, such as family members and formal sources, such as, ministers, a service club and the mental health network.

Table 8. Attempts families make to solve problems

Number of Respondent	Before the Programme	After the Programme
1	Sit down and discuss	We (Husband & Respondent) discuss the problem. If necessary involve kids
2	Remain calm, speak calmly and observe	We normally discuss it
3	We seek help	Choosing the best solution
4	Family helps	Identify the problem, find the best way, try to cope
5	Group discussion. Speaking to the experts	No response to the questionnaire
6	Generate alternative solutions	Discussion leading to consensus
7	This is a new thing and we're still trying to deal with it.	Talk
8	No response	Being fully supportive and sympathetic to patient

Before the programme, six respondents (75%) reported appropriate attempts by the family to solve problems. One respondent (12,5%) reported that she was still trying to deal with the problem and one respondent (12,5%) did not respond. At the end of the programme, six respondents (85,7%) reported appropriate ways of resolving problems. The person who had initially said that she was still trying to deal with the problem, said that she talked. One respondent (14,3%) did not respond. The person who did not respond initially was more appropriate at the end and one person who responded appropriately initially, was the person who did not respond (to the post-test questionnaire). Respondents One, Three and Four gave an indication that they had worked through the problem solving strategy as discussed at the focus group session Four (See Chapter Five:56-57).

Table 9. Respondents' considerations of alternate ways to solve problems

Number of Respondent	Before the Programme	After the Programme
1	No	To brainstorm with the family – at first
2	Maybe	No
3	No	No
4	No	No
5	No	No response to the questionnaire
6	Yes, analyse the problem and define the issues before generating alternatives	Benevolent autocracy
7	No	No
8	No response	No

Before the programme, five respondents (62,5%) reported that they did not consider alternate ways, one respondent (12,5%) said maybe, one respondent (12,5%) proposed an alternative and one respondent (12,5%) did not respond. After the programme, five respondents (71,4%) reported that they did not have alternate ways to solve problems and two respondents (28,6 %) suggested an alternative.

Table 10. Respondents' descriptions of communication in the family

Number of Respondent	Before the Programme	After the Programme
1	Good but index patient does not like communicating	Good
2	Very good	Good
3	Very close	Calm
4	Good	Calm
5	Good	No response to the questionnaire
6	Through the mother	Family staggered – much of the communication via the mother
7	On a scale 1 to 10 the answer would be 6	All right
8	No response	Very good

There was no change before and after the programme. In the beginning, five respondents (67,5%) suggested that communication was good, one respondent (12,5%) reported that it was all right, one respondent (12,5%) stated that communication was via the mother and one respondent (12,5%) gave no response. After the programme, six respondents (85,7%) suggested that their communication was good and one respondent (14,3%) still claimed that communication was via the mother.

Table 11. Respondents' descriptions of how communication could be improved

1	If index patient could join in	To have one sport or hobby that interests all
2	No response	If we watch less T.V. and have hobbies all can participate in
3	Being interested in each other	Closeness to family
4	No	If we talk more, come together as a family
5	No	No response to the questionnaire
6	Setting aside a fixed period (meals) and disallowing interruptions	Communicate more
7	Taking time	With patience
8	Developing more understanding	No response

Before the programme, two respondents (25%) stated that they did not need to improve communication, five respondents (67,5%) gave constructive ideas as to how to improve in this area and one respondent (12,5%) did not respond. After the programme, six respondents (85,7%) of respondents gave suggestions of how improvements could be made, and one respondent (14.3%) gave no response.

Table 12. Respondents' descriptions of what happens when they feel angry

Number of Respondent	Before the Programme	After the Programme
1	Feel depressed and want to be alone	Am quiet or will go for a walk
2	Go out and cool off	Keep to myself or go fishing
3	It comes out and goes away quickly	Don't stay angry
4	Sad	Try to calm myself and control anger
5	Need to suppress anger	No response to the questionnaire
6	Want to correct situation	Tend to bottle it up
7	Quiet or stating my reasons	Get quiet a lose temper for a short while
8	No response	Get upset with myself

Before the programme, three respondents (37,5%) reported fairly constructive ways of managing anger, two respondents (25%) reported feeling sad, two respondents (25%) suggested suppressing their anger and one respondent (12,5%) did not respond. At the end of the programme, four respondents (57,1%) expressed constructive ways of managing their anger, one respondent (14,3%) expressed sadness, 14,3%) expressed losing his temper and one respondent (14,3%) expressed suppressing the anger.

Table 13. Respondents' descriptions of how they communicate anger

Number of Respondent	Before the Programme	After the Programme
1	Not the right way	Not good – one should talk about others shortenings
2	Talk in a cool voice	Not very good
3	Taking anger not too seriously	Don't get uptight anymore
4	No response	Stay calm – realise Debbie will get worse
5	Distance myself	No response to the questionnaire
6	Wait for appropriate moment	Losing it, warning about that which is not liked
7	Impulsively	No response
8	No response	Being unreasonable and saying the wrong thing

Before the programme, two respondents (25%)expressed anger appropriately, two respondents (25%), expressed anger inappropriately, two respondents (25%) avoided anger and two respondents (25%) did not respond. After the programme, two respondents (28,6%) expressed anger appropriately, four respondents (57,1%) expressed anger inappropriately and one respondent (14,3%) did not respond.

Table 14. Respondents' descriptions of what happens when they convey criticism

Number of respondent	Before the Programme	After the Programme
1	My heart aches	I don't like to criticise
2	Talk in a cool and clear tone	I feel bad
3	No response	Don't normally criticise
4	No response	Don't argue anymore, stay calm, less one talks the better
5	No response	No response to the questionnaire
6	Sometimes immediately, sometimes wait for issue to settle and tackle positively	Bite the bullet, try to be constructive by pointing out agreed values and objectives
7	Feel uncomfortable	Feel uncomfortable
8	No response	Try to be as tactful as possible

Before the programme, four respondents (50%) did not respond. Only one respondent (12,5%) indicated feeling quite objective when expressing criticism. The remaining three respondents (37,5%) gave varying replies of an emotive nature. At the end of the study, all respondents answered the question. Four respondents (57,1%) seemed to approach criticism objectively and three respondents (42,9%) reported a dislike for criticism.

Table 15. Respondents' descriptions of how they communicate criticism

Number of Respondent	Before the Programme	After the Programme
1	Don't normally show anger	Good/well
2	No response	Disagree
3	No response	Quietness
4	No response	Stay calm and quite
5	No response	No response to the questionnaire
6	Describe situation, illustrate what is wrong. Suggest more suitable solution	Bite the bullet Warning about that which is not liked
7	Tactfully	With difficulty
8	No Response	By action or discussion

In the beginning, five respondents (62,5%) gave no response, two respondents (25%) indicated that they try to express anger constructively and one respondent (12,5%) indicated that she did not express anger. At the end, all respondents answered the question with a range of answers.

Table 16. Respondents' examples of how they may have expressed over involvement

Number of Respondent	Before the Programme	After the Programme
1	No	No
	No	No
3	Yes, My daughter has been suffering for twelve years and I as mother, am also suffering	She mostly does things for herself
4	Yes, take too much responsibility	No, goes to clinic on her own and makes her own food
5	No	No response to the questionnaire
6	No	No
7	Yes	Not so much new that index patient has been discharged
8	No	Concerned, but not overly involved

Before the programme, six respondents (75%) stated that they were not over involved with their family member and two respondents, Three and Four (25%), said that they were over involved. After the programme, seven respondents (100%) said that they were not over involved and the parents who initially had stated thus, reported that at the end of the programme their daughter had become more independent.

Table 17. Respondents' examples of how they may have expressed over concern

Number of Respondent	Before the Programme	After the programme
1	Yes, always worry about his tablets, where he is	Yes, if he goes out with friends always worry about index patient being safe
2	No	No
3	Yes, the daughter becomes violent	Not anymore. The group meetings meant a lot to us – we learnt quite a lot
4	Yes, become very worried	Not anymore Lately do not get over anxious since attending the programme, - have more knowledge
5	No	No response to the questionnaire
6	Yes, concerned about index patient when parents are unable in the to support her financially	Yes, concern at what happens in 5 to 10 years time especially if one is left alone without family
7	Yes	Yes, very aware of mood swings
8	Anxious at times	Concerned about the future of the index patient and how she will handle this

Before the programme, five respondents (65,5%) stated that they were over concerned, two respondents (25%) stated that they were not and one respondent (12,5%) stated being anxious. After the programme, three respondents (42,9%) stated over concern and four respondents (57,1%) stated that they were not over concerned.

Table 18. Respondents' examples of how they may have expressed overprotection

Number of Respondent	Before the Programme	After the Programme
1	Definitely yes, seldom want him to go out till late at night. Worried about him getting into the bus, taxi, etc.	Yes, sometimes as he is very clumsy - probably due to medication
2	No	No
3	Yes, she leaves the house and doesn't tell me where she is going	Not anymore – if index patient goes out
4	Yes, worry about the safety	Not anymore – went out other day for the first time and came home without any problem
5	Yes, feel anxious when she is left alone too long especially in evening	No response to the questionnaire
6	At time when I'm alone	No
7	Yes	Yes, check on her constantly
8	Yes	No

Before the programme, six respondents (75%) reported feeling overprotective, one respondent (12,5%) reported feeling overprotective when her daughter was on her own and one respondent (12,5%) said he did not feel overprotective. After the programme, five respondents (71,4%) reported that they did not feel overprotective, one respondent (14,3%) still reported feeling over protective and one respondent (14,3%) said that she felt overprotective sometimes.

Table 19. Family members who respondents may turn to in a crisis

Number of Respondent	Before the Programme	After the Programme
1	Husband	Husband Communicate well with each other and husband listens
2	No response	My wife. She understand me better than anyone else
3	Children (grown up) because we are very close	Husband Always solve problems with husband
4	No response	Wife We must work together
5	Husband. Feel she is our child and we should be able to support one another in our anxiety	No response to the questionnaire
6	Generally try to face it myself – like to be self sufficient	Wife, she is a partner
7	Don't turn to family. Try to solve problem on own [as I am] stubborn	If I can't deal with it myself, I speak to a friend. I'm the strongest in the family
8	Husband	Husband Most understanding and supportive

Before the programme, three respondents (37,5%) stated that they turned to a spouse (all respondents were married), two respondents (25%) relied on themselves, one respondent (12,5%) turned to the adult children and two respondents (25%) did not respond. After the programme, 6 respondents (85,7%) stated that they turned to a spouse, one respondent (14,3%) who initially relied on herself reported that she talked to a friend as she is the strongest in the family.

Table 20. Respondents' contributions to the family

Number of Respondent	Before the Programme	After the Programme
1	See to everyone's needs Look after, washing etc.	To love, cherish and listen
2	No response	Breadwinner, loving parent
3	Very "close maker" *	Cooking for family
4	No response	Father – children always turn to me for advice
5	Stabilise, support	No response to the questionnaire
6	Was unifying head – no longer	Head of household
7	Organiser	Organiser
8	No response	Attempt to create harmony

* This verbatim response is understood as the mother seeing her role as keeping the family together

Before the programme, (37,5%) of respondents did not respond this question. Four respondents (50%) were clear about their contributions / roles. These four respondents were the four mothers. One respondent (12,5%) felt he who had been a unifying head of the family, no longer knew what his contributions to the family were. After the programme, all seven respondents (100%) were clear about their roles.

Table 21. Those in the family who set the rules

Number of Respondent	Before the Programme	After the Programme
1	Respondent and husband	All of us have our likes and dislikes and we respect each other's do's and don'ts.
2	Respondent and wife	Parents
3	Husband	Parents
4	No response	Parents
5	Both	No response to the questionnaire
6	Each/share	Parents – modified increasingly by young adults
7	Respondent	Mostly me
8	Respondent	Parents

Before the programme, the rules were set by four of the parents (50%). Two parents (25%) stated that rules were set by the other parent and one respondent (12,5%) did not respond. After the programme, five respondents (71,4%) reported that both parents set the rules, one respondent (14,3%) said just the one parent set the rules and one parent (14,3%) implied that the family set the rules.

Table 22. Means that families use to ensure that rules are adhered to

Number of Respondent	Before the Programme	After the Programme
1	We try but sometimes rules are broken	We reward each other
2	We talk	Remind each other
3	Satisfied	Agree
4	No response	Agree
5	By acceptance	No response to the questionnaire
6	Criticism	Trust but objection if not adhered to
7	Not very well	A bit lenient
8	No response	By accepting parents' decisions

Before the programme, four respondents (50%) suggested that they had appropriate means to ensure that the rules are adhered to. One respondent (12,5%) stated that criticism was used and one respondent (12,5%) reported that she did not do well. Two respondents (25%) did not respond. After the programme, six respondents (85,7%) were able to give more appropriate answers and one respondent (1%) felt that they were too lenient.

Table 23. Those in the family who ensure that rules are adhered to

Number of Respondent	Before the Programme	After the Programme
1	Respondent and husband	We work as a steam
2	Mother	All of us together
3	Mother	Parents
4	No response	Parents
5	Members of our family	No response to the questionnaire
6	The objector	Individual
7	Mother will try, depends on problem Father will have say	Mother
8	No response	Usually mother

Before the programme, two respondents (25%) reported that the parents ensure that the rules are adhered to, two respondents (25%) reported that the mother ensures this, one respondent (12,5%) said that the family members ensure this and one respondent (12,5%) said that the objector ensures that rules are adhered to. Two respondents (25%) did not respond. After the programme, two respondents (28,6%) said that the family did this, two respondents (28,6%) said that the parents did this, two respondents (28,6%) indicated that the mother did this and one person (14,3%) still claimed that the individual did this.

Table 24. Respondents' assessments of consistency in ensuring rules are adhered to

Number of Respondent	Before the Programme	After the Programme
1	No	Yes
2	Yes	Yes
3	Yes	Yes
4	No response	Yes
5	More or less	No response to the questionnaire
6	Not always	Yes
7	No	No
8	No response	Yes – generally

Before the programme, only two respondents (25%) stated that they were consistent and two respondents (25%) stated that they were inconsistent. After the programme, six respondents (85,7%) claimed that they were consistent and only one respondent (14,3%) still claimed being inconsistent. This respondent (Seven) only attended the workshop and second focus group session.

Table 25. Question 11. Examples of how families cope with change

Number of Respondent	Before the Programme	After the Programme
1	First time index patient feel ill, the family was shattered. We All cried buckets full	Good – no we have now accepted son as a schizophrenic. We all don't go into panic stage as we are getting stronger the more we learn about the sickness
2	No response	Good – we encourage each other
3	It will always be the same	They accept
4	No response	Get on and manage the new situation
5	Okay	No response to the questionnaire
6	No response	We rally together
7	This is the biggest change and [I] can't communicate [this] yet	No response
8	No response	No response

Before the programme, four respondents (50%) did not respond, two respondents (25%) indicated that they experienced difficulty, one respondent (12,5%) indicated a sense of hopelessness and one respondent (12,5%) seemed to cope. After the programme, five respondents (71,4%) stated that they were able to cope with change and two respondents (28,6%) did not reply.

SECTION C

The Likert Scale was used and will be presented as follows -

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I	I
1	2	3	4	5

Table 26. Respondents' good understanding of schizophrenia

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	2	2	5	3	2	3	3	2
After the Programme	2	2	2	2	–	3	2	2

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I	I
1	2	3	4	5

Table 27. Respondents' acceptance of schizophrenia in the family member

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	3	2	3	3	2	2	2	2
After the Programme	2	2	1	2	–	1	2	2

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I	I
1	2	3	4	5

Table 28. Respondents' appreciation of the importance of support

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	2	2	2	2	2	2	3	2
After the Programme	2	2	1	2	–	3	1	1

Strongly Agree Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I
1	2	3	4

Table 29. Respondents' attempts to solve issues by discussing these together as a family

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	1	2	3	2	2	3	3	2
After the Programme	2	2	2	2	–	2	2	1

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 30. Respondents' perceptions of their openness with each other

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	5	2	2	2	2	4	3	3
After the Programme	2	2	2	2	–	2	3	1

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 31. Respondents' abilities to communicate anger in a healthy way

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	3	2	2	1	3	4	4	3
After the Programme	2	2	1	2	–	3	4	2

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 32. Respondents' abilities to communicate criticism in a healthy way

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	3	2	2	1	3	2	2	–
After the Programme	1	2	2	2	–	2	4	2

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 33. Respondents' over involvement most of the time with the family member with schizophrenia

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	2	2	2	2	2	4	2	2
After the Programme	2	2	2	4	–	4	2	3

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I	I
1	2	3	4	5

Table 34. Respondents' over concern most of the time with the family member with schizophrenia

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	1	2	2	2	1	3	1	2
After the Programme	3	3	4	3	–	4	1	1

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I	I
1	2	3	4	5

Table 35. Respondents' over protectiveness most of the time with the family member with schizophrenia

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	1	2	2	2	2	2	1	2
After the Programme	3	3	4	4	–	4	1	3

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I	I
1	2	3	4	5

Table 36. Respondents' perceptions of all problems being openly discussed by the whole family

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	2	2	2	2	3	4	3	–
After the Programme	3	3	4	4	–	3	4	2

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I	I
1	2	3	4	5

Table 37. Respondents' perceptions of only some problems being openly discussed by the whole family

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	4	2	2	4	3	3	2	1
After the Programme	2	2	2	2	–	2	2	–

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 38. Respondents' need for clarity about the roles that they could play in the family

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	4	4	2	1	2	3	4	–
After the Programme	5	5	4	4	–	2	4	3

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 39. Respondents' confidence about the contributions they make in the family

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	2	2	2	2	3	2	4	1
After the Programme	1	1	2	2	–	2	–	2

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 40. Respondents' difficulties in agreeing on accepted standards of behaviour

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	3	–	2	1	2	5	4	–
After the Programme	4	4	4	4	–	4	2	4

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 41. Respondents' difficulties in accepting change most of the time

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	2	–	2	2	4	3	3	–
After the Programme	4	4	4	4	–	4	2	2

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 42. Respondents' ease in adapting most of the time

Number of Respondent	1	2	3	4	5	6	7	8
Before the Programme	2	3	2	4	2	2	3	2
After the Programme	3	2	2	2	–	2	4	2

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	2	3	4	5

Table 43. Respondents' ratings of areas of family functioning before and after the programme

Question Number	Areas of family functioning	Before the Programme		A fter the Programme	
		Total mean score	*n**	Total mean score	*n**
1	A good understanding of schizophrenia	2,75	8	2,14	7
2	Acceptance of schizophrenia in the family member	2,38	8	1,71	7
3	Appreciation of the importance of support	2.13	8	1,71	7
4	Attempts to solve issues by discussing these together as a family	2,25	8	1,86	7
5	Perceptions of openness with each other	2,88	8	2,00	7
6.1	Ability to communicate anger in a healthy way	2,75	8	2,29	7
6.2	Ability to communicate criticism in a healthy way	2,14	7	2,14	7
7.1	Over involvement most of the time with the family member with schizophrenia	2,25	8	2,71	7
7.2	Over concern most of the time with the family member with schizophrenia	1,75	8	2,71	7
7.3	Over protectiveness most of the time with the family member with schizophrenia	1,75	8	3,14	7
8.1	Perceptions of all problems being openly discussed by the whole family	2,57	7	3,29	7
8.2	Perceptions of only some problems being openly discussed by the whole family	2,63	8	2,00	6
9.1	Need for clarity about the roles respondents could play in the family	2,86	7	3,86	7
9.2	Confidence about the contributions respondents make in the family	2,25	8	1,67	6
10	Difficulty agreeing on accepted standards of behaviour	2,83	6	3,71	7
11.1	Difficulty in accepting change most of the time	2,67	6	3,43	7
11.2	Ease in adapting most of the time	2,50	8	2,43	7

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I	I	I	I	I
1	2	3	4	5

n* = the number of respondents who answered the item.

Table 44. Relationships between the differences of the rank scores of the questions in Section C of the Pre-and Post Test questionnaires

Question number	Valid number	T	Z-score	P-value	Significant
1	7	0.00	1.603567	0.054405	No
2	7	0.00	1.825742	0.033949	Yes
3	7	2.000000	1.095445	0.136665	No
4	7	3.000000	1.213560	0.112463	No
5	7	0.00	1.603567	0.054409	No
6.1	7	3.000000	1.213560	0.112463	No
6.2	6	2.500000	0.267261	0,393635	No
7.1	7	2.500000	no score *	no score *	No
7.2.	7	2.500000	1.677256	0.046751	Yes
7.3	7	0.00	2.201398	0.013858	Yes
8.1	6	2.500000	1.677256	0.046751	Yes
8.2	6	0.00	1.603567	0.054409	No
9.1	6	2.000000	1.483240	0.069011	No
9.2	6	2.000000	0.534522	0.296492	No
10	5	5.000000	0.674200	0.250095	No
11.1	5	1.500000	1.618080	0.52828	No
11.2	7	4.000000	0.365148	0.357502	No

* No score . The Z-score and Probability level could not be calculated as most of the before and after scores remained the same. This indicates that there is no evidence of statistical significance.

The Wilcoxon matched pairs test will be used to ascertain statistical significance. This is a "non-parametric statistical test for ordinally scaled variables used with matched or correlated samples". It looks at the magnitude of the difference between the pairs of scores (Runyon,1991:500-501) and is suitable when the sample is small. The level of statistical significance is indicated where $P< 0.05$. T represents the test statistic and Z represents the standardised Z score. Valid N represents the valid number of respondents in each question that completed both the Pre-test and Post-test questionnaires. A one tailed test was used to obtain the P-value as there were *a priori* reasons to expect a change in a particular direction. The dependent variables were the aspects of family functioning mentioned in Section C of both questionnaires and the independent variable was the psychoeducation programme. The null hypothesis (which is an hypothesis of "no effect") states that family functioning in families in which a member has schizophrenia does not improve with psychoeducation (Siegel & Castellan,1988:7).

APPENDIX G

PILOT STUDY

1. INTRODUCTION

A single family was studied. The family consisted of the mother, father and son of nineteen years. The son was at school and both parents worked. The father had been married previously and divorced. From this marriage there was a son and a daughter who lived in Johannesburg and Zimbawe respectively.

2. QUESTIONNAIRE

The same questionnaire was administered in the pre-test and post-test except where indicated with an asterisk (*). This indicates that the question was only asked in the post-test.

SECTION A

1. How would you explain the term "schizophrenia"?

2. When you think of your family member having schizophrenia what do you feel?

3. List people / organisations / groups that give you support.

4. When faced with a problem in the family, how do you attempt to solve it?

5. How would you describe communication in the family

6. How do you communicate criticism and anger

7. Describe your expression of concern in the family *

8. When you feel stressed who in the family do you turn to?

9. How would you describe your role in the family?

10. How do you ensure that actions of family members conform to your expectations?

11. How do you cope with change?

SECTION B

Circle your response

How would you rate your.....

1. **Knowledge of schizophrenia**

Excellent Good Average Poor Non-existent

2. **Support networks**

Excellent Good Average Poor Non-existent

3. **Acceptance of schizophrenia**

Excellent Good Average Poor Non-existent

4. **Ability to solve problems**

Excellent Good Average Poor Non-existent

5. **Communication style**

Excellent Good Average Poor Non-existent

6. **Ability to effectively communicate criticism and anger**

Excellent Good Average Poor Non-existent

7. **Ability to effectively communicate concern**

Excellent Good Average Poor Non-existent

8. **Ability to perform your expected role in the family ***

Excellent Good Average Poor Non-existent

9. **Ability to balance respect for privacy with need for involvement with family members ***

Excellent Good Average Poor Non-existent

10. **Ability to ensure that family members conform to your expectations**

Excellent Good Average Poor Non-existent

11. **Your ability to make changes**

Excellent Good Average Poor Non-existent

SECTION C *

During our family sessions what have you found to have had the most impact?

What would you like to recommend be changed, omitted or added?

The goal of all the sessions was to improve family harmony.
To what extent do you think this has been accomplished and please give reasons for your answer.

3. FINDINGS OF THE PILOT STUDY

3.1 Knowledge of schizophrenia

Initially the family were more subjective in their understanding of the illness. There was a move from descriptions such as "terrifying", "forgetfulness being a thousand times worse in schizophrenia" and "unbelievable tension" to describing the illness as leaving the person "disorientated", "unable to cope with life as a person not suffering from it" and that it

made the person feel "different". While there were still some emotional descriptions, these were less, indicating that with education there could be a more balanced and holistic understanding.

The rating scale indicated that the mother made only marginal gains (that is, one point on the rating scale), the father did not report any change and the son reported having improved in his knowledge. The rating scale did not accurately reflect the parents increased knowledge and understanding of the illness.

3.2. Acceptance of the illness

The parents only responded to this question. There was a change from anger and frustration to sadness. According to Kubler Ross (1993) this would indicate that there was move towards acceptance of the loss of a mentally healthy son.

The rating scale indicated that the mother had made no change and the father's was marginal.

3.3 Support networks

Data from before and after the programme indicate that there were no changes in the extent of the support networks. The rating scale was only introduced in the post-test and this revealed that the mother and son have good support networks and the father average. The time frame of three months was probably too short to show significant changes. This suggests that the multiple family group format may help towards the extending of meaningful support and also accelerating this process. Further, due to the time limit of a psychoeducation programme, emphasis may need to be focused more on families understanding of the importance of a social network.

3.4 Problem solving

From solving problems "my way" and experiencing this as involving conflict, the father began to discuss problems and use compromise. Initially the son indicated some measure

of trying to understand others and then solve the problem alone. In the end he reported that he tried to ignore problems.

The rating scale indicated that the mother had not improved and the father had. It is doubtful that these results reflect the real picture. The son who initially felt he had average problem solving skills, reported at the end that they were non-existent which may have been more indicative of his deteriorating mental state which is characterized by withdrawal.

3.5 Communication skills

The parents both moved from "not too good" and "poor" to a sense of improvement with an acknowledgment that in time this would continue to improve. The son showed no progress or deterioration.

The rating scale reflected marginal improvement in the mother and son and marginal deterioration in the father.

3.6 Expression of anger and criticism

The mother changed from expressing anger with shouting to more insight into the effects of her style. The father was initially very autocratic. Although he did not change his position significantly, he reported attempting to remain calm. The son reported that he expressed these emotions with silence and later reported that he did this through his art.

The rating scale indicated no change in the mother and marginal deterioration in the father. This result did not concord with the descriptions which were more accurate as the father, in particular, had made much effort to change. However his increased insight into the effects of criticism and anger may account for this.

5.7 Expression of concern in the family

This question was only asked after in the post test questionnaire. The mother expressed her concern in the family by being the arbitrator, the father by being distant and the son by being harmonious.

The rating scale looked at the ability to effectively communicate concern. The mother and father both reported average skills for this and that the son felt he was good. Due to the son's affective blunting he did not give the impression that he was able to communicate concern so well. His response may reflected his wish to do so.

3.8 Roles

The mother saw herself as a "doer" and then added to this one of "supporter". When the father answered this on the first questionnaire there had been a number of sessions already. Although he was initially the dominant person in the family he, at this stage, was doubting his position and responded by saying that he did not know. Later he reported that he saw himself as a role model for his son, a provider and supporter. The son only answered this at the end when he reported that he saw himself as the leader. The son's experience of himself as a leader may reflect his feeling of the one in the family to give direction, possibly as a result of the parental conflict that is diverted through him.

The rating scales introduced at the end only, concurred with the descriptions. The mother seemed to expand her role with education and support as did the father.

3.9 Boundaries

Mother reported on both occasions that she only turned to friends when under stress. The father reported on both occasions that he turned to no one and the son said he that he turned to his mother.

The rating scale was only introduced at the end. The mother rated herself as average, the father poor and the son excellent.

These results indicate that the parents did not turn to one another when under stress, reinforcing the poor parental subsystem. They still tended to remain fairly isolated from one another with the son in an enmeshed relationship with the mother.

3.10 Behaviour

Initially the mother reported that she ensured conformity to behaviour by doing activities herself. After the programme she said that she realised that being authoritarian was not effective. Being avoidant created guilt for the family which was also not acceptable. Initially the father said that he also did activities by himself and added that he was "dictatorial". At the end he said that he ensured conformity "by any means (devious or otherwise)". The son reported that he kept to himself and blocked people off.

There was a reasonable correlation between the mother's description and the rating scale. In the father and son's cases none of the results of the rating scale could be considered accurate.

3.11 Capacity to accept change

Initially the mother said that she coped with change. In the post-test she reported that she had been exposed to little change but had lost the capacity to be spontaneous. The father initially said that he accepted change with difficulty. At the end he repeated this and added that for the sake of peace and harmony conceded to change. The son reported that he just adapted.

The results of the rating scales seem to more accurately describe the changes that took place.

4. EVALUATION OF THE PILOT STUDY

4.1 Evaluation of the intervention

The index patient was invited to attend if he felt able. He attended five of the eight sessions. When the index patient attended, issues were dealt with superficially so to avoid affective overload. His concentration was poor, he needed to move about and he was not able to engage consistently in the discussions. When the patient was absent more contentious issues such as the father's negative attitude to his son, mother's enmeshement with him and their problems around agreeing to consistent limit setting, could be addressed.

Through psychoeducation, the following improvements in the family could be made

* The family felt that they had developed a greater acceptance of the illness.
* There was a realisation that they are not alone.
* The father acquired a greater understanding of the illness although not total acceptance of his son's negative approach to life.
* They acknowledged the importance of support.
* The family felt that the goal, to improve family harmony, had been accomplished.

4.1 Evaluation of the questionnaire

The overall impression of the questionnaire was that it did reveal some changes that could be verified in the descriptions. Some of the questions were not specific enough, such as putting anger and criticism in the same question. The concept of over concern was not addressed.

Generally there could have been more questions to elicit more detail.

The rating scales did not consistently reflect the answers to similar descriptive questions.

The addition of Question 7 in Section A and Questions 8 and 9 in Section C were added in the post-test, as these issues arose as important during the process of intervention

5. RECOMMENDATIONS FROM THE PILOT STUDY

The following recommendations could be made:

* The questionnaire needs to reflect more detail.

* Apart from just the respondent's understanding of schizophrenia, it would be useful to determine how this is understood by other members of the family, in the event that they would not able to attend.

* Some questions need to impart the assumption that families have strategies for coping that work well or may just need enhancing.

* As appropriate expressed emotion is so important in preventing relapse, this section would require more specific questions (Keefler,1994:372).

* In order to improve the reliability of the rating scale, there will be a change to the use of a Likert Scale which has a less "ambiguous ordinality of response categories" (Rubin,1991:205).

* There will also be an attempt to more closely align the questions seeking description with those corresponding in the rating scale.

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