

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

An exploratory study on the needs of families with a relative with schizophrenia who are utilising services at Cape Mental Health Society

By  
Paula Ann Sellmeyer – SLLPAU002

DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SOCIAL SCIENCE IN CLINICAL SOCIAL WORK

SUPERVISOR: SHONA STURGEON

DEPARTMENT OF SOCIAL DEVELOPMENT  
UNIVERSITY OF CAPE TOWN  
DECEMBER 2002

THIS WORK HAS NOT BEEN PREVIOUSLY SUBMITTED IN WHOLE, OR IN PART, FOR THE AWARD OF ANY DEGREE. IT IS MY OWN WORK. EACH SIGNIFICANT CONTRIBUTION TO, AND QUOTATION IN, THIS DISSERTATION FROM THE WORK OR WORKS, OF OTHER PEOPLE HA BEEN ATTRIBUTED, AND HAS BEEN CITED AND REFERENCED.

Signature: Paula Ann Sellmeyer

Date: 29/05/2003

## ABSTRACT

This study aims to better equip mental health professionals to meet the needs of families. The purpose of this research is to explore the needs of families whose relative has been diagnosed with schizophrenia and who are utilising services at Cape Mental Health Society. The motivation for this study comes from the fact that families play a crucial role in psychiatric rehabilitation of their relative with schizophrenia. If the needs of the family are adequately addressed then the family is better able to cope, with their relative's schizophrenia and they are then able to play a role in the psychiatric rehabilitation of their relative. Research has found that mental health professionals are often unprepared and unaware of what the family's needs are.

The sample for the study was drawn from people with schizophrenia whose families were involved with their relative during the time of diagnosis and are currently utilising social work services at Cape Mental Health Society. Of the fourteen subjects eleven were interviewed. An in-depth interview schedule was designed using closed and open-ended questions. Questions were designed to explore the experience and needs of the family from the time when their relative first presented with symptoms of schizophrenia until now. The data was then analysed using content analysis.

The data revealed that the needs of the families could be categorised into three areas - support, education and practical needs. Additional findings were that a high percentage of the families interviewed carried large amounts of guilt associated with their relative's schizophrenia and that the experience of schizophrenia disempowers the families. It is recommended that families be effectively educated on schizophrenia and supported throughout the course of their relative's illness.

**“What is the purpose of life? I believe that satisfaction, joy and happiness are the ultimate purposes of life. And the basic sources of happiness are a good heart, compassion, and love. If we have these mental attitudes, even if we are surrounded by hostility, we will feel little disturbance.”**

- H.H. THE DALAI LAMA

(Johnson, 1994)

University of Cape Town

## **ACKNOWLEDGEMENTS**

I would like to acknowledge the following people for making this  
dissertation possible:

The families who so willingly participated this research,  
My supervisor, Shona Sturgeon, for her patience, dedication and support,  
My family and friends for their understanding and care.

## TABLE OF CONTENTS

Abstract	i
Acknowledgements	iii
<b>CHAPTER ONE: GENERAL INTRODUCTION</b>	<b>1</b>
1.1 Introduction	1
1.2 Motivation for the Research	2
1.3 Purpose of the Research	3
1.4 Research Question	4
1.5 Limitations of the Study	5
1.6 Ethical Considerations	5
1.7 Organisation of the Dissertation	5
<b>CHAPTER TWO: LITERATURE REVIEW</b>	<b>7</b>
2.1 Introduction	7
2.2 Schizophrenia	8
2.2.1 Epidemiology	10
2.2.2 Etiology	11
2.2.3 Subtypes	14
2.2.4 Diagnosis	15
2.2.5 Treatment	16
2.3 Factors which contribute to the course of schizophrenia	18
2.3.1 Genetics	18
2.3.2 Family – expressed emotion	19
2.3.3 Social functioning and relationships	24
2.3.4 Physical environment	28
2.4 The Family	29
2.4.1 The experience of schizophrenia for the family	29
2.4.2 The effects of schizophrenia on the family	33
2.4.3 Needs of the family	37
2.5 Intervention for families affected by schizophrenia	40
2.6 Benefits to a person with schizophrenia when their family receives treatment.	44
2.7 Concluding Comments	46
<b>CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY</b>	<b>47</b>
3.1 Introduction	47
3.2 Research Design	47
3.3 Sampling	48
3.3.1 The Population	48
3.3.2 The Sample	48

3.3.3 Sampling Procedure	48
3.3.4 Sample Size	49
3.4 Data Collection	49
3.5 Interview Schedule	51
3.6 Data Analysis	52
3.7 Limitations	53
3.8 Ethical Considerations	53
<b>CHAPTER FOUR: RESULTS AND DISCUSSION OF RESULTS</b>	<b>55</b>
4.1 Respondents	55
4.1.1 How are you related to your relative with schizophrenia?	56
4.1.2 What is your relative with schizophrenia's gender?	56
4.1.3 What is your first language?	57
4.2 Diagnosis	57
4.2.1 When was your relative diagnosed with schizophrenia?	57
4.2.2 What was your relatives' age at the time of diagnosis?	58
4.2.3 Who diagnosed your relative with schizophrenia?	59
4.2.4 What happened when your relative first started experiencing the symptoms of schizophrenia before a diagnosis was made? What was this experience like for you?	60
4.2.5 Who told you about the diagnosis?	63
4.2.6 Was your relative present when the diagnosis was disclosed to you?	64
4.2.7 If not, was your relative aware that the information was being disclosed to you?	65
4.2.8 Who was present when the diagnosis was disclosed to you?	66
4.2.9 Tell me how the information was disclosed to you? i.e. what did he/she say, how did you feel about the person disclosing the information?	67
4.2.10 Was the diagnosis and the implications of the diagnosis explained fully to you and your relative?	68
4.2.11 Do you think the diagnosis was explained in a sensitive manner to you?	69
4.2.12 What was your experience when the diagnosis was disclosed?	70
4.3 Needs of the families	71
4.3.1 How has your relative's illness affected your life?	71
4.3.2 What could have happened at the time of diagnosis which would have made the experience easier for you?	73
4.3.3 What could have happened at the time of diagnosis, which would have made the experience easier for your relative with schizophrenia, and the rest of your family?	74
4.3.4 What were your immediate needs when the diagnosis was being disclosed?	75
4.3.5 What needs did you have shortly after diagnosis was disclosed? i.e. when you got home/a couple of days later.	76
4.3.6 What needs do you have currently?	77
4.3.7 Do you feel your needs would have been different if the way the diagnosis had been handled had been different?	78
4.3.8 What assistance have you received since the diagnosis was made?	78
4.4 Interviews	79

4.4.1 The experience of conducting the interviews	79
4.4.2 Climate of the interviews	80
<b>CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS</b>	<b>81</b>
5.1 Conclusion	81
5.1.1 What is the experience for the family when one of its members is diagnosed with schizophrenia?	81
5.1.2 What does the family need?	82
5.1.2.1 Support	82
5.1.2.2 Education	83
5.1.2.3 Practical needs	83
5.1.3 What are the factors which make the experience of schizophrenia easier for the family?	84
5.2 Recommendations	85
5.2.1 Recommendations for the person diagnosing schizophrenia	85
5.2.2 Recommendations for all mental health professionals	85
5.2.3 Recommendations for mental health policy makers	86
5.2.4 Recommended Research	86
<b>REFERENCE LIST</b>	<b>88</b>
<b>ANNEXURE ONE: INTERVIEW SCHEDULE</b>	

# CHAPTER ONE

## GENERAL INTRODUCTION

### 1.1 INTRODUCTION

In 1997 as a student at Valkenberg Psychiatric Hospital the urgent need for services to be provided for families of people with a mental illness became apparent to me. As a result I undertook to assess how these families function. One of the aims of this research project was to encourage further research to determine the needs of families. On completion of my time at Valkenberg Hospital I began working at a mental health organisation called Cape Mental Health Society. There I continued to work with people with a mental illness and their families.

Schizophrenia is a mental illness which is classified as a psychotic disorder. Schizophrenia is characterised by the presence of positive and negative symptoms. Positive symptoms include hallucinations, delusions, bizarre behaviour and thought disorder. Negative symptoms include flat affect, ambivalence, apathy, social withdrawal and a lack of motivation (Kaplan *et al* 1994).

What consistently emerged for me while working with people with schizophrenia and their families was how a diagnosis of mental illness such as schizophrenia became a catalyst for family crisis (Lipton *et al* 1981). There are various reasons for this. A family is already traumatised prior to the diagnosis being made, as they have had to deal with the many disturbing symptoms of mental illness and had to watch their family member suffer due to the symptoms. Beels (1981) explains how frightening an episode of schizophrenia is for those close to the person - family and friends. Families are fearful of their relative's behaviour and of not knowing what is happening to their relative. They may lack knowledge on mental illness or they may also believe some of the many myths associated with mental illness. Beels (1981) says the schizophrenic crisis produces temporary to complete reliance by the person with schizophrenia on their relatives. As mental illness tends to have its onset in young adulthood the family will also in time have to deal with letting go of the expectations they had for their child. The

onset of the mental illness, schizophrenia, thus demands role changes in the family and families often struggle to adapt to their new roles (Spaniol *et al* 1992).

Due to the fact that professionals often lack knowledge when it comes to dealing with the family of a person with mental illness, the family could be further traumatised by a professional who does not know how to deal with their needs.

This study acts upon the recommendations of the 1997 research project addressed in paragraph 1 on page 1 and focuses on the needs of families of people with the mental illness, schizophrenia.

## **1.2 MOTIVATION FOR THE RESEARCH**

Previous studies on the social supports – including the family - of people with schizophrenia have been motivated by the implementation of the policy of deinstitutionalisation, a process which is occurring in many parts of the world, including South Africa. These studies have also been motivated by an increased interest in gaining a better understanding of support systems in relation to schizophrenia (Hammer, 1981). Deinstitutionalisation results in people with schizophrenia staying more often with their families and professionals will need to ensure that the family is able to adapt to living with their mentally ill relative.

If the needs of the family are adequately met the overall mental health of the family is strengthened and this has many benefits for a family member with schizophrenia. When the family's needs are met the family can play a major role in maintaining the psychological integrity of the family member with schizophrenia. A family who is a support system meets many of their family members' basic needs such as giving and receiving love and affection, and providing a sense of belonging. Being part of a supportive family raises self-esteem, self-confidence and feelings of self-worth, which maintain and promote psychological adjustment (Greenblatt *et al* 1982). The family is able to operate in such a way that it mobilises the resources of its family members, which, in turn, enables the person with schizophrenia to deal with their emotional problems and to improve their problem-solving capabilities. A family can be a resource for a person with schizophrenia, particularly in assisting in developing a strategy for

coping with the many demands of schizophrenia in a successful way (Spaniol *et al* 1992).

It would seem therefore that professionals should assist the family to be an adequate support system for their relative with schizophrenia. According to Spaniol *et al* (1992) one of the key areas which require improvement is increased collaboration between the families of people with mental illness and mental health professionals. This collaboration will have many benefits for the person with mental illness and the family but, most importantly, what is necessary at this stage is to help the mental health professional gain a better understanding of the experience of the family. Professionals are often very unprepared and unaware of what the families need. Often what the family experiences is similarly experienced by the professional; both feel helpless, angry, despairing and anxious. A number of studies have shown a dramatic difference between professionals' perceptions and the families' own perception of what their needs are (Hatfield *et al* 1982 and Spaniole & Zipple, 1988 in Spaniole *et al* 1992). This results in added distress for families. There is very little information on how to help the family with a relative with schizophrenia with the predictable result that professionals do not know how to assist these families (Spaniol *et al* 1992). The advances in the past 20 years in the field of schizophrenia notwithstanding, the experience of the family is still very much unknown (Spaniol *et al* 1992).

Professionals need to gain an understanding of the complex and highly emotional experience of the family in order to develop new techniques to assist the family. Professionals can help families to see that their experience is a normal reaction to a traumatic situation. Professionals can then help families develop new skills that will assist them in coping with and adapting to the new situation (Spaniol *et al* 1992).

### **1.3 PURPOSE OF THE RESEARCH**

Research has been undertaken internationally on the needs of families whose relative has been diagnosed with schizophrenia. This material will be discussed in the literature review. However it is not known to what extent these findings are relevant to the experience of families that are receiving services from Cape Mental Health Society.

The purpose of this research is to develop a better understanding of the needs of these families.

As the deinstitutionalisation process is progressing in Cape Town and families have to play a more major role in the care of their relative with schizophrenia it is imperative that their needs are better understood. It is not known how these families experience the process of diagnosis nor what their fears and beliefs are regarding the illness. This research aims to understand what the experience was like for the family at the time of diagnosis, what their needs were at this time and whether their needs have changed over time. The study does not explore how these needs should be met.

This research will be made accessible to social workers at Cape Mental Health Society working with families in order to sensitise them to the needs of families with a relative with schizophrenia.

#### **1.4 RESEARCH QUESTIONS**

Interest in the needs of local families with a relative with schizophrenia can be expressed in the following three questions.

- ❖ What is the experience for the family when one of its members is diagnosed with schizophrenia?
- ❖ What does the family need?
- ❖ What are the factors which make the experience of schizophrenia easier for the family?

## **1.5 LIMITATIONS OF THE STUDY**

The study sample is drawn from people utilising services at Cape Mental Health Society, which cannot be considered to be representative of all families with a relative with schizophrenia.

## **1.6 ETHICAL CONSIDERATIONS**

Permission was required from all the people interviewed. Interviewees were informed prior to granting permission that their responses will be written up and used as data for research. The interviewees' identities have been protected by not using their names or other identifying information.

The sensitive nature of this topic did evoke feelings and issues, which needed to be dealt with during the interview. All the families interviewed were clients at Cape Mental Health Society. They all have social workers who were available to provide necessary follow-up interventions.

## **1.7 ORGANISATION OF THIS DISSERTATION**

The dissertation has been organised into five chapters. Chapter Two presents an overview of the literature. This chapter starts with an overview of schizophrenia as a disorder. Discussed next are factors which contribute to the course of schizophrenia including genetics, expressed emotion in the family, social functioning and relationships and the physical environment. The experience, effects and needs of the family with a relative with schizophrenia are then presented. Finally a review is given on interventions for the family with a relative with schizophrenia.

Chapter Three – the methodology chapter - will outline the research design used, the sampling procedure, how the data was collected and analysed and it will introduce the interview schedule. Chapter Four will present the results of the research and a discussion of the results. In Chapter Four the answers to each question from the interview schedule will be described and analysed. Quotes are presented in this

chapter to give the reader a rich and comprehensive understanding of the results of this research. Chapter Five concludes the research and recommendations are made.

University of Cape Town

## CHAPTER TWO

### LITERATURE REVIEW

#### **2.1 INTRODUCTION**

The phasing out of mental institutions has resulted in the responsibility for the care of people with mental illness being transferred to the community. Families have had to be more involved in the care of their relatives with mental illness and are often the primary caregivers. What is surprising, then, is how little professionals understand about the experiences of families who have relatives with schizophrenia. Without a comprehensive understanding of the difficult tasks these families face and what their needs are, the development of effective approaches to help the family is unlikely.

Hatfield, (1987b) believes that the meaning of mental illness to the family and the way mental illness impacts on the family is affected by three factors. The first factor is where their relative lives, the second is the way the illness is understood by the family (which is mainly influenced by causal factors), and the third is the amount and quality of care, support and understanding given by the community (Hatfield, 1987b).

What is often overlooked is how traumatic schizophrenia is for the family of the person with the illness (Hatfield, 1987b). What will become evident through this literature review is how much literature there is on how the family contributes to the onset and course of the schizophrenia in a family member. However there is little literature on what the experience is for the family and what their needs are when faced with a relative with schizophrenia.

The review will start by briefly discussing the condition, schizophrenia. The review will discuss factors which contribute to the course of schizophrenia which include genetic factors, factors in the family, social functioning and relationships of a person with schizophrenia and the physical environment. It will examine the experience of schizophrenia for the family, the effect of schizophrenia for the family and needs of the

family. Lastly intervention for the family and the benefits to a relative with schizophrenia when their family receives treatment are explored.

## **2.2 SCHIZOPHRENIA**

In 1896, a German psychiatrist, Emil Kraepelin (1856-1929) first identified schizophrenia. He named it "Dementia Praecox" a term which means "madness of the young." It was soon realised that it is not only a condition that affects young people. Patients with dementia praecox were characterised as having an illness with a long-term deteriorating course, hallucinations and delusions. It was also soon discovered that not all people with schizophrenia suffer a long-term deteriorating course. In 1911 Eugen Bleuler (1857-1939), a Swiss psychiatrist, changed the term "dementia praecox" to "schizophrenia". He conceptualised the term as referring to a schism between thought, emotions and behaviour in affected people (Kaplan *et al* 1994; Gillis, 1986).

Schizophrenia is a psychiatric disorder. No symptom or clinical sign seen in schizophrenia is unique to schizophrenia and can be seen in other psychiatric and neurological disorders. An understanding of a patient's history is essential for the diagnosis of schizophrenia to be made. The symptoms of schizophrenia change over time. It is very important that a patient's culture, education and intelligence are taken into consideration before a diagnosis is made (Kaplan *et al* 1994).

Schizophrenia is an illness which has a gradual onset. Premorbid signs and symptoms occur before the prodromal phase of the illness starts. Typical premorbid signs and symptoms are often seen as simply personality traits such as being quiet, passive and introverted. These signs and symptoms are often only recognised after the diagnosis has been made. Prodromal symptoms are seen as low-grade symptoms which include loss of interest in work, social activities and in personal appearance and hygiene. Generalised anxiety and mild degrees of depression precede the onset of psychotic symptoms by weeks or months (Keith & Matthews, 1991). Characteristically the symptoms and signs of the premorbid stage begin in adolescence followed by the development of prodromal symptoms. The onset of the more disturbing symptoms is often triggered by a social or environmental change (Kaplan *et al* 1994). As Wig *et al*

(1987) state, independent life events such as moving house and family deaths play a role in precipitating the onset of schizophrenia.

Beiser *et al's* (1993) study shows that a large number of people were psychotically ill for over a year before seeking treatment. Differences in symptoms are one explanation for this. The research found that self-destructive symptoms brought people more quickly into treatment. However factors such as the fear of stigmatisation explain the large time lags between the onset of symptoms and their treatment (Beiser *et al* 1993). The onset of the illness starts when the person first experiences psychotic symptoms such as speaking in a confused way, neglecting normal daily tasks, ceasing to talk or eat or ranting and people around him/her beginning to regard the person as mentally ill (Keith & Matthews, 1991). Vaillant (1964 in Beiser *et al* 1993) describes onset as the period between the first signs of psychosis and the start of treatment.

After the first psychotic episode the person gradually returns to relatively normal functioning. However each psychotic relapse is followed by a further deterioration in functioning. The pattern of the illness in the first five years normally predicts the future course of the illness (Kaplan *et al* 1994).

Research has shown that only 10 – 20 % of people with schizophrenia have a positive prognosis. More than 50 % can be described as having poor outcomes with repeated hospitalisation, exacerbations of symptoms, episodes of major mood disorders and suicide attempts (Kaplan *et al* 1994).

Currently the DSM-IV, Diagnostic and Statistical Manual of Mental Disorders has set out diagnostic criteria for schizophrenia which follow:

#### Diagnostic Criteria for Schizophrenia

- A. *Characteristic symptoms:* Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):
- (1) delusions
  - (2) hallucinations
  - (3) disorganized speech (e.g., frequent derailment or incoherence)
  - (4) grossly disorganized or catatonic behavior
  - (5) negative symptoms, i.e., affective flattening, alogia, or avolition

**Note:** Only one criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behavior or thoughts, or two or more voices conversing with each other.

- B. *Social/occupational dysfunction*: For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning, such as work, interpersonal relations, or self-care, are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).
- C. *Duration*: Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).
- D. *Schizoaffective and mood disorder exclusion*: Schizoaffective disorder and mood disorder with psychotic features have been ruled out because either: (1) no major depressive, manic, or mixed episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.
- E. *Substance/general medical condition exclusion*: The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.
- F. *Relationship to a pervasive developmental disorder*: If there is a history of autistic disorder or another pervasive developmental disorder, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

*Classification of longitudinal course* (can be applied only after at least 1 year has elapsed since the initial onset of active-phase symptoms):

**Episodic with interepisode residual symptoms**

(episodes are defined by the reemergence of prominent psychotic symptoms); *also specify if: with prominent negative symptoms*

**Episodic with no interepisode residual symptoms**

**Continuous** (prominent psychotic symptoms are present throughout the period of observation); *also specify if: with prominent negative symptoms*

**Single episode in partial remission**; *also specify if: with prominent negative symptoms*

**Single episode in full remission**

**Other or unspecified pattern**

Table from DSM-IV, *Diagnostic and Statistical Manual of Mental Disorders*, ed 4. Copyright American Psychiatric Association, Washington, 1994. Used with permission.

(Kaplan *et al* 1994)

## 2.2.1 Epidemiology

According to Kaplan *et al* (1994) schizophrenia is equally prevalent in men and women. However some research has found differently. For example, Makikyro *et al* (1998) states that the male gender is more strongly associated with schizophrenia than the female gender. The characteristics of onset and course are different for men and women (Kaplan *et al* 1994). Males are more at risk of developing schizophrenia when

they are 3 - 4 years younger than females (Makikyro *et al* 1998). More than half of men who develop schizophrenia develop it before the age of 25 years, whereas one third of women develop schizophrenia before the age of 25 years. The peak age of onset for women is between 25 and 35 years and for men 15 and 25 years (Beiser *et al* 1993). Some research has shown that men more often have negative symptoms. In Leff *et al*'s (1987) study they associate poor outcome with the male sex and unmarried status. In another study by Leff *et al* (1987) the seven males who relapsed during the study were single. The relapse rate for women (8%) was found to be less than half that of the men sample (22%) (Leff *et al* 1987). Women tend to have a better outcome and function better socially. Suvisaari *et al*'s (1998) study found that women who are older at the onset of schizophrenia are hospitalised for shorter periods of time. Schizophrenia emerges earlier than other psychiatric illnesses including depression and bipolar mood disorder (Beiser *et al* 1993).

Approximately 50% of people who suffer from schizophrenia commit suicide. The risk factors which increase the chance of suicide are the presence of depressive symptoms, young age and high levels of premorbid functioning (Kaplan *et al* 1994).

Three fourths of people who suffer from schizophrenia smoke cigarettes. Studies have found that cigarette smoking is associated with high dosages of antipsychotic medication. This may be because smoking increases the metabolic rate and so reduces the efficacy of the medication. Cigarette smoking also decreases the side effects of medication particularly Parkinsonism (Kaplan *et al* 1994).

Schizophrenia has been described in all cultures and socio-economic groups. People who suffer from schizophrenia are often found in low socio-economic groups in industrial nations. Homelessness is also commonly associated with schizophrenia (Kaplan *et al* 1994).

### **2.2.2 Etiology**

The cause of schizophrenia is not known. However research into the causes, particularly organic causes, is progressing rapidly. It has been found that people with schizophrenia do have structural and functional abnormalities in their brain. A large

amount of research has been undertaken on the pathophysiological role of certain areas of the brain. The main areas of the brain studied are the limbic system, the frontal cortex and the basal ganglia. Research is done using brain imaging of living and deceased persons. The earliest studies of the brain used computed tomography and produced the most convincing data that schizophrenia is a disease of the brain. These studies have consistently shown that the brain of a person with schizophrenia has lateral and third ventricular enlargement (Kaplan *et al* 1994). Research undertaken by Salokangas *et al* (2002) found that people with schizophrenia have smaller left frontal grey matter volume compared with people with psychotic depression and depression. This research confirms that people with schizophrenia have structural brain abnormalities. (Salokangas *et al* 2002) Similarly research undertaken by Lawrie *et al* (2002) concludes that people at high risk of schizophrenia show reductions in temporal lobe volumes.

Research has demonstrated a strong genetic component to schizophrenia. Early studies of the genetics of schizophrenia have shown how a person is likely to develop schizophrenia if a person in their family has schizophrenia. The risk is greater the closer the relationship, for example first-degree relatives – so children of a parent with schizophrenia are at greater risk of also developing the illness than those at a further genetic remove (Kaplan *et al* 1994).

The large body of research into the genetic and biological influence in schizophrenia has resulted in a need to understand the individual, family and social issues that affect the person with schizophrenia. The stress-diathesis model integrates biological factors, psychosocial factors and environmental factors. In this model a person is born with a vulnerability to the development of schizophrenia. When stressful environmental factors occur, this person will develop schizophrenia (Kaplan *et al* 1994). Psychoanalytic theory, especially that of Sigmund Freud, emphasises the importance of early childhood experience in shaping human behaviour (Hatfield, 1987a). Freud suggests that schizophrenia results from a fixation during the development process. Freud describes an ego deficit occurring for people who develop schizophrenia. This ego deficit and the early fixation result in intrapsychic conflict, which fuels the psychotic symptoms. Margaret Mahler describes how the child is unable to separate from the mother and

progress beyond the closeness and dependence of the mother-child relationship in the oral stage of development. She suggests a person with schizophrenia has never reached object constancy, resulting in a lack of a sense of secure identity. Psychoanalytic theory suggests that symptoms of schizophrenia have symbolic meaning for the person suffering from it (Kaplan *et al* 1994).

In the past professionals spent much time investigating the cause of mental illness with little emphasis placed on helping families to cope. After World War II there was a belief that problems in adulthood could be located in child rearing and the family environment. Various theories were then developed. The following are three examples:

- ❖ “Schizophrenogenic mother” was a theory developed by Fromm-Reichmann in 1948. According to her theory, schizophrenia is caused by infantile relations with the mother, who unconsciously projects her feelings of rejection onto her child. In this theory schizophrenogenic mothers are considered cold and distant, their lack of warmth and affection preventing the development of necessary psychological and social skills. This theory had a strong influence on the etiological beliefs of this time (Hatfield, 1987a).
- ❖ Bateson’s Double Bind hypothesis (1956 in Hatfield, 1987a) also influenced the theories of the cause of schizophrenia during this period. Bateson believed that schizophrenia is due to a type of learning context a child grows up in and cannot escape from. A child receives two or more messages that are incompatible on different levels of communication. These children are then placed in an intolerable situation due to the ambiguities; this results in the person denying aspects of reality as a way of coping.
- ❖ A further theory is that one or both parents of a person with schizophrenia has a personality disorder. The parent or parents are self-centred and egocentric to the extent that they deny the needs of others.
- ❖ Some theorists have gone so far as to reject any genetic or organic basis of the disorder and view schizophrenia as a behavioural problem (Hatfield, 1987a).

It is very important to state that there are no well-controlled and reliable studies which indicate that any specific family patterns play a causative role in the development of

schizophrenia. There is no reliability in the assumption that people with schizophrenia come from dysfunctional families (Kaplan *et al* 1994).

Hatfield, (1987a) feels that these old theories still influence the way mental health professionals deal with families. The labels “over-involvement”, “enmeshment”, “communication deviance”, “isolated”, “learnt helplessness” and others are still used and it results in feelings of blame and guilt for the families. The focus of treatment is then only on a family’s deficits and not on its strengths.

In the 1970s self-help movements for families of mentally ill people emerged and provided very necessary assistance to families, which helped to ease the burden and stress. These movements also put pressure on professionals and policy makers to pay attention to the difficulties faced by families (Hatfield, 1987a). Today we know much more than we did 40 years ago, but the challenge is to put this knowledge to work to help people with mental illness (Bachrach, 1997).

### 2.2.3 Subtypes

Schizophrenia is divided into five subtypes:

- ❖ paranoid,
- ❖ disorganised,
- ❖ catatonic,
- ❖ undifferentiated and
- ❖ residual types.

Below is the DSM-IV, Diagnostic and Statistical Manual of Mental Disorders criteria for schizophrenia subtypes.

#### Diagnostic Criteria for Schizophrenia Subtypes

##### Paranoid Type

A type of schizophrenia in which the following criteria are met:

- A. Preoccupation with one or more delusions or frequent auditory hallucinations
- B. None of the following is prominent: disorganized speech, disorganized or catatonic behavior, or flat or inappropriate affect.

##### Disorganized Type

A type of schizophrenia in which the following criteria are met:

- A. All of the following are prominent:
  - (1) disorganized speech
  - (2) disorganized behavior
  - (3) flat or inappropriate affect
- B. The criteria are not met for catatonic type.

**Catatonic Type**

A type of schizophrenia in which the clinical picture is dominated by at least two of the following:

- (1) motoric immobility as evidenced by catalepsy (including waxy flexibility) or stupor
- (2) excessive motor activity (that is apparently purposeless and not influenced by external stimuli)
- (3) extreme negativism (an apparently motiveless resistance to all instructions or maintenance of a rigid posture against attempts to be moved) or mutism
- (4) peculiarities of voluntary movement as evidenced by posturing (voluntary assumption of inappropriate or bizarre postures), stereotyped movements, prominent mannerisms, or prominent grimacing
- (5) echolalia or echopraxia

**Undifferentiated Type**

A type of schizophrenia in which symptoms that meet criterion A are present, but the criteria are not met for the paranoid, disorganized, or catatonic type.

**Residual Type**

A type of schizophrenia in which the following criteria are met:

- A. Absence of prominent delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behavior.
- B. There is continuing evidence of the disturbance, as indicated by the presence of negative symptoms or two or more symptoms listed in criterion A for schizophrenia, present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

Table from DSM-IV, *Diagnostic and Statistical Manual of Mental Disorders*, ed 4. Copyright American Psychiatric Association, Washington, 1994. Used with permission.

(Kaplan *et al* 1994)

## 2.2.4 Diagnosis

Diagnosis by a psychiatrist is vital and often the first step for the family in receiving help for their relative with schizophrenia. However a diagnosis can cause much suffering for the family. A diagnosis of schizophrenia evokes the many myths and stigmas associated with the illness. It is the myth of a lunatic in a straitjacket and a criminal that causes the diagnosis to be a frightening experience for the family. Much distress is also caused in the family if the family believes that schizophrenia is a result of intra-familial interactions. They may blame each other and themselves for the cause of the schizophrenia. As years go by family members privately blame one another and this results in much tension (Terkelsen, 1987).

When first diagnosed, some families have a simplified view of the prognosis for their relative with schizophrenia. Some cannot believe that their relative may face severe deterioration. Other families cannot predict a favourable outcome for their relative with schizophrenia. Families often move between these two extreme views. This often results in a lack of flexibility in their view of the prognosis of schizophrenia and an inability to accurately assess their relative's abilities (Terkelsen, 1987).

### 2.2.5 Treatment

What follows is a brief historical overview covering trends in types of treatment offered in America to people with mental illness which includes schizophrenia. In the 17<sup>th</sup> century people with mental illness were not cared for by the state. Families took complete responsibility for their relatives with mental illness. There was no support from outside the family and no medication. Little is known about how these families coped. However there are stories of families chaining or locking their relatives up in cellars or attics. Families were influenced by the theories which said that mental illness was punishment for sins. In the 18<sup>th</sup> century the first hospital in America was opened which offered care to people with mental illness. Treatments were barbaric but it was also the first time that people were attempting to find a cure for mental illness. Asylums were first established in the 19<sup>th</sup> century. They provided more humane and helpful care, however they were situated on the outskirts of cities and towns away from family and the community (Hatfield, 1987a).

The 1950's marked the greatest advancement in psychiatry which was the introduction of psychiatric medication. This resulted in many people with mental illness being able to function in the community. In this period there was also an increased awareness of civil rights of all citizens. It was felt at this time that long-term hospitalisation had many negative consequences for people with mental illness. Community care was seen as having many benefits for people with mental illness. Deinstitutionalisation was believed to be a process which would be effective due to these two reasons. This process involved moving chronic and severely mentally ill people from hospitals into the community. It provides an opportunity for people with mental illness who were once accommodated in isolation from the rest of the community to live a more fulfilling life as part of the community. Deinstitutionalisation is a complex process, which requires interplay between the mental health professionals, the public, politics and the economy. It is a process fraught with controversy on the one hand and praise on the other (Hatfield, 1987a; Kaplan *et al* 1994). Unfortunately it has become a process plagued with problems for the following reasons:

- ❖ There was a lack of planning initially for such a complex process,

- ❖ Professionals are often resistant to working with people with mental illness,
- ❖ Treatment is often inaccessible,
- ❖ There is severe stress placed on families and
- ❖ The community is often resistant.

The process is further complicated by a group of people with mental illness who are resistant to treatment and require long-term care (Hatfield, 1987a).

In order for deinstitutionalisation to work effectively it is necessary for there to be a political climate which is enabling with values of integration and a strong focus on the community. There needs to be a mutual, respectful and symbiotic relationship between central and local government. The economic climate should be one in which growth is steady and sustained, and public resources should not be seen as a burden on the economy. These ideal conditions have not even existed in a well-resourced country such as the United Kingdom (Carrier, 1990 in Carrier & Kendall, 1997). The result has been many stories in the press about psychiatric hospitals dumping their patients in the streets. Communities were viewed as careless for not dealing with people with mental illness (Carrier & Kendall, 1997). As the deinstitutionalisation process occurs currently in South Africa we too are plagued with stories of the lack of care for people with mental illness. Deinstitutionalisation is seen as a positive process as it prevents the many negative consequences of institutionalisation such as a person becoming severely withdrawn due to the impoverished and inactive environment of hospital wards and repetitive daily routine. However deinstitutionalisation can only become a positive process if the community, the family and the people with mental illness are adequately prepared for the process and adequate structures such as community group homes and trained staff exist to ensure the success of deinstitutionalisation.

It is now recognised that when a diagnosis of schizophrenia has been made treatment should begin immediately. Treatment includes medication, therapy and other psychological and social interventions. Medication is a vital part of the treatment. The main type of medications used are antipsychotic medications or, as they are otherwise known, neuroleptics. Side-effects to medication do occur and need to be discussed with the doctors. Hospitalisation often becomes necessary during the course of

schizophrenia. Hospitalisation is indicated for diagnostic purposes, stabilisation and when the person with schizophrenia's safety is considered to be threatened such as when they are suicidal or harming themselves. It is also indicated to treat gross disorganised or inappropriate behaviour including the inability to take care of one self. Therapy can include behavioural techniques such as skills training, family-orientated therapies, group therapy and individual psychotherapy (Kaplan *et al* 1994).

The literature indicates that the family plays a role in the predisposition to, the diagnosis and treatment of schizophrenia. It is also clear that schizophrenia has a powerful impact on the family. The rest of the literature review will explore research relating specifically to the family's role in managing the illness, the impact of the illness on the family and the need to provide the family with support.

## **2.3 FACTORS WHICH CONTRIBUTE TO THE COURSE OF SCHIZOPHRENIA**

### **2.3.1 Genetics**

The results of a study by Verdoux *et al* (1996) gives evidence on familial loading being a predictor for persistent negative symptoms over a follow-up period in schizophrenia. Familial loading is defined by Hinsie & Campbell (1970:293) as "a normal or morbid trait tending, or observed, 'to run in families'." High familial loading for schizophrenia is associated with early onset and poor outcome of schizophrenia according to Suvisaari *et al* (1998). In the results of this study the mean annual duration of hospitalisation after the onset of schizophrenia was 68 days for the sample group of patients with high familial loading and 50.6 days in the low familial loading sample group, indicating that high familial loading is associated with longer hospitalisations. The duration of hospitalisation is also affected by the availability of treatment, and on family tolerance or recognition of symptoms (not only psychotic symptoms). The study found that an earlier age at onset, longer hospitalisation and higher risk of retirement on disability pension - all of which indicate poor outcome - are also associated with high familial loading. Therefore low familial loading is associated with later onset and better outcome. The study also found that later onset often occurred for a second family

member affected by schizophrenia. This implies that the families who already have an affected family member are able to tolerate the symptoms of schizophrenia longer before needing to seek help (Suvisaari *et al* 1998).

### 2.3.2. Family - Expressed Emotion

Expressed emotion (EE) index is a well-established tool for assessing and describing families of people with a mental illness. EE is defined by examining critical comments expressed in the family, degrees of hostility in the family and emotional over-involvement (Barrowclough *et al* 1987; McCreadie *et al* 1991). Expressed emotion is a measure of family members' attitudes to their relative with a mental illness. It is estimated using a standardised interview with a non-affected relative. This interview is called the Camberwell Family Interview and it was developed in 1960 (Wig *et al* 1987).

Ratings are made on five factors;

- ❖ criticism,
- ❖ hostility,
- ❖ over-involvement,
- ❖ warmth and
- ❖ positive remarks (Wig *et al* 1987).

"Criticism" is a statement made in a manner which makes it an unfavourable comment upon the behaviour or personality of the person to whom it refers. "Hostility" is generalisation of criticism, rejection of the relative as a person or a combination of the two. "Over-involvement" is either assessed during the interview from the subject's behaviour or from reported behaviour outside the interview. Elements of over-involvement include; unusually self-sacrificing and devoted behaviour, over-protection that is age-inappropriate and a lack of boundaries between the relative with schizophrenia and the subject's existence. "Warmth" is expressed emotions about the relative with schizophrenia and not a general quality. A "positive remark" is a statement, which expresses praise, approval or appreciation of the behaviour or the personality of the relative (Wig *et al* 1987). Of the five scales the rated factors "critical comment" and "emotional over-involvement" are the two most powerful predictors (Szmukler *et al* 1987).

Magana, Goldstein, Karno *et al* (1986 in Friedmann *et al* 1993) developed another method to measure EE. This measure looks at comparable affective attitudes expressed by relatives during a Five-Minute Speech Sample (FMSS-EE) monologue. The FMSS-SS provides a more conservative estimation of high EE families compared to the Camberwell Family Interview measure (Friedmann *et al* 1993)

Families assessed as high EE make significantly more critical statements during direct interactions with their relative with schizophrenia than families assessed as low EE. Studies by Miklowitz *et al* (1984 in Szmukler *et al* 1987) prove that the status of high EE assessed during interviews is a reliable status as it corresponds to direct interactions away from an interview setting with their relative with schizophrenia. Szmukler *et al* (1987) found similar results and demonstrated that critical comments noted in individual interviews also occurred in family interactions. High EE families tend to believe that their relative with schizophrenia can control their symptoms and are often unsympathetic towards the illness. Low EE families understand and believe that the illness is legitimate therefore take the symptoms seriously (Vaughn & Leff, 1981 in Barrowclough *et al* 1987). It was suggested that the reason for the beliefs of high EE families was due to a lack of knowledge about schizophrenia (Brown *et al* 1972 in Barrowclough *et al* 1987). However further research, which implemented educational programmes for high EE relatives, failed to support the hypothesis that high EE families know less about schizophrenia than low EE families. Barrowlough *et al* (1987) studied the functional value of relatives' knowledge about schizophrenia. The research found that more critical relatives had more negative information about schizophrenia. The research also supports the theory that the main characteristic that distinguishes low EE from high EE families is attitude towards the illness. One of the questions in Barrowlough *et al*'s (1987) study asked whether the relative believed that the "problems" they had with their relative had to do with the illness or the relative's natural self. Relatives who believed the symptoms were part of their relatives' natural self were rated as critical and hostile towards their relative with schizophrenia. A study done in 1976 (Leff & Vaughn, 1976) indicates that relatives who are highly critical are often reacting to premorbid, long standing personality traits rather than illness related behaviour (Leff & Vaughn, 1985). Features of high and low EE families were developed by Leff (1979) and Brown (1972 in Beels, 1981). In low EE families, relatives with

schizophrenia needed less medication than in high EE families. Non-compliance on medication was related to early relapse in high EE families but not in low EE families. People with schizophrenia who have no contact with others but with their family who they live with are more likely to be high EE families. High EE is associated with intrusiveness, feeling that the patient's illness was unjustified, disappointment and putting pressure on the patient to act normally (Beels, 1981).

In low EE families, family members are often better able to adapt to their relative with schizophrenia's needs. High EE families are often unable to do this. Relatives with low EE are better able to accept the symptoms of schizophrenia such as social withdrawal and social isolation and are willing to respect their relative's desire for social distance. High EE families find this acceptance difficult. Low EE relatives make more effort than high EE relatives to understand their relative's mental illness and sought information on schizophrenia. Low EE relatives have higher tolerance levels for their relatives' low level of functioning than high EE families. Low EE relatives seem to have lower expectations for their relative with schizophrenia. Low EE families have much better ability than high EE families to remain calm and self-contained when their relative with schizophrenia acts in a agitated or bizarre way (Leff & Vaughn, 1985). Leff & Vaughn (1985) feel that it is the low EE family's quality of flexibility that best distinguishes low EE families from high EE families.

From this, it can be seen that the concept EE is more than the expression of positive and negative feelings. It is a reflection of the quality of the pre-illness relationship between patient and relative, and of the atmosphere in the home (Leff & Vaughn, 1985).

The behaviour of family members has been seen to increase the risk of relapse because relatives of the mentally ill tend to communicate by sending confused and disorganised messages, which severely jeopardise the relationship. It has been suggested this is not due to the illness but rather to problematic supportive social ties (Greenblatt *et al* 1982). The measure of EE has been found to be a reliable determinant in predicting relapses in schizophrenia (Brown *et al* 1972; Vaughn & Leff, 1976a; Vaughn *et al* 1982 in Szmukler *et al* 1987). High EE also predicts relapses in people

who suffer from depression, (Hooley, Orley & Teasdale, 1986 and Vaughn & Leff, 1976b in Friedmann *et al* 1993), and in Bipolar Mood Disorder (Miklowitz *et al* 1989 in Friedmann *et al* 1993). Tarrier *et al* (1994) studied relapse rates of schizophrenia. Their data supports the theory that EE is a predictor of relapse rate. People with schizophrenia returning home to high EE relatives have a higher rate of relapse than those going home to low EE families (Barrowclough *et al* 1987). When a person with schizophrenia returns home after hospitalisation, relatives often react with hostility, over-involvement and criticism, which are seen as high EE. This results in the return of symptoms within nine months (Greenblatt *et al* 1982).

Brown, Birley and Wing (1972 in Beels, 1981) studied expressed emotion (EE). Their results showed that in a sample of 101 patients, 58% relapsed when sent home to high EE families compared with 16% in low EE families. Research has shown that the family's ability to tolerate symptoms and to recognise symptoms are also indicators for the length of hospitalisation for the relative with schizophrenia (DeLisi, 1992 in Suvisaari *et al* 1998). Research has proven, with statistically significant results, that critical comments can be the only factor of EE occurring in a family which will result in the relative with schizophrenia relapsing (Macmillan *et al* 1987). Due to this result Macmillan *et al* (1987) says that treatment of critical comments is essential and that a positive change after treatment does occur. Baker *et al* (1979 in Greenblatt *et al* 1982) conclude their study, where the results proved that high EE predicts relapse, by stating that people returning home after a psychiatric admission should enter an environment which is warm and accepting and filled with close relatives and friends.

It is important to note that all measures of EE status rely on an outsider's observation of the families' emotional attitude towards their relative. There has been little research on relatives' perceptions of their own feelings towards their relative with mental illness. Friedmann *et al* (1993) researched this in their study. This study suggests that the relative's perception of their emotional attitude towards their relative with mental illness is similar to what was assessed by raters outside the family. The relatives appear to hold attitudes about their relative with mental illness which influence their evaluation of their relative and the nature of their interaction with their relative. Many relatives were able to acknowledge that they had a critical attitude towards their relative with mental

illness. This may be due to the fact that they believe that their negative attitude is a reaction to their relative's aversive behaviour. Relatives who are viewed as critical by raters do not perceive themselves to be consistently negative. Families who were rated as high EE on both Camberwell Family Interview measure (CFI) and Five-Minute Speech Sample (FMSS-EE) measures were more likely to rate both their own behaviour and their relatives with mental illness's behaviour as more negative compared with low-EE families (Friedmann *et al* 1993).

EE has become a controversial issue, as families believe it is a way to blame them for the illness. Research on high EE has resulted in blaming parents of people with schizophrenia for contributing to the illness. As a result parents are often excluded from treatment programmes (Leff & Vaughn, 1985). Some authors have therefore developed alternative ways of correlating EE and the outcome of schizophrenia (Mintz *et al* 1987). One model has shown that EE and the outcome both have the same cause: the duration of the illness. Controlling for the duration of the illness then eliminates the relationship between EE and the outcome. This model was suggested by Macmillan *et al* (1986 in Mintz *et al* 1987) and shows that high EE is due to a longer period of illness. This model is then reversed and reveals that high EE in the home is a factor which can lengthen the duration of the illness. The measure of duration used by Macmillan *et al* (1986 in Mintz *et al* 1987) was reported by the relatives themselves. One suggestion for this reversed model is that high EE families may not attribute deviations in behaviour to schizophrenia prior to the first psychotic admission. This results in a longer untreated illness, which in turn results in a poorer outcome. Another suggestion for this model may be that high EE families might report longer periods of illness than low EE families. High EE families may simply be more sensitive to early signs of schizophrenia or it may reflect another criticism of the patient. There are many possibilities attendant on this theory. In all of them EE and the outcome are not associated. Macmillan *et al* (1986 in Mintz *et al* 1987) also suggest that the reaction to the stress of an untreated psychiatric illness in a relative has prognostic implications. Some authors have also said that high EE in the family is due to the relapsed relative, and that the high EE status can change when the relative with schizophrenia improves (Hogarty *et al* 1986 in Macmillan *et al* 1987). However regardless of these suggestions, it continues to be found that EE is the better predictor of outcome. In a study on neuroleptic treatment in a clinical trial it

was found that EE is a better predictor for outcome than active neuroleptic treatment (Mintz *et al* 1987)

Family therapists have criticized studies on EE. They feel that measurements used to measure EE do not include the whole family system and do not take into consideration the interactive nature of EE factors. Family therapists also feel that a label of high EE has negative consequences for families since it results in a lack of empathetic understanding – the kind of understanding that would build up the family's strengths. These criticisms have resulted in the development of alternative EE measures by family therapists. (Doane *et al* 1981 and Szmukler *et al* 1987 in Vostanis *et al* 1992).

What is very important to note is that high EE is a culturally-bound phenomenon. What is seen in Western cultures as high EE may be an accepted behaviour in other cultures (Leff *et al* 1987).

On surveying the literature, it can be concluded that even though EE is useful when looking at certain elements of schizophrenia, it is not useful when working with families. When professionals use the term EE it only serves to intensify the guilt families already feel. Similarly other family factors seen as possibly contributing to the onset of schizophrenia should not be used when working with families.

### **2.3.3 Social Functioning and Relationships**

It has been found that social functioning is correlated with prognosis. People who had good premorbid social functioning have a better prognosis than people who functioned poorly socially before they became psychiatrically ill (Lipton *et al* 1981). In research by Lipton *et al* (1981) findings indicate that social isolation is not a prominent characteristic in the early life of people who suffer from schizophrenia. This finding is supported by Kohn & Clausen (1955 in Lipton *et al* 1981) in their research on schizophrenia. Social network changes only tend to occur in the life of a person with schizophrenia after their first hospitalisation. After the first hospitalisation the person experiences a marked reduction in the number and complexity of social contacts in their life. In addition the writers found that after the first admission there is considerable emotional withdrawal by the person with schizophrenia. A possible reason for the very dramatic change in

social contacts could be due to the onset of schizophrenia resulting in a need for the person to re-evaluate their self image and their need to acquire a new social network. The social network change in Lipton *et al* (1981)'s study was not due solely to the person's social inabilities but also the responses of others to the sufferers' psychotic behaviour. A person who has been recently diagnosed requires additional emotional support. However they have to deal with a concurrent network crisis. A person with schizophrenia is placed under additional stress to redefine him or herself and to find acceptance in his/her social network. This has important implications for mental health professionals, as they need to try to restore the social network of the person suffering from schizophrenia. Active intervention is required after the first admission to prevent a social network collapse (Lipton *et al* 1981).

The onset of a serious mental illness such as schizophrenia disrupts the life cycle of the family, resulting in the family and the person affected not being able to develop types of social support. The onset of schizophrenia coincides with the developmental stage of young adulthood. As schizophrenia usually occurs in early adulthood the person affected is often prevented from moving into employment, forming intimate and stable relationships, and developing a circle of friends in order to develop good social exchanges. The association between poor social support and schizophrenia is common (Beels, 1981). Studies undertaken by Sokolovsky *et al* (1978 in Hammer, 1981) have found that people with schizophrenia are dramatically unbalanced in their giving and receiving relationships. In other words people with schizophrenia are not always able to contribute fully to a relationship, for example in conversation and caring and supportive behaviour. Similarly they are not always open to receiving these types of benefits from relationships. The study also found that people with schizophrenia have markedly fewer multiplex relationships (relationships in which people have multiple roles, for example, neighbour, relative and members of common religious organisation). Multiplex relationships are stronger, more important and more supportive than uniplex relationships. It can therefore be seen as problematic that people with schizophrenia have many fewer multiplex relationships in comparison to people who do not suffer from schizophrenia (Hammer, 1981).

A possible reason for this was found. Silberfeld (1978 in Hammer, 1981) found that there are major differences in the way people with schizophrenia socialise in comparison with people who do not have schizophrenia. People with schizophrenia tend to spend less time with other people. Uniplex relationships normally develop into multiplex relationship over time as the interconnectedness between two people increase. Pattison *et al* (1979 in Greenblatt *et al* 1982) found that people who did not suffer from a mental illness were able to recall 22 to 25 people who are important to them. People with a mental illness were only able to recall 5 or 6 people who are important to them. People in the social network of sufferers of schizophrenia tend to be a relative of the mentally ill person, resulting in fewer links to the outside world for the person. At the same time, research has found that people with schizophrenia tend to be less involved with their relatives than a control group of people without schizophrenia (Silberfeld, in Greenblatt *et al* 1982).

The social network, which is empirically defined as groups of family, neighbours and friends, has certain characteristics for people with schizophrenia (Beels, 1981). Researchers have found that social networks of people with schizophrenia differ in quality and quantity from people without schizophrenia (Greenblatt *et al* 1982). For example studies have found that the social network of a person suffering from schizophrenia tends to be smaller and denser than that of a control sample of people without schizophrenia. Changes in network size and function for a sufferer of schizophrenia usually occur at or before the first hospitalisation. People who suffer from schizophrenia often feel overwhelmed by their social networks rather than supported. Research has found that having a confidant can be problematic for a sufferer of schizophrenia. What often happens in the family is that members of the family becomes disappointed by the sufferer's refusal to accept them as their confidante. Members of the family then try hard to become their relative's confidante. This behaviour is often associated with intrusive and negative family attitudes, which are particularly detrimental to a person with schizophrenia (Beels, 1981).

Relatives who suffer from schizophrenia and their family are in a difficult situation with regards to social support. People who suffer from schizophrenia are vulnerable to two different social stresses. Too much social support is experienced as intrusive and may

lead to a relapse. Too little social support can induce the presence of the negative symptoms of schizophrenia, which include social withdrawal, slowness, under-activity and apparent lack of motivation (Beels, 1981).

"Insight" is a term Beels (1981) uses to refer to the patient, family and mental health professional having a common understanding of the nature of the illness and treatment. It implies a consensus of the group that is participating in treatment. Insight would help in dealing with the dilemma the patient and the family are faced with when dealing with supporting the patient. What many studies have found is that the quality of the relationship is the important factor when it comes to schizophrenia and social networks that are helpful in one type of situation may be less helpful in others (Greenblatt *et al* 1982).

Social support has been found to be very important for people with psychiatric disorders. This is illustrated in a study by Brown *et al* (1975 in Greenblatt *et al* 1982), which found that women with psychiatric disorders were rarely in intimate and confiding relationships with other people. Social support for a person with schizophrenia according to Beels (1981), should result in fewer or shorter hospitalisations, more independent social functioning and less symptomatic distress. A study by Meszaros & Meszaros (in Greenblatt *et al* 1982) indicates that the attitudes of people with schizophrenia towards their relatives affect their outcome and treatment. People with schizophrenia who were isolated from their relatives were poorly socially adjusted. People who felt positive towards their families did better socially (Greenblatt *et al* 1982).

Social isolation is often associated with schizophrenia. There have been debates and research on whether social isolation is a predisposing factor of schizophrenia, a consequence of schizophrenia or an etiological factor. Leff *et al*'s (1981 in Lipton *et al* 1981) research has shown that when people with schizophrenia return home to high EE families they have a high risk of relapsing. Leff *et al* (1981) therefore propose that, rather than social isolation being a pathological symptom, it may actually be a healthy mechanism used by sufferers to protect themselves from their high EE families (Lipton *et al* 1981)

### 2.3.4 Physical Environment

Studies have found that people with schizophrenia do better in rural areas than in urban areas (Wig *et al* 1987). A two-year follow-up study undertaken by WHO, (1979 in Leff *et al* 1987) gives evidence to the fact that the prognosis for people with schizophrenia living in Agra and Ibadan was better than people who lived in Europe and North America. A recent study was undertaken by Pedersen and Mortensen (2001) and concluded that although family history is the strongest individual risk factor in the development of schizophrenia, the environmental factor - place of birth - is a strong risk factor at a population level. They found that living in urban areas increases the risk of the development of schizophrenia (Pedersen & Mortensen, 2001). Possible explanations have been given for this discrepancy such as divergence in diagnostic practices or more tolerant family attitudes to disabilities in rural areas. Another very likely possibility is the differences in lifestyle such as the higher likelihood of rural people to live with extended families than urban people. Emotions are then dispersed throughout the network of an extended family rather than being concentrated in a small nuclear family. There have also been discussions on the possibility that rural families have lower expectations and are more tolerant of their relatives than those of urban families (Wigg *et al* 1987).

Leff *et al*'s (1987) study also indicated that there were more relapses for people with schizophrenia who lived in urban areas (19%) than in rural areas (9%). This research found that this was due to higher expressed emotions in urban areas. Thirty percent of urban families were classified as having high expressed emotion as compared to only eight percent of rural families. An important finding in the Leff *et al* (1987) research was that the expression of anger in the form of hostility regardless of cultural factors result in the same effect on a sufferer of schizophrenia. Hostility was found to contribute the most to relapses in this research for people living in North America, Britain, Denmark and North India (Leff *et al* 1987). In Western culture there is a greater emphasis on introspection and the spontaneous expression of emotions, which could impact high EE. This does affect positive and negative emotions and requires further research (Wigg *et al* 1987).

Harrison (2001) studied the association between schizophrenia and social inequality at birth. The study revealed that the risk of the development of schizophrenia is greater the greater the level of deprivation at birth. This conclusion adds to the suggestion that environmental factors are important determinants in schizophrenia (Harrison, 2001). Parental loss and dysfunctional families have for long been considered risk factors in the development of psychopathology in adulthood. Studies have similarly found that premature death of a parent can be a contributing factor in the etiology of schizophrenia (Watt & Nicholi, 1979 in Makikyro *et al* 1998). A 1996 study found that psychotic disorders were more common in people from single parent families particularly when children are raised without a father figure (Moilanen and Rantakallio, 1998 in Makikyro *et al* 1998). However in Makikyro *et al*'s (1998) research they did not find that single-parent families increase the risk of the development of schizophrenia. They did find that single-parent families do increase the risk of the development of alcoholism, personality disorders and, to a lesser degree, anxiety disorders (Makikyro *et al* 1998).

What needs to be noted at this point is that environmental factors are not always determinants in the development of schizophrenia.

## **2.4 THE FAMILY**

### **2.4.1 The Experience of Schizophrenia for the Family**

When a person is diagnosed with schizophrenia the family goes through a very different process of adjustment and recovery from that of the affected person. The family and their relative will go through the normal stages of shock, denial, depression, anger, acceptance, coping and final affirmation. However, in addition, the family will be faced with the difficulty or the lack of clarity around the course and prognosis of schizophrenia, which often causes families to move between cycles of hope, then despair. The family experiences these changes in feelings as extremely painful and confusing. However changes in the family's feelings towards schizophrenia need to be seen as a normal and healthy part of adapting and adjusting to schizophrenia for the family. Professionals when dealing with families are often baffled by the changes in

feelings the family experience and believe the reactions to be pathological in nature (Spaniol *et al* 1992).

In the early stages of the diagnosis of schizophrenia the family will experience guilt, embarrassment and self-blame. At this stage it is crucial that the family has contact with a caring professional who can normalise these feelings for the family. As the symptoms of the illness persist the family may become pessimistic and despairing and often lose faith in the professionals. Once the family has realised what can be done, they start to focus on managing symptoms and improving the functioning of their relative. The family may start to experience less self-blame and become more assertive and may want to work more closely with trusted caring professionals (Spaniol *et al* 1992).

Bergman *et al* (1993) studied the short-term stability of intrafamilial speech patterns among families with a member who has schizophrenia. The families were asked to discuss two issues, both which resulted in conflict for the families. Cue statements about the issues were tape recorded and played to the family, provoking a discussion. Family roles were then categorised as "mother-patient central", which is when there is predominant communication between mother and the patient with the father taking a secondary role and *visa versa* called "father-patient central". Dual parental focus was when both parents appear to be central to the discussion.

The results did not support the hypothesis that high degrees of negativity in the first discussion would result in a shift in role structure in the second discussion. Tests showed that mothers in mother-central families had a higher number of negative affective statements than mothers in father-central families and dual-parental groups. The study suggests that when a person with schizophrenia and their family has discussions about a difficult family issue, speech patterns (who speaks to whom) do not change. The patterns remain stable. The findings also suggest that the negative affect expressed during discussions may be due to one parent being central in the discussion. It was found that a shift to a single parent central structure was associated with a greater number of negative statements (Bergman *et al* 1993).

Families with a relative with schizophrenia will develop their own meaning for the mental illness. This meaning will be based on various factors. The premorbid personality of their relative is a contributing factor in the meaning the family gives to the mental illness. Relatives have a thorough knowledge of the personality of their relative with schizophrenia before the diagnosis was given. They therefore see the whole person. What their feelings are towards their relative will play a part in the meaning the family gives to the mental illness. The person with schizophrenia's behaviour will also influence the families' meaning of the mental illness. Behaviours such as being withdrawn, bizarre, irritable and aggressive will all evoke feelings in the family, which will in turn shape the meaning the family gives to the mental illness. Other factors, which may influence the meaning, include issues like the stage and course of the illness, and their relative's level of compliance. Each relative will also give meaning to the mental illness based on aspects of their life experience. For example mental illness has different meanings for people of different ages in the family. Family members' ages will also give them different resources for coping with the mental illness. A relative's personality structures will shape how the mental illness is perceived and coped with. A relative's prior experience with mental illness will also influence the meaning they give the mental illness (Terkelsen, 1987).

The way the family experiences the mental illness will change over time. Terkelsen (1987) has identified progressive stages that the family goes through. The first phase often involves the family ignoring the mental illness. Mental illness emerges subtly in a person and family members will often initially ignore the early warning signs. The second phase is called "the first shock of recognition". Something happens which becomes a trigger for major concern in the family. The family at this stage takes action such as taking their relative to a doctor or mental health professions. The third phase is called "stalemate" where very often something happens which results in help being rejected. The affected person may not be ill enough to accept treatment. Family members not affected may begin minimizing, normalizing or temporising the mental illness. The fourth phase is "containing the implications of the illness". The fifth phase involves transformation to official parenthood. This is when the affected person becomes in need of care. Phase six involves the family searching for the causes of the illness. In the seventh phase the family searches for effective treatment. In the two

previous stages the family believed that their relative would return to his/her previous level of functioning. In the eighth phase the family loses hope. Once they have lost hope they need to mourn the loss of the expectations they had had for their relative with mental illness. This is the ninth phase. Phase ten is called "picking up the pieces" as once the mourning is over they need to restore family life (Terkelsen, 1987).

Johnson (1994) describes five phases that characterise family relationships during the course of mental illness. Her phases are:

1. **Early warnings** – Families often feel isolated and bewildered when early signs of the illness appear.
2. **Keeping the peace** – Families begin to realise that changes in their relative are serious and permanent. They do not seek professional help for various reasons such as they:
  - ❖ have not yet managed to discuss the problem as a family,
  - ❖ fear blame and,
  - ❖ disagree on what needs to be done.

Most families live through several psychotic episodes before seeking help.

3. **Rude Awakening** - The family seeks help and a diagnosis is made.
4. **Just Coping** – The family learns coping skills, which allows them to survive.
5. **A delicate Balance** – Alternative ways to live with the disabling effect of mental illness are created by the family. This balance is about how the family provides care and how much care is provided, how much responsibility should the family take for someone else's life and emotional well-being. Families in this stage look for and are open to alternatives, and decide what to do to improve their and their relative's life. They know that in order to effectively care for others they must care for themselves (Johnson, 1994).

These phases are useful in increasing our understanding of the experience families go through. In the research undertaken in this dissertation it is easily identified that families interviewed were in different phases of dealing with schizophrenia in their family.

It is interesting to note the lack of literature and research on the experience of schizophrenia for the family. It again indicates how little professionals know about what it is like for the family when their relative has schizophrenia.

#### **2.4.2 The Effects of Schizophrenia on the Family**

Johnson (1994) writes about the disruption mental illness has on the lives of families. She says that mental illness often disables the whole family. She says that no one can live with the symptoms of mental illness present in a relative and not be affected. Families do not always acknowledge the effect the illness has on them because it may make them feel blamed. Families often respond to symptoms of mental illness by feeling frustrated, confused, angry, hopeless, and secretive. They also deny or minimize the problem (Johnson, 1994). Johnson (1994) explains that families with a relative with mental illness become accustomed to meeting the needs of others. When life at home is chaotic, certain family members make it tolerable for themselves and learn to survive by becoming caretakers. However, the more involved the caretakers become in meeting the needs of others, the more they neglect themselves. This neglect is evident when caretakers:

- ❖ No longer set personal goals for themselves,
- ❖ No longer maintain intimate relationships,
- ❖ abuse substances or
- ❖ ignore their own feelings.

Depression is common in caretakers. Depression is often a painful signal that a caretaker needs to discover a new approach to their life and problems. Caretakers often foster unnecessary dependency. They become less capable of drawing a distinction between what they should and should not give, and so give more than is appropriate or healthy. Caretakers may feel fear, guilt, insecurity, hopelessness, loneliness, anger, resentment, self-pity and shame. What becomes important is for the caretaker to let go of this role and to function rather as a "caregiver". Caretakers become completely absorbed with taking care of their ill relative whereas a "caregiver" is able to give care but does not allow it to take over their lives. When a person takes on the role of "caregiver" they are freer to choose when and how to give of themselves. They are not stuck with an ultimatum but see many alternatives (Johnson, 1994).

A family's ability to cope with severe mental illness depends to a significant extent on how well their need for support is being met (Hatfield, 1987b). Hatfield (1987b) feels that the effect of mental illness on the family is an area in which there is a lack of research.

The onset of mental illness produces a state of crisis for the family. It becomes a crisis as the onset of mental illness is seen as a sudden change with no way of escaping from it. In a crisis, normal problem-solving skills become inadequate. There is therefore a rise in tension, helplessness, confusion and distress. The family's resources for coping are inadequate to meet the demands of the consequences of mental illness. One of the many tasks the family has to deal with is the disappointment in seeing that their loved one is unable to fulfil expectations. This may necessitate a mourning process for the person affected by the mental illness and their family. Guilt is a powerful emotion often experienced by family members, as they may believe they have failed their relative with mental illness (Hatfield, 1987b).

Individual family members will cope differently with mental illness in the family. Individual variations in coping may be due to personality factors, use of defence mechanisms, prior life experiences, cultural background, role in the family and other such factors (Hatfield, 1987b). A family's ability to successfully adapt to mental illness would depend on each member's capacity to maintain a state of psychological comfort and equilibrium. It would depend on each family member's motivation to adapt to the changes in the family due to the mental illness. Families must have the necessary skills and abilities to meet the new demands in their environment. The family's ability to maintain their old support systems can be very difficult, as their life situation has changed so dramatically (Hatfield, 1987b).

In a study undertaken by Gibbons *et al* (1984) they found that in 90% of the families of people with schizophrenia they studied there was evidence of emotional and/or physical ill health and/or problems with children. The families' distress was directly related to their relative's mental illness, mainly the psychosis, disturbed behaviour and duration of the illness. A similar study by Brown & Birtwistle (1998) found that families suffer

ongoing distress when their relative with schizophrenia lives with them. Brown & Birtwistle (1998) studied 179 subjects who were living with a person with schizophrenia. Their results show how carers of people with schizophrenia displayed significant signs of psychological distress at both initial and follow-up interviews. The study also proves that family care is an option that results in a better outcome for people suffering from schizophrenia. However the negative effect is the distress experienced by the carers.

There are therefore many reasons why it is so important to provide services to support the carers of people with schizophrenia. There are no long-term outcome studies on the effect on families who care for relatives with schizophrenia. This is an area where research is lacking (Brown & Birtwistle, 1998).

Oldridge & Hughes (1992) explored psychological well-being in families with relatives who suffer from schizophrenia. The results show that carers have few resources from social or professional support services. Of the sample of carers, 24% believed that there was no one in their lives who was a source of support to them. More than 50% of the sample lived alone with their relative who suffered from schizophrenia. Potential supporters were more often daughters. Most carer's only source of support was received during their relative with schizophrenia's appointments at the psychiatric clinic. Most carers had not considered what type of intervention might help them now or in the future. Very few carers knew what diagnosis their relative had (Oldridge & Hughes, 1992).

Families of people who are recently diagnosed with schizophrenia are often most distressed by the positive psychotic symptoms their relative' experiences. One of the main long-term effects is thus stress on the carer, which is due to the unrewarding nature of their relative with schizophrenia's behaviour. In Oldridge & Hughe's (1992) study it states that we should not forget that there are a percentage of families who are managing to care for their relative with schizophrenia and are not suffering psychological distress. It would be interesting to look at why they manage to cope and what support is in place for them (Oldridge & Hughes, 1992).

Relatives who care for their relative with psychiatric illnesses are affected socially and financially. They have difficulties coming to terms with and understanding their relative's illness. Despite the tremendous burden, relatives have been found to not complain often and receive little support, advice or information from professionals. Failure to help the family has a negative effect on them and their relative with a mental illness (Fadden *et al* 1987).

Some of the most difficult issues that families have to deal with are:

- ❖ administering medication,
- ❖ bizarre and abnormal behaviour,
- ❖ antisocial and aggressive behaviour,
- ❖ social withdrawal and isolation,
- ❖ educational needs and a lack of employment,
- ❖ poor self-care and appearance and
- ❖ self destructive and suicidal behaviour (Spaniol *et al* 1992).

These problems require specialised treatment and coping strategies, which most families are not equipped to provide. Families often find themselves alone and tormented in coping with day-to-day issues. (Spaniol *et al* 1992).

A very early study on the consequences of mental illness on the family found families to feel underprivileged and marginalized. They felt a need to conceal the mental illness (Caulsen & Yarrow, 1955 in Hatfield, 1987b). A study of 410 families found that the effect of mental illness on the family showed that families were placed under a large burden, particularly for families who already have personal and health problems (Grad & Sainbury, 1963 in Hatfield, 1987b). In 1974, Creer and Wing (in Hatfield, 1987b) found that the sources of difficulty for families were issues like:

- ❖ Uncertainty as to how to deal with the behaviour of their relative with schizophrenia and
- ❖ Concerns about their relative's future.

Hoenig & Hamilton (1966 in Hatfield, 1987b) defined the "object burden" as the effect on material things and the "subjective burden" as the sense of loss, grief, guilt and

anxiety due to the abnormal behaviour. Doll (1976 in Hatfield, 1987b) changed "subject burden" to "affective burden". In his study of "affective burden" he found families to be ambivalent in their feelings; they had felt caring and concern mixed with resentment and anger. In a study by Doll (1976 in Hatfield, 1987b) it was found that families tolerated a large amount of deviant behaviour from their relative with schizophrenia. This tolerance results in many negative consequences for the family and is not always beneficial to their relative's adjustment. Kreisman & Joy (1974 in Hatfield, 1987b) state that mental illness has a profound effect on the family and that mental health professionals do not adequately meet families' needs. Kincin (1975 in Hatfield, 1987b) questioned whether it was fair to have relatives with mental illness living at home because of the high level of stress for the families. He felt that families run out of emotional strength to cope (Hatfield, 1987b).

### **2.4.3 Needs of the Family**

It has been found that the needs of families with a relative with schizophrenia have been poorly assessed (McElroy, 1987). The reality is that families do have many needs when their relative has been diagnosed with a mental illness. Professionals who treat people with schizophrenia often fail to assist families with coping and adaptation skills. Because professionals are seen as not effectively assisting the families, families have had to become the sole caregiver for their relative with mental illness. Due to lack of knowledge professionals tend to rely too much on families and so place even more pressure on families' resources. This situation is compounded by the lack of community mental health facilities. Families often lack the specialised knowledge, skills and support systems to provide the care their relative requires. Mental illness affects people from all walks of life. Families therefore vary greatly in their levels of intellectual, emotional and material resources when dealing with a relative with schizophrenia. Some families are therefore not able to offer significant assistance without personal support for themselves (Spaniol *et al* 1992).

One of the very difficult and frightening issues for families to deal with is managing the delicate balance between independence and age-appropriate behaviour such as living independently and the limitations due to the disability. Families find it very difficult to separate from their caregiver role and allow their relative the independence they

require. The poor state of mental health structures and financial difficulties add to the hesitation families have (Spaniol *et al* 1992).

It has been found that families coped well when their relative with schizophrenia is on effective medication which is well managed. Relatives' of people with schizophrenia whose medication did not effectively control their symptoms were described as not able to cope (McElroy, 1987).

Families often need to discuss issues such as their relative's:

- ❖ Violent behaviour,
- ❖ Child-like behaviour,
- ❖ Withdrawal,
- ❖ Loneliness and
- ❖ Non-compliance with medication (McCreadie *et al* 1991).

Spaniol *et al* (1987) studied the needs and coping strategies of families in United States of America who are the primary caregivers for their family members with schizophrenia. The writers used a family needs survey which showed a high overall dissatisfaction with mental health services. Services which families were dissatisfied with included social rehabilitation, vocational rehabilitation, individual therapy and medication. Family members were also dissatisfied with treatment co-ordination, practical advice, and information about the illness, emotional support and referral assistance. Families' main needs from professionals are practical advice, information about the illness and treatment co-ordination. Fifty eight percent of family members said that professional had not helped them to adequately understand their family members disability. The information given was often too vague, incomplete or contradictory. Ninety five percent of family members with schizophrenia who participated in the study were on medication. Forty seven percent of family members indicated that they were not informed about how the medication would help their relative. Sixty percent were not informed about side effects. Seventy one percent did not know what to do in case of side effects. Family members reported an increase in levels of stress they experienced due to their relatives' illness. Family members felt anxious, frustrated, worried, burdened, depressed, grief, fear and anger. Families wanted to be better informed

about their relatives' illness but they often felt ignored or discounted by mental health professionals (Spaniol *et al* 1987).

Even though families were dissatisfied with the mental health services they wanted more contact with professionals. Families were willing to work with professionals to improve services. Much of the information families require seems to pertain to dealing with practical problems surrounding medication management for their relative with schizophrenia. Family members also seem to have on-going difficulties with their own stress management. The source of stress seems to be due to attitude and coping skills. The writer defines attitude as the family's beliefs around responsibility for the illness and responsibility for managing the illness. Coping skills are seen as the family's ability to handle difficult situations as they arise. Other sources of stress are problems around caring for their relatives with schizophrenia and dealing with an unreceptive and alienating mental health system (Spaniol *et al* 1987).

McElroy (1987) studied the educational needs of families of relatives with serious mental illness. McElroy found that families felt that professionals did not understand their perspective. The study compared families' needs to the perception of families needs by a group of professionals. The study indicated many differences between these two groups. The families rated access to information on mental illness to be one of the most important needs they had. The professional group did not perceive this as a need. The educational needs that the families had were (in order of importance):

- ❖ Information of psychotropic medication
- ❖ Management techniques to promote independence and self-esteem
- ❖ Updates on research on mental illness
- ❖ Housing options
- ❖ Information on how to deal with burn out for themselves

The most important issues that the families had difficulty with were:

- ❖ The inability of their relatives to achieve their potential,
- ❖ Their relative's lack of motivation and
- ❖ Their relative's inability to work (McElroy, 1987).

In a pamphlet compiled by Eli Lilly (SA) they say that families of sufferers need time to accept the difficult situation and they need information, as knowledge leads to power.

## **2.5 INTERVENTION FOR FAMILIES AFFECTED BY SCHIZOPHRENIA**

The family plays a vital role in the course and treatment of schizophrenia. In a fifteen-year outcome study undertaken by Brown & Birthwistle (1998) they find that subjects who no longer live with their families spend almost three times as long in acute hospital beds than those who continue to live with their family. Subjects not living with their family were much more likely to still be in contact with mental health services. This becomes problematic for mental health services as people with schizophrenia then become dependent on mental health services, as there is no family to assist them. They suggest that the course of schizophrenia does not differ whether the person lives with family or not but rather that family care reduces the rate of readmissions (Brown & Birthwistle, 1998).

Dixon & Lehman (1995) reviewed the efficacy and effectiveness of existing family intervention programmes. They found evidence that certain family intervention programmes improve the functioning of a person suffering from schizophrenia and the well-being of the family. Family interventions include a combination of psychoeducation, addressing behavioural problems, behavioural problem solving, family support and crisis management. Having an understanding of high EE has played an important role in the design and implementation of family intervention programmes. Interventions often target families with high EE and attempt to promote characteristics of low EE families (Dixon & Lehman, 1995). Goldstein *et al* (1978 in Dixon & Lehman, 1995) study found that patients assigned to a low-dose medication and no therapy group had a 48 % relapse rate while 0% of the moderate-dose medication and therapy group relapsed. This is a significantly revealing result for the positive effect of family intervention. However not all studies have had such conclusive results. Leff *et al* (1989 in Dixon & Lehman, 1995) studied 24 high EE families who showed no significant differences between the groups (one group received family intervention and the other did not) in relapse rate. Vaughan *et al* (1992 in Dixon & Lehman 1995) had similar findings. Many other studies have found improvements, such as Levene *et al* (1989)

and Zastowny *et al* (1992) and Randolph *et al* (1994) and McFarlane *et al* (1995 in Dixon & Lehman, 1995).

Mari and Striner (1994 in Dixon & Lehman, 1995) met the criteria for an outstanding review of their methodology in their family study. The results showed that family intervention had a significant effect on the amount of relapses. Dixon and Lehman (1995) reviewed all the research done on family interventions. They concluded that there is robust and consistent evidence of the effect of family interventions in delaying - if not preventing relapses. Lam, (1991 in Dixon & Lehman 1995) suggests that family intervention can prevent relapses. Studies have also found that family intervention improves the functioning of their relative with schizophrenia. (Falloon *et al* 1982; Falloon & Pederson, 1985 in Dixon & Lehman, 1995) Studies have also found that family interventions improve the well-being of the family (Falloon *et al* 1982 and 1985; Zastowny *et al* 1992 in Dixon & Lehman, 1995). All these results suggest that including the sufferer of schizophrenia in the intervention is important. They also suggest that while a psychoeducation approach has positive effects, on its own, however, it is not effective in reducing relapses. A psychoeducational approach focuses on giving information or developing skills in the family (Hatfield, 1987b). Lam, (1991 in Dixon & Lehman, 1995) have put together components of family intervention which are beneficial to the family:

1. Taking a positive approach and establishing a working relationship
2. Providing structure and stability
3. Focusing on the here-and-now
4. Using family concepts
5. Working on cognitive restructuring
6. Taking a behavioural approach
7. Improving communication

Brown & Britwistle, (1998) drew up guidelines for professionals dealing with families. Professionals should:

- ❖ negotiate their roles in relation to the family in an adaptive way in order to help the family. In other words, the role should change over time.

- ❖ work collaboratively with the families, using a team approach, when assisting the relative with a mental illness.
- ❖ use an educational approach with the family. Families need education and often feel comfortable in the learner role. They can use the knowledge professionals give them to educate other families.
- ❖ learn to respond to intense feelings expressed by the family. Families at times need professionals just to listen to them.
- ❖ identify strengths in the family and use the family's strengths in assisting the family (Brown & Birtwistle, 1998).

Families' distress while caring for their relative with schizophrenia is exaggerated by:

- ❖ the lack of emotional support,
- ❖ isolation,
- ❖ the lack of acute hospital admissions for their relative and
- ❖ the lack of day treatment facilities for the relative.

These are all areas which need to be worked on by professionals to make the experience of caring for a relative with schizophrenia a less distressing experience (Brown & Birtwistle, 1998).

Vostanis *et al* (1992) studied EE factors to assess whether they change during family therapy. They aimed to see whether EE could be used as a measure of change. The family therapists based their clinical model on the Milan approach. In the Milan model symptoms and problems are seen as a system's solution to an evolutionary impasse. In therapy the families were helped generate new patterns of meaning for their behaviours. Change is seen as being facilitated by gaining an understanding of what is happening in the family. Families were seen in therapy for an average of five sessions each. The results of the research showed a significant reduction in emotional overinvolvement and critical comments between the first and the last family therapy sessions, and the first and the second sessions. Warmth increased at a later stage with significant increases between the first and the last sessions. All the major factors – emotional over-involvement, critical comments and warmth – changed significantly from the first to the last sessions. A reduction in over-involvement was evident from as early

as after the first session. Changes in criticism were evenly distributed throughout therapy while warmth only increased in the later stage of therapy, possibly as a substitute for the reduction of emotional overinvolvement and criticism (Vostanis *et al* 1992).

One of the main aims of McCreadie *et al*'s (1991) research was to bring together families with high EE and families with low EE, and to encourage low EE families to explain their coping mechanism to high EE families. After an 18-month follow-up after this intervention most families felt that things were easier at home. A loose network of families continued after the intervention programme.

As a carer for a mentally ill relative it often becomes easy for the carer to put more attention on the ill relative and to neglect other aspects of their life. A balanced life becomes essential. Carers need to learn to live a balanced life. Johnson (1994) outlines four ways to be involved in a relationship with a mentally ill relative and still maintain serenity and independence. They are:

1. Identify and ask for what you need;
2. Develop a network of support outside the family;
3. Learn to say no; and
4. In all circumstances, be true to yourself.

As families start to heal and cope with the situation they can then support other families, and support groups can start up. Support groups for families have been found to be very beneficial in providing a space for the family to share their experiences with other family members. Support groups also assist families in developing coping mechanisms and in mourning their loss. Families often feel distressed, alone, helpless and vulnerable in their situation and they need to be heard in a non-blaming environment such as a support group. Families can learn through the support group to function more effectively. Advocacy on a personal, organisational and legislative basis is also a part of the adjustment and recovery process for the family (Spaniol *et al* 1992).

Some research has found that it is difficult to engage families in treatment programmes. Families give reasons such as things are “fine”. Families often feel resignation, pride and resentment. Vigorous outreach to families is important to enable families to accept help (McCreadie *et al* 1991).

## **2.6 BENEFITS TO A PERSON WITH SCHIZOPHRENIA WHEN THEIR FAMILY RECEIVES TREATMENT**

The biggest benefit for a person with schizophrenia comes when they live with their family. There is much literature on the positive association between social support and mental health outcome. Relationships have been found to improve the outcome for people with schizophrenia. Erickson *et al*'s (1998) findings state that a supportive social environment prior to the first psychotic episode predicts five-year outcome. A consistent research finding has been the impact of family intervention on relapse rates. Research has shown a reduction in relapses through family intervention. If these intervention programmes were designed to dispel high EE characteristics in the family then the reduction in relapse rate may be associated with reduction in the high levels of expressed emotion in the family (Leff *et al* 1982, 1985, 1989; Tarrier *et al* 1988, 1989; Falloon *et al* 1982; Hogarty *et al* 1986 in McCreadie *et al* 1991). A substantial body of research has proven that family intervention programmes in conjunction with medication significantly reduce the rate of relapses when compared to a control sample (Goldstein *et al* 1978; Leff *et al* 1982; Falloon *et al* 1985; Hogarty *et al* 1986 in Mintz *et al* 1987). Family intervention programmes, which have reduced the high EE status of families, have also reduced the relapse rate in people with schizophrenia (Szmukler *et al* 1987). Tarrier *et al* (1994) concluded their study by stating that relapses can be prevented through family management soon after discharge and that this has long-term benefits.

Family intervention programmes have been found by Lenior *et al* (2001) to help parents support their children with schizophrenia, and that this results in a reduced need for institutional care. An intervention programme was implemented with the underlying aim of improving social networks. They brought together all the people in a person with schizophrenia's social network and invited them to a psychotherapy session. In the sessions they defined the patient's problems and looked for pathology within the

network that might be negatively affecting the patient. They believed that psychopathology existed in the social milieu of patients and that treating the network was essential to the patient's recovery (Greenblatt *et al* 1982).

Families have been found to be resistant to receiving treatment. In a President's Commission on Mental Health (1978 in Beels, 1981) they state that treatment should focus on strengths in the individual and in the family rather than on the illness. They also found this will encourage families to receive treatment because this type of approach reduces stigma.

Several studies have reported that giving information on schizophrenia to families reduces the relative's relapse rate. Informing families contributes to an improvement in the relative's condition (Berkowitz *et al* 1984, McGill *et al* 1983, Goldstein, 1981; Barrowclough & Tarrier, 1984 in Barrowclough *et al* 1987). In Barrowclough *et al's* (1987) research they looked at providing relatives with knowledge on schizophrenia and how this knowledge can be improved or changed. Their main interest was on the functional value this information may have. They found that the family's knowledge improved significantly after an information session. The family's functional responses also changed from negative to positive after the session. This research provides evidence of the success of brief information giving intervention in assisting the patient. The research also shows how the duration of the illness affects the relatives' reception of the information. The shorter the length of the illness the less the relatives know and the more receptive they were to acquiring information. This means that over time families develop an individual view of the illness, resulting in families being less influenced by professional opinions. Early education about schizophrenia is therefore important in influencing families' behaviour. Another finding of this study was that families develop their own understanding about the cause of the illness, and tend to retain their own version of the aetiology after information-giving. (Barrowclough *et al* 1987)

## **2.7 CONCLUDING COMMENTS**

Schizophrenia is a disease of the brain resulting in disturbances of thinking, feeling, emotions and changes in behaviour. When a diagnosis of schizophrenia is made, the family experience many complex feelings such as sadness, shame, guilt, bitterness and denial.

The literature review discusses the central role of the family in the course of treatment of their relative with schizophrenia. It highlights how little is done by professionals to assist families and their need for information and support. However there is far more research and literature on the causes of schizophrenia. Research on the cause of schizophrenia often views the family as part of the cause, ignoring their supportive role and their own suffering due to the presence of the illness in their lives.

Schizophrenia needs to be understood as a disease which affects the family as a whole. Once this is achieved families will not feel blamed and will be enabled to focus on a solution to the many complex difficulties schizophrenia brings. The writer feels that the ultimate aim of professionals should be to assist families to achieve a delicate balance in dealing with their relative with schizophrenia (Johnson, 1994). Professionals are able to achieve this with families by understanding and then meeting their needs. This research dissertation aims to explore the needs of families utilising services at Cape Mental Health Society.

## CHAPTER THREE

### RESEARCH DESIGN AND METHODOLOGY

#### 3.1 INTRODUCTION

In this chapter the method used to undertake this research has been described. It includes information on the research design, the sample and population, how the data was collected, information on the interview schedule and how the data was analysed.

The objective of the research is to answer the following research questions:

- ❖ What is the experience for the family when one of its members is diagnosed with schizophrenia?
- ❖ What does the family need?
- ❖ What are the factors which make the experience of schizophrenia easier for the family?

#### 3.2 RESEARCH DESIGN

The aim of the research is to explore what the needs of these families are and, consequently, the research design is exploratory. The results are therefore not conclusive or statistically sound. They do, however, build onto the body of knowledge on schizophrenia (Grinnell, 1988) and encourage further and more conclusive research into this area (Finestone & Kahn, 1975).

This study uses both qualitative and quantitative methods. The majority of the research is qualitative. Words have been used to explore and analyse the research rather than numbers or statistics. The qualitative dimensions of the research are evident in the sections of the interview schedule which allowed for a rich data to be conveyed by the interviewees. The interviews were semi-structured with mainly open-ended questions and some closed-ended questions (York, 1998).

### **3.3 SAMPLING**

#### **3.3.1 The Population**

Powers, Meenaghan and Toomey (1985:27 in De Vos & Strydom, 1998:190) define the population "as a set of entities for which all the measurements of interest to the practitioner or researcher are represented." The population for this research was therefore people with schizophrenia whose families were involved with their relative during the time of diagnoses and are currently utilising social work services at Cape Mental Health Society.

#### **3.3.2 The Sample**

The sample according to Arkava and Lane (1983 in De Vos & Strydom, 1998) is the part of the population considered for inclusion in the study. The sample for this research was parents, or a spouse or a family member of a person with schizophrenia who was living or closely involved in the person's life at the time the diagnosis was made and who gave permission to be interviewed for the research.

#### **3.3.3 Sampling Procedure**

Nonprobability sampling is often used in exploratory studies. Nonprobability sampling is a type of sampling in which randomisation is not done. Purposive sampling is the type of nonprobability sampling used in this research. It is characteristic of purposive sampling that the sample selected is based on subject's availability and accessibility (Seaberg, 1988; De Vos & Strydom, 1998).

The sample was recruited by presenting the research proposal and interview schedule to all the social workers at Cape Mental Health Society doing case work (12 social workers) and the social worker co-ordinating the psycho-social groups for people with mental illness. Social workers were asked to scan their caseload for clients, who fitted the profile of the sample for the research. Social workers then approached the writer individually to discuss possible cases. Three cases were excluded as the relative had a

dual diagnosis; schizophrenia and intellectual disability. It was felt that this would add an extra variable into the research, which would affect the results. Three other subjects were not interviewed because one was uncontactable via the phone number given, one subject chose not to participate and attempting to meet with one subject failed twice. Therefore of the fourteen subjects, eleven were interviewed.

It seemed unusual that a mental health organisation which serves 2 000 people with mental health problems every year would have such a limited number of suitable subjects for this research. After enquiring with the social workers as to why they had so few suitable subjects it appeared that many of their clients with schizophrenia did not have contactable family or family who would be prepared to be interviewed. It is believed that this is due to the large number of people with schizophrenia who are abandoned by their family. This research has shown how difficult it is for the family to understand, support and accept a relative with schizophrenia. It is also believed by the writer that many of the clients at Cape Mental Health Society with schizophrenia have come to Cape Mental Health Society for social work services because they have no caretakers. This is a possible area for further research.

### **3.3.4 Sample Size**

According to Seaberg (1988) a correct sample size is determined by characteristics of the population and the nature of the research questions. In this research the sample size was adequate to the purpose of this dissertation – to gain a better understanding of the needs of families with a relative with schizophrenia. For the study the sample comprised of fourteen subjects of which eleven were interviewed.

## **3.4 DATA COLLECTION**

The data collection method used was face-to-face interviews. The interviews were semi-structured with some open and some closed-ended questions. Interviewing was used as it offers naturalness, spontaneity and flexibility. Interviewing also offered the opportunity to pick up nonverbal responses, which are particularly useful in an interview of such a sensitive nature. Interviewing offers the advantage of the writer being in control of the interview environment. This includes being aware of how interviewees were influenced by others such as in cases where more than one person was

interviewed at one time. Being in control of the interview environment also has the advantage of the writer preventing interruptions during the interview. The disadvantage of interviews is that the research is dependent on self-report and the writer can influence the interviewee by her tone of voice, phrasing of the questions and non-verbal behaviour (Gochros, 1988).

It is important to note that the writer has worked for the last five years with people with mental illness and their families. This has a number of advantages, of which one is that being familiar with these families assisted in the quick and easy development of rapport. This has the advantage of families sharing openly and honestly. However the disadvantage of this is that the writer may be influenced by the stories and experiences of others families worked with, and who were not interviewed for this research.

The first interview undertaken was a pilot interview which Mindel and McDonald (1988) states is a crucial stage in the development of the interview schedule and assists in giving a true indication of how well subjects will understand questions. After the pilot interview the interview schedule was re-examined and necessary changes were made. Dilman (1978 in Mindel & McDonald, 1988) provides pre-test questions, which should be answered after a pre-test has been undertaken. The following questions were used during re-examination of the questionnaire. They include:

- ❖ Does each question measure what it is intending to,
- ❖ Are the terms easy to understand,
- ❖ Do all the closed-ended questions have a response rate and
- ❖ Does the interview create a positive impression.

One question had to be reworded in order to make it more comprehensible for the interviewee, and the sequence of the interview schedule was changed.

Interviews were conducted from June 2002 to August 2002. Dates, times and places were negotiated individually with interviewees. Due to the fact that not all the subjects have access to Cape Mental Health Society's offices it was decided that an offer would be made to conduct the interview at the subject's home. It was important for the interviewee to feel comfortable in the surroundings where the interview takes place due

to the sensitive nature of the data under discussion. However there was awareness that interviewing in a subjects' home can result in interferences. Subjects were informed before the interview that a private place where there would be no interruptions was necessary for interviews. Seven of the interviews undertaken were done in the interviewee's home and four were undertaken in an office at Cape Mental Health Society.

It was decided to use a tape recorder to record interviews. However due to circumstances beyond the writers' control only two of the interviews were recorded. It therefore became important to rely on handwritten recording for the remaining interviews. The writer was aware that handwritten recording is not the safest procedure for recording interviews. Therefore extreme care was taken while recording. The distractions created by the writer writing during the interview were taken into consideration during the interviews. When taking down verbatim responses extreme care was taken and at times requests were made that interviewees repeat phases. Time was allowed during the interview for recording purposes. Immediately after each interview the writer spent time recording what had not been recorded during the interview. Shortcuts and codes were developed to make recording more efficient (Gochros, 1988).

### **3.5 INTERVIEW SCHEDULE**

The interview schedule was based on the writer's experience of working with families of sufferers of mental illness for the past five years and on the relevant literature. The interview schedule used both closed- and open-ended questions. The closed-ended questions merely aimed to gain an understanding of what the circumstances were at the time when the relative was diagnosed with schizophrenia. This data assisted in identifying the factors, which made the experience positive or negative for the family. It helped in understanding how the manner in which the diagnosis was disclosed to the family impacted on the family.

A further aim of the closed-ended questions was to help take the family back to the time of diagnosis so they are able to answer the open-ended questions while they are, in a sense, reliving the experience of being told the diagnosis. The data from the close-

ended questions was used to analyse whether there are any striking differences in issues such as age, gender that may have bearing on the responses to the open-ended questions.

The open-ended questions helped in gaining an understanding of how the disclosing of the diagnosis of schizophrenia was experienced by the family. They generated insight into what it was like for the family when one of their members was diagnosed with schizophrenia. They also elicited what the family's needs were at the time of diagnosis, shortly after diagnosis and currently at the time of the interview. Through the open-ended questions information was gathered on what could have been done to make the experience easier for the families.

The sequencing of the questions changed after the pilot interview. In the pilot interview all the closed-ended questions were asked first. This was in order to help the families go back to the time of diagnosis by first asking all the facts around diagnosis and then going onto what the experience was like for them. However it was found that the interview did not flow well and it was decided to adjust the sequencing of the questions in the altered schedule. Related closed-ended questions were combined with open-ended questions and, consequently, the second interview flowed more smoothly. Another change was that an additional question was included: What is your first language? Language is an important part of in-depth interviews. Language influences interviewees' understanding of questions and the writer's understanding of interviewees' responses. It was therefore important to be aware of any possible communication problems.

### **3.6 DATA ANALYSIS**

The third phase of the research was to analyse the results. There was a need at this stage to make sense of the interviews. Looking for common themes in the interviews was a way of doing this. It was necessary when analysing the data to reduce words to themes such as identifying when interviewees used different words to describe the same issues. It was necessary to separate broad themes from more specific themes (York, 1998).

Another strategy used in analysing the research was to note the amount of times in an interview reference was made to the same issue. Similarly, I noted the amount of times the same word was used when the interviewee was describing the issue. Certain common issues were brought up in all eleven interviews and the amount of times this happened was noted (York, 1998). It is very important when doing this type of analysis, which York (1998) refers to as content analysis, to be objective.

### **3.7 LIMITATIONS**

The limitations of this study need to be considered in view of what the research sets out to achieve. This research sets out to identify what the needs are of families with a relative with schizophrenia receiving services at Cape Mental Health Society. The aim is to better equip mental health professionals to meet the needs of these families. This research cannot be generalised to all families with a relative with schizophrenia. A limitation of the methodology used is the disadvantages of using interviews. As mentioned previously, interviews rely on self-report and there are many influences which can occur during interviewing. A further limitation was that the majority of the interviews were not recorded using a tape recorder. The writer needed to rely on handwritten recording which is not as reliable. The sample was limited to families who were willing and available to participate. The interview topic was sensitive and therefore families had to volunteer to participate.

### **3.8 ETHICAL CONSIDERATIONS**

In order to do research at Cape Mental Health Society the research proposal has to be approved by Cape Mental Health Society's Research Department. The research proposal and interview schedule was submitted to the Research Department in May 2002. The Research Department then approved the research. The method of recruiting subjects and the issue of confidentiality were discussed with the Research Department. It was decided that it was necessary to inform the interviewee that the discussion during the interviews is confidential, and would not be made known to their caseworker at Cape Mental Health Society. However, if it were necessary to discuss certain issues with the caseworker the writer would get the interviewee's permission.

Interviews were therefore not written up or noted in case files at Cape Mental Health Society.

Each interviewee was clearly informed that the interview is part of a master's dissertation to obtain a Masters Degree at the University of Cape Town. Interviewees were assured that their identity and any identifying information would be concealed. The identity of all participants in this study has been protected by not using any identifying information. Each interviewee was made aware that the research was important to help ensure that the needs of families with relatives with schizophrenia are met in the future.

As this is a sensitive topic, and I was aware that the interview questions would evoke painful and difficult feelings, the interviews were completely voluntary. In order to take part subjects therefore had to be prepared to discuss these difficult issues. The writer was sensitive to the needs of the family while discussing such emotional issues, and offered containment and support when necessary (York, 1998). Follow-up counselling was provided to some of the families after the interview.

## CHAPTER FOUR

### RESULTS AND DISCUSSION OF RESULTS

In this chapter the results will be presented and discussed. Information on the interviewees is presented. Data on the issues around diagnosis is presented and information is given on what the families felt their needs are. At the end of this chapter there is a section on the overall experience of the interviews.

The results are presented in the order the questions appeared on the interview schedule. Each question will be specified, results will then be presented and discussed.

#### 4.1 RESPONDENTS

The first three questions which are closed-ended questions have been included on one table below.

INTERVIEWEE	RELATIONSHIP TO RELATIVE	RELATIVE'S GENDER	FIRST LANGUAGE
One	Parents	Female	English
Two	Parents	Male	Afrikaans
Three	Mother	Female	Afrikaans
Four	Father	Male	English
Five	Mother	Female	English
Six	Mother	Female	Xhosa
Seven	Mother	Female	Afrikaans/Sotho
Eight	Mother	Male	English
Nine	Father	Male	English
Ten	Mother	Male	English
Eleven	Mother	Male	English

Table one: The respondents

#### 4.1.1 How are you related to your relative with schizophrenia?

As shown in Table One the majority of interviewees were mothers of children with schizophrenia. Two interviewees were fathers, and in two interviews both parents were interviewed. The research was not limited to parents of people with schizophrenia. However all the subjects were parents. It could possibly be due to fact that as schizophrenia is traumatic, difficult to deal with and associated with a number of pejorative stigmas and myths a person with schizophrenia is often abandoned by people and relatives who were close to them prior to them being diagnosed. It is therefore often only the parents who are left to care for and support their child with schizophrenia. This hypothesis could be linked to the issue - as discussed earlier under the methodology section - that people with schizophrenia are often abandoned by people and relatives close to them. This hypothesis was made because so few suitable subjects were located for this research. This is an interesting area for further research.

#### 4.1.2 What is your relative with schizophrenia's gender?

As Chart One and Table One indicates, 54% of the interviewee's relatives were male and 45% of the interviewee's relatives were female. This is an even distribution of gender.

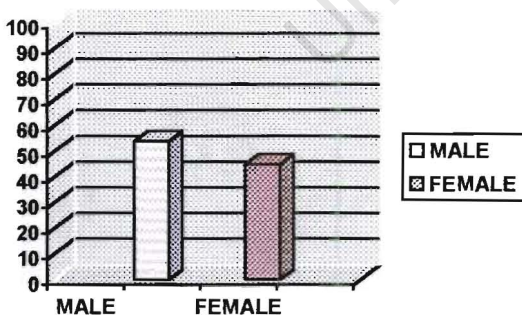


Chart One. Relatives with schizophrenia's gender

### 4.1.3 What is your first language? (Refer to Table One and Chart Two)

English is the first language of 63.63% of the interviewee. This is by far the majority. Eighteen point eighteen percent of the interviewees speak an African language as a first language. Similarly 18.18% of the interviewees have Afrikaans as a first language. A variety of languages such as other South African languages are not well represented in this research as Chart Two indicates. Possible reasons for this are:

- ❖ A high percentage of the clients receiving services at Cape Mental Health Society are English speaking;
- ❖ The writer is English speaking; and
- ❖ In African cultures a medical model is not always used to explain and treat mental illness. In these cases this research would not be relevant.

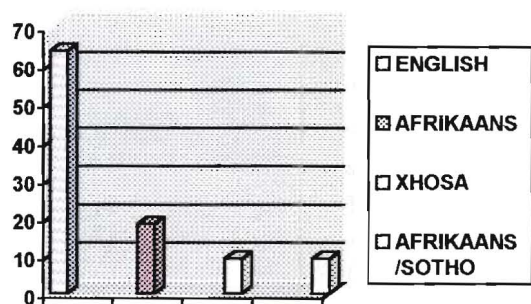


Chart two. First language of respondents

## 4.2 DIAGNOSIS

### 4.2.1 When was your relative diagnosed with schizophrenia?

INTERVIEWEE	PERIOD
One	10 months ago
Two	8 years ago
Three	10 years ago
Four	10 years ago
Five	20 years ago
Six	20 years ago
Seven	27 years ago

Ten	5 years ago
Eleven	22 years ago

Table two. Period since relative's diagnosis

As shown in Table Two there is a large variation in when interviewee's relatives were diagnosed. The range is from 22 years to 5 months ago.

#### 4.2.2 What was your relative's age at the time of diagnosis?

INTERVIEWEE	AGE
One	20 years old
Two	22 years old
Three	16 years old
Four	14 years old
Five	20 years old
Six	27 years old
Seven	18 years old
Eight	17 years old
Nine	25 years old
Ten	25 years old
Eleven	25 years old

Table three. Relative's age at diagnosis

As indicated in Table Three ages range from 25-14 years, which correlates to what the literature says on the age of onset. (Kaplan *et al* 1994)

#### 4.2.3 Who diagnosed your relative with schizophrenia?

INTERVIEWEE	WHO DIAGNOSED RELATIVE
One	Psychiatrist private practice
Two	Psychiatrist Valkenberg Hospital
Three	Psychiatrist private practice
Four	Psychiatrist Lentegeur Hospital
Five	Psychiatrist Valkenberg Hospital
Six	Can't remember
Seven	Psychiatrist Valkenberg Hospital
Eight	Clinical Psychologist private practice
Nine	Psychiatrist Valkenberg Hospital
Ten	Professor Groote Schuur Hospital
Eleven	Psychiatrist Valkenberg Hospital

Table four. Diagnoses

As shown on Table Four, 45% of the interviewees' relatives were diagnosed with schizophrenia at Valkenberg Hospital. It was surprising to the writer how few interviewees took their relatives to private psychiatrists (27%), which the writer assumes the majority could afford to do.

A possible reason for this is that it was only when their relative was psychotic and required hospitalisation that the families got help. There is literature which supports this theory. In the literature review of this dissertation Terkelsen's (1987) progressive stages that families go through are reviewed. In the first stage the family ignores the mental illness. It is only when something overwhelming happens that they seek help for their relative. Similarly Johnson (1994) describes how families silence themselves and one another in the hope that the problem will go away. It is often only when a person with schizophrenia becomes homicidal or suicidal that families find help.

Another possible reason is that the acceptance that their relative has schizophrenia only occurred when their relative was in a psychiatric hospital. Being in a hospital among other people with psychiatric disorders and faced with psychiatric staff may force some families to acknowledge that their relative has schizophrenia. The shock of a diagnosis of schizophrenia is so great for the family that many may have taken their relative to private practitioners prior to their relative being admitted into a psychiatric hospital, but at that time could not deal with the diagnosis so chose to deny it or block it out. Some families may then go to various different medical or mental health professionals to try to find a less traumatic explanation for their relative's problems. One interviewee interviewed for this research at the time of the interview was having great difficulty believing any medical or mental health professional's diagnosis that her son had schizophrenia. The writer feels this is a common experience among families. It was not investigated fully during these research interviews but could be an area for further research.

#### **4.2.4 What happened when your relative first started experiencing the symptoms of schizophrenia before a diagnosis was made? What was this experience like for you?**

This question was difficult for all the interviewees to answer. Interviewees preferred to focus on their relative's experience rather than their own. Each interviewee started answering this question by giving a history of what happened to their relative prior to being diagnosed. It was clear that even after prompting from the writer, interviewees preferred to talk about what happened to their relative when symptoms first started appearing rather than their own emotions during this period. Three interviewees said it was difficult to answer what the experience was like for them. It is possible that the difficulty lay not in the question but in describing the emotions that they, as parents, had during this time. This may be linked to feeling traumatised at the time of diagnosis and to blocking out certain events.

Nine out of the eleven interviewees believed that what was happening to their relative was something other than schizophrenia. Interviewees thought:

- ❖ It was due to hormones
- ❖ It was due to depression

- ❖ It was because of using dagga
- ❖ Their relative was “going through a phase”
- ❖ It was because their relative was studying too much
- ❖ It was because his son’s mother was being too hard on his son
- ❖ Their relative would grow out of it,
- ❖ It was due to drugs and alcohol
- ❖ It was because her son was always a very spiritual and psychic person.

One family said, “mental illness was the last thing on our mind.” It is possible that families believed that what was happening to their relative before a diagnosis was made was something other than schizophrenia because they were in denial. They possibly denied the schizophrenia because it was too difficult to accept. However a more obvious reason could be because schizophrenia is not a well known or talked about illness the symptoms were therefore not familiar to the families.

The majority of the interviewees did not recognise what was happening to their relative, as schizophrenia resulted in them feel helpless. The feeling of helplessness was common among interviewees. This sense of not knowing made this time frightening for the interviewees.

Seven of the interviewees described a long struggle involving different doctors and professionals before their relative was diagnosed and treated correctly. One interviewee was angry with the doctor at the time the diagnosis was given and still now feels anger towards doctors. This interviewee said she felt anger due to her feeling that the doctor does not trust her information about her relative’s behaviour at home. It also may be anger she is feeling due to the fact that her son has schizophrenia, which she is projecting onto the doctors. As mentioned earlier, these families feel very helpless due to not being able to control the fact that their child has been diagnosed with schizophrenia. The feelings of helplessness can become anger. This could be occurring for this family.

Five interviewees believed that the behaviour their relative was presenting with was due to drugs. A wide range of substances, including drugs, can induce symptoms of

psychosis. A diagnosis is then given of a substance-induced psychotic disorder. However if symptoms persist and the patient is not taking drugs then other diagnoses such as schizophrenia are considered. Seven of the eleven interviewee's relatives had at some stage during the initial period of diagnosis used drugs. This is a very high number of people. A possible reason for this is that in the early stages of the development of schizophrenia the sufferer experiences very unusual and frightening experiences such as delusions and hallucinations. These experiences are difficult to describe to others. Drug use could possibly be a coping mechanism to deal with these experiences. The judgement of people with schizophrenia is often impaired, resulting in them being more vulnerable to deviant behaviour such as using drugs (Kaplan *et al* 1994).

One interviewee said that it has taken her many years to believe that her daughter has schizophrenia and not just a drug problem. One interviewee described how her son had been offered the drug ecstasy at a party. The drug had been mixed with other substances, which caused him to have a bad experience leading to the onset of schizophrenia. This interviewee believes that the drug caused the schizophrenia. It may be easier for families to accept drug abuse rather than schizophrenia as nowadays drug abuse is such a common problem and there is so much information available on it.

Three interviewees thought that this was a short-term problem. One mother said that, "if you get sick you get better". She cannot understand why her daughter is not getting better. Three of the interviewee described being afraid of their relative. These interviewees' relatives had become violent in the initial phase of their illness.

One interviewee spoke about feeling guilty that they did not take their relative to a psychiatrist earlier and believes that the delay may have resulted in their relative's problems being worse now. Another interviewee said it was "very painful and it was a shock" and that mental illness was the, "last thing we expected for our child."

One interviewee said that it caused stress for her husband. Another said that it was very difficult for a long time. Another spoke of concern for their child. Feelings of being out of control and helplessness were described.

One interviewee described the agony of “wanting to help but not knowing what to do or where to go.” One interviewee said that at first she and the family ignored their relative’s symptoms. They turned a blind eye as she talked and laughed to herself, studied the whole night, never slept and said that the radio was talking to her. This is an example of how the family does not initially get help as the literature describes. This interviewee said they only got help for their relative when the school their relative was attending insisted that they take her to Groote Schuur Hospital. The family’s experience bears out what is described in the literature: something big happens to force the family to take action (Johnson, 1994; Terkelsen 1987).

#### 4.2.5 Who told you about the diagnosis?

INTERVIEWEE	WHO TOLD INTERVIEWEE
One	Psychiatrist private practice
Two	Psychiatrist Valkenberg Hospital
Three	Psychiatrist private practice
Four	Psychiatrist Lentegeur Hospital
Five	Psychiatrist Valkenberg Hospital
Six	Can't remember
Seven	Psychiatrist Valkenberg Hospital
Eight	Clinical Psychologist private practice
Nine	Psychiatrist Valkenberg Hospital
Ten	Professor Groote Schuur Hospital
Eleven	Psychiatrist Valkenberg Hospital

Table five. Receiving the diagnosis

This question was asked to discover whether the person who diagnosed the interviewee’s relative and the person who informed the interviewee were the same person. The same person who did the diagnosis informed all interviewees. The writer’s experience is that in some cases a psychiatrist may do the diagnosis and then another mental health professional such as a psychiatric nurse or a social worker breaks the news to the family. The writer recommends that this happen if doctors are too busy to give the families enough time. Interviewee six did not appear to have been

informed that her relative had schizophrenia even though the relative was often admitted into a psychiatric hospital – as indicated in Table Five.

#### 4.2.6 Was your relative present when the diagnosis was disclosed to you?

INTERVIEWEE	WAS RELATIVE PRESENT?
One	Yes
Two	No
Three	Yes
Four	Yes
Five	No
Six	Not informed of diagnosis
Seven	Not informed of diagnosis
Eight	No
Nine	Yes
Ten	Yes
Eleven	No

Table six. Was relative present?

As shown in Table Six, 45% of the interviewees' relatives were present when the diagnosis was broken to them. Two of the interviewees did not appear to have been formally told that their relative had schizophrenia. The writer believes that in these two particular cases language may have been a problem as they are both Xhosa-speaking. However the writer did manage to interview them so the person diagnosing could have explained the diagnosis to them. It makes treatment and healing for the family so difficult if a formal process has not been followed in terms of informing the family of the diagnosis. For one of these interviewees the writer felt the interviewee did not know the word schizophrenia but could describe the symptoms her daughter presented with.

This question brings up ethical issues around disclosing a diagnosis to a person. For example if a doctor were to inform an adult (as all the relatives of the interviewees were at the time of diagnosis) that they had cancer, is it ethically correct to inform the person

in front of their relatives? It could then be argued that when a person with schizophrenia is psychotic are they capable of dealing with a diagnosis of schizophrenia without the intervention of relatives? This is an area which requires some debate and possibly further research.

#### 4.2.7 If not, was your relative aware that the information was being disclosed to you?

INTERVIEWEE	WAS RELATIVE PRESENT?	WAS YOUR RELATIVE AWARE?
Two	No	No
Five	No	Yes
Eight	No	No
Eleven	No	No

Table six. Was your relative aware?

Three out of four relatives were not informed that their parents were being told that they have schizophrenia – as indicated in Table Six. This is also an ethical issue - is a medical practitioner allowed to disclose a diagnosis to relatives without the patient's consent? However, as mentioned previously, there is another dilemma which needs to be taken into consideration. This is being the rights of a psychotic person. For example, if someone is at risk of harming themselves due to their psychosis, is it ethically correct to inform relatives of the person's diagnosis without their permission? This question will concern the patient more than the family. It may have been interesting to ask the relatives with schizophrenia whether it was a concern of theirs that they were not informed that the information was going to be disclosed to their parents. The writer does not have answers to these rather complex issues but feels that further discussion and research are necessary and would assist in gaining clarity and generating guidelines for professionals diagnosing schizophrenia.

#### 4.2.8 Who was present when the diagnosis was disclosed to you?

INTERVIEWEE	WHO WAS PRESENT?
One	Both parents and relative
Two	Only mother (informed over telephone)
Three	Both parents and relative
Four	Father and relative
Five	Mother
Six	(Not formally told)
Seven	(Not formally told)
Eight	Mother
Nine	Father and relative
Ten	Both parents and relative
Eleven	Mother

Table seven. Who was present at diagnosis?

As shown in Table Seven in four cases the information was disclosed to one person on their own. In three cases the information was disclosed to the relative with both their parents present. In two cases the information was disclosed to the relative with one of their parents present. The other two interviewees did not have or cannot remember a formal process of the diagnosis being disclosed to them – as table seven indicates. As mentioned previously the impact of not having a formal process of the diagnosis being disclosed has many negative consequences for the family in terms of their own healing and their abilities to cope with their relative with schizophrenia.

The results of this research have found disclosing the diagnosis is traumatic for the family. The person disclosing the diagnosis needs to assess whether it is suitable to give the information to a relative on his/her own or whether another relative should be present for support. This would also apply if the information were being disclosed to the patient.

#### **4.2.9 Tell me how the information was disclosed to you? i.e. what did he/she say, how did you feel about the person disclosing the information?**

Four interviewees indicated that they felt how their doctors handled presenting the diagnosis was inadequate. These interviewees described the doctors as too busy. One of these interviewees said, "the doctor was very clinical and very busy". The doctor had used terminology which the interviewee had not understood. Another parent said that the doctor told her that her daughter had a "chemical imbalance". This is a very important issue which mental health professionals need to remember. When explaining the diagnosis to the family they need to use terminology that the family understands.

Three interviewees said that the doctors were "very nice". One described the doctor as "motherly and confident." Another said that the doctor listened well, but was also firm with her son about taking medication. This interviewee was happy that the doctor had done this as she was worried that her son would not take his medication. One interviewee had liked the way the doctor convinced her son to be admitted to the hospital. The doctor had said that he must come and have a holiday at Valkenberg Hospital.

One interviewee said that they have had a "very trying and frustrating time dealing with the doctors." One interviewee said that the doctor only told them about the positive things about the diagnosis. Another felt they needed more time to answer questions but the doctor was too busy. One interviewee said that the doctor had empathized well with them and she could see that the system was the problem. One father said that he never expected much from the hospital as he realised the shortage of staff at state hospitals. However, he was disappointed that there was no counselling for him. This interviewee was able to identify that he needed support in order to cope with his son's schizophrenia. One interviewee felt intimidated by the doctor. She had read a lot about schizophrenia and she felt that the doctor did not like the fact that the interviewee had so much information.

What is important to mention is the power doctors have over patients and their families. This is a possible reason why interviewees did not give as much information when answering this question as the writer would have liked. There may have been a fear of criticising a doctor, someone who is often seen by people as being an important and powerful person.

#### 4.2.10 Was the diagnosis and the implications of the diagnosis explained fully to you and your relative?

INTERVIEWEE	WERE THE IMPLICATIONS EXPLAINED FULLY TO YOU AND YOUR RELATIVE?
One	No
Two	No
Three	No
Four	No
Five	Yes
Six	No
Seven	No
Eight	No
Nine	No
Ten	"to a certain extent"
Eleven	No

Table eight. Explanation of diagnosis and implications of diagnosis

As Table Eight indicates 81% of interviewees did not feel that the implications of schizophrenia were explained fully to them or their affected relative at the time of diagnosis. It was a difficult experience for the writer to hear how many families had to battle to understand the illness that their relative was suffering from. Throughout the interviews it was clear that families battled to understand and get adequate information on schizophrenia. There are examples of how families had to go to different doctors before getting a clear diagnosis explained to them. One interviewee who had psychiatry training suspected for a long time that her son had schizophrenia. It took her a long time to get a doctor to diagnose and treat her son. At least five of the interviewees had been to more than one doctor before a diagnosis of schizophrenia was made and explained clearly to the family. Another interviewee was sent from one

doctor to an alcohol rehabilitation centre before being sent to Valkenberg Hospital to get an explanation.

#### 4.2.11 Do you think the diagnosis was explained in a sensitive manner to you?

INTERVIEWEE	WAS THE DIAGNOSIS EXPLAINED IN A SENSITIVE MANNER?
One	No
Two	No
Three	Unsure
Four	Yes
Five	Yes
Six	No formal process
Seven	"don't remember"
Eight	Yes
Nine	Yes, very
Ten	Yes
Eleven	Yes

Table nine. Sensitivity of diagnosis explanation

An interesting result is that even though 81% of interviewees felt that the implications of the diagnosis were not explained fully to them, 54 % felt it was explained in a sensitive manner -as Table Nine indicates. This result tells us that even though the person disclosing the diagnosis of schizophrenia to the family did not explain the diagnosis and implications fully, he or she did disclose the information in a sensitive manner.

This gives support for the last argument that after the diagnosis is given the person diagnosing should ensure that the family is followed up, whether by him or herself or another organisation.

As Table Nine indicates, of the seven subjects whose relatives were diagnosed in a government hospital, five felt that the diagnosis was explained to them in a sensitive manner. One interviewee felt the diagnosis was not explained in a sensitive manner

and one interviewee was not sure. These results are positive feedback for state hospitals.

#### **4.2.12 What was your experience when the diagnosis was disclosed?**

The expression of feelings of guilt was common throughout the interviews. In this question four interviewees spoke about feeling guilty for various reasons. One interviewee said she felt guilty that she may have genetically passed this illness onto their child. Two interviewees said they always suspected that there was something wrong with their relative but never did anything and should have acted earlier. Two interviewees described how traumatic it was to have to certify their relative, and the tremendous guilt they now feel for doing this. One set of elderly parents described feeling guilty for trying to hide their son's schizophrenia. They explained that when they were growing up no one spoke about mental illness, and the tendency was to cover up mental illness in the family. They feel guilty that this may have had a negative effect on their son with schizophrenia.

Interviewees described the experience of the diagnosis being disclosed in various ways. Two interviewees said they felt relief on hearing the diagnosis, as now they knew what was wrong with their relative. Two interviewees said they felt disbelief when they first heard the diagnosis. Two interviewees spoke about the excessive worry. One interviewee still believes that her relative is suffering because of drug use and not schizophrenia. Interviewees said they went into mourning, felt anger, sadness and shock. One interviewee said he felt disappointment as his affected child was the eldest and he had had high life expectations for him.

One interviewee formed her own support group for parents with mentally ill relatives. This has a very positive effect on her experience of schizophrenia. One interviewee said she felt "very very sad..... overwhelmed..... quite afraid". The same interviewee described how "my heart fell to my toes" when she heard "Valkenberg Hospital." The myths and stigmas attached to schizophrenia and psychiatric hospitals made families fearful.

The most common feelings described in this question by the interviewees are guilt, relief, disbelief, worry, sadness and a sense of going into mourning.

### **4.3 NEEDS OF THE FAMILIES**

#### **4.3.1 How has your relative's illness affected your life?**

Each interviewee's life has been severely affected by their relative's illness. Many interviewees spoke in different ways about the continued concern they experience about who will care for their relative when they are no longer there. Four interviewees spoke about the constant preoccupation with concerns such as where their relative is, what will happen when they are no longer there, and what will happen if their relative does not get better. One of these interviewee said, "what is going to happen to her?" She described how she and her daughter are always together. She worries that her daughter is too dependent on her and who will care for her daughter when she dies. One interviewee said, "My worst fear is that my son will have a breakdown which is beyond help." She explained further that this fear was that her son would become so sick that medication and the doctors could not help him.

Three interviewees described the difficulties they experience because of their relative's lack of motivation. This low level of interest is a symptom of schizophrenia. Two interviewees spoke about how they have to continuously check up on their relative. This can be a dilemma for families. It was discussed in one interview how their relative is an adult yet he is unwell in a way that compromises his adult status. The dilemma is how much care do you give him versus how much independence you allow him. Spaniol *et al* (1992) describes this dilemma that families experience. He describes how families have to manage the delicate balance between independence and age-appropriate behaviour. He gives the example of living away from the family and still having to deal with the limitations schizophrenia imposes (Spaniol *et al* 1992).

Two interviewees said that they felt their relative's illness would make them sick. Two interviewees described the effect as very emotional and stressful. One interviewee said it has brought on depression and constant heartache. Two interviewees brought up the

sadness they felt because their relative with schizophrenia had such potential. One of the challenges families have to face is dealing with their disappointment as the expectations they had for their child will not be fulfilled.

One set of parents interviewed said, "We all feel the pain". They explained further that the pain their relative experiences with the schizophrenia has now become a shared pain in the family. One interviewee spoke about how she is carrying the burden of caring for her daughter with schizophrenia alone. She cannot talk to her husband as he has a heart problem and she does not want to cause him further stress. She describes crying at night when everyone else has gone to bed. Interviewees used phrases like "tremendous effect" and "devastating effect". One mother said that she does not manage her daughter with schizophrenia at all. Another interviewee described how dysfunctional her family has become. One mother said her son is "trapped in a prison of mental restrictedness". One mother described the daily battle she faces with her relative, and how drained she feels the whole time due to the schizophrenia. She said that every time her phone rings she worries that it is another problem related to her daughter.

All the effects that the families describe give them the feeling that they are also "sick" because of their relative's illness. It is possibly a type of "emotional sickness" and to do with the difficulties they have with coping with this illness. This is clear evidence of the disabling effect schizophrenia has on the whole family. If no one in the family is strong enough to cope with the illness, then in a sense the whole family is emotionally sick. This would have an extremely negative impact on the prognosis of the relative with schizophrenia. In a study undertaken by Gibbon (1984) the results were that 90% of the sample, which were people who care for their relative with mental illness, showed significant physical and emotional ill health directly related to caring for their relative.

What was interesting in the answers to this question was how it appears that families are at different stages when it comes to coping with their relative's schizophrenia. One interviewee whose son was diagnosed 22 years ago appears to have reached a stage of acceptance. She said "age brings compensations of accepting the world as it is". There was another interviewee who seemed close to a stage of acceptance. She has used a spiritual way of understanding the illness and it appears to have helped her to

cope. She said that this is “one of the things life deals out to you”. The stages described by Johnson, (1994) and Terkelsen (1987) support the idea that families move through progressive stages of accepting mental illness.

The majority of families interviewed are at a point where it is too difficult to even imagine ever experiencing this feeling of truly accepting and being at peace with the illness. For them, all they can focus on is coping from day to day. However, as Johnson (1994) describes, these families’ coping methods are very limited and can often be destructive. Such destructive coping strategies include abusing alcohol.

#### **4.3.2 What could have happened at the time of diagnosis which would have made the experience easier for you?**

Five interviewees felt more information on schizophrenia would have been helpful.

They needed Information on:

- ❖ treatment
- ❖ side-effects
- ❖ prognosis.

Three interviewees said that they felt alone and needed support. Two interviewees said that they would have liked to be told about support groups and social workers who could help them. Two interviewees said it would have been better if their relatives could have stayed longer in hospital. Two interviewees felt that the doctor did not tell them all the implications of the illness and they felt cheated as the doctor had not been completely honest. In one interview the parents who were interviewed said they needed more time with the doctor to ask the questions they needed answers to. One interviewee said she needed more understanding from hospital staff particularly at the time when she had to take her son to hospital. Another interviewee said that the hospital was, “not client friendly.” They described how they wanted more communication from the hospital when their son was in hospital however there were many barriers to getting to speak to the doctors. “Doctors were often busy, did not return their calls and were not in the ward when they wanted to speak to them. One interviewee felt satisfied with the experience. He said the reason was that he had a social worker who has helped him through the process.

What is important to note from the answers to this question is how the families felt disempowered. The sense of hopelessness and helplessness, which has come through in different ways in this research, gives evidence of how disempowered these families feel. The families need to be empowered. Information is an important tool in making people feel empowered. Through feeling empowered families would cope better with their relative with schizophrenia. Treatment in terms of a psycho-educational model becomes important. This involves informing families about the cause, the symptoms, treatment and prognosis of schizophrenia. The family is also given information on how to support and care for their relative with schizophrenia. This education can be done in the form of groups with other families using visual aids and written handouts (Van Staden, 1995).

#### **4.3.3 What could have happened at the time of diagnosis, which would have made the experience easier for your relative with schizophrenia, and the rest of your family?**

Few interviewees answered this question correctly. Despite the writer assisting the interviewees to focus on the time of diagnosis most still answered by saying what could happen now to make things easier for their relative. Four of the interviewees said it would be helpful if their relative had more friends and people to talk to. One interviewee said, "my son is dying for a social life." A large percentage of interviewees wanted more social groups for their relative to attend. Social isolation or social withdrawal are one of the symptoms of schizophrenia. From this we can see that families find this symptom difficult to deal with. They believe that if their relative was not so socially isolated then things may be easier. Research undertaken by Leff & Vaughn (1985) found that families with high EE (expressed emotion) find the symptom of social withdrawal difficult to accept.

Two interviewees spoke about their relative needing more information on schizophrenia and that this would have made things easier. Two interviewees spoke about medication. One interviewee said that if the medication worked more effectively then the experience would be easier for their relative. Another interviewee said it would have been easier for their relative if their relative was compliant with their treatment.

Possibly what these relatives are saying is that they would like something to give their relatives which would make them better. One interviewee said it would have been easier for their relative if he had one doctor whom he sees when he attends the clinic instead of seeing different doctors every time. Consistency becomes an important issue when dealing with people with schizophrenia. As people with schizophrenia are often so socially withdrawn to have to trust a different doctor each time they go to the clinic or hospital can be problematic.

#### **4.3.4 What were your immediate needs when the diagnosis was being disclosed?**

Six out of the eleven interviewees said that their immediate needs were for support and information on schizophrenia. Four of the interviewees said they needed to speak to other families who had been through a diagnosis of schizophrenia and could share their experience with them. One interviewee spoke about how he needed an after hours emergency plan. Soon after his daughter had been diagnosed with schizophrenia she had experienced a bad reaction to the medication during the night. It had been very difficult for him to get effective help for her. One interviewee said she needed emotional support. Another wanted to be put in contact with a social worker to assist her. One interviewee describes the denial she felt at this stage and believed the schizophrenia would go away. One interviewee said she wanted someone to visit her at her home to help her understand this illness. Home visits offer many benefits to people in helping them to not feel so alone. The message when a professional visits a person's home is very powerful. The person feels that someone cares enough to come all the way to their home. Home visits make people feel supported and this will have a healing effect on them and their relative with schizophrenia.

One interviewee responded to this question by asking questions that arose for her at the time the diagnosis was being disclosed. They were: What do I do now? What if I can't cope? These are very powerful and complex questions for a doctor to deal with. They indicate how alone and afraid this interviewee felt at this time.

Each interviewee said it in different ways but the immediate need is for support at the time when the diagnosis is being disclosed to the family. Families need emotional support, to understand that this is a traumatic time, a feeling that they are not alone with

this problem. This would involve putting them into contact with other families, someone who will spend time listening to them and answering all their questions and the knowledge that there is a supportive person they can contact. The need to feel supported is also a basic human need, which ensures that we cope with our lives.

#### **4.3.5 What needs did you have shortly after diagnosis was disclosed? i.e when you got home/ a couple of days later.**

Practical needs started becoming important at this stage for some of the interviewees. Two interviewees said they needed care and supervision for their relative. One interviewee said they needed a recovery home - a place where their relative could go in-between hospital and coming home. This would have the function of giving the family extra time to prepare themselves for their relatives' return. The feeling by this interviewee is that the hospitals do not keep the patients long enough so they are not completely well when they are discharged. Spending time in a recovery home could ensure that they are completely well before returning to the family.

One interviewee spoke about how this stage her life had been taken over with questions and thoughts about her child. She said she even thought about shooting herself and her son. She said she needed to know how to cope. This again indicates how the family feels so alone and it is the aloneness with makes it difficult to cope.

Once again at this stage information on schizophrenia and on different medication was important. One interviewee said he needed more time with the doctor to understand the illness. Again needing time indicates that the families had so many questions to ask but the doctor seemed too busy. Often people feel that their questions are ignorant because they know so little about schizophrenia. They therefore need to feel that the doctor is caring and has time for them to ask the questions. By giving time to the family the family will feel supported and be able to deal with the diagnosis of schizophrenia more effectively.

#### 4.3.6 What needs do you have currently?

Current needs for most of the interviewees were around who will care for their relative when they are no longer there. Two interviewees wanted a permanent place for their relative to stay away from the family. Three of the interviewee's relatives were not currently living with them because they believe that it was too traumatic for the family and their relative to live together. However most residential facilities are unaffordable for the majority of the South African population. To help families cope better it is necessary that there are affordable residential facilities available for people with schizophrenia. This will help families feel reassured that when they are no longer able to care for their relative there will be a place for them to go. It will also help in situations when the relative and the family cannot live together because it is too conflictual or traumatic.

One interviewee spoke about a need for her son to have friends. Another interviewee had a need for her son to stay on medication. This interviewee's son was not always compliant on his medication. While he took his medication he was well. It was therefore very frustrating for her to see him refusing to take the medication and then becoming ill. There was again a need for a support group for parents. One interviewee said that she needed to be able to cope with her relative's schizophrenia. This sense of needing to cope is also a theme throughout the research. The important issue for professionals to consider is that if the family is coping then their relative with schizophrenia is better able to cope. Hatfield (1987b) states that a family's ability to cope depends to how well their needs are met.

One interviewee answered this question by saying, "I am deeply concerned about his smoking addiction which is financially crippling us." The literature states that three fourths of people with schizophrenia smoke cigarettes and that smoking decreases the side effects of the medication. However the consequence is that the family often have to bear the financial burden of the cigarettes as in the case above.

#### 4.3.7 Do you feel your needs would have been different if the way the diagnosis had been handled had been different?

INTERVIEWEE	WOULD YOUR NEEDS HAVE BEEN DIFFERENT IF THE DIAGNOSIS HAD BEEN HANDLED DIFFERENTLY?
One	Yes
Two	Yes
Three	"can't say"
Four	No
Five	No
Six	Yes
Seven	"Yes, definitely"
Eight	(did not answer the question directly)
Nine	Yes
Ten	No
Eleven	Yes

Table ten. Relating current needs to diagnosis

As Table Ten indicates 54% of interviewees felt that their needs would have been different if the diagnosis had been handled differently. Two of the interviewees did not answer this question. What could have happened at the time of diagnosis to make the situation easier for the family has been specified under sections 4.3.2 and 4.3.3.

#### 4.3.8 What assistance (psychiatry, educational, support groups, counselling etc) have you received since the diagnosis was made?

Assistance received by interviewees were:

- ❖ Support and assistance from Cape Mental Health Society which includes homevisits, education and information on schizophrenia, someone to phone in an emergency, supportive counselling, family counselling and to be put into contact with various support groups, clubs, accommodation facilities and others.

- ❖ Support from the doctor at Valkenberg Hospital including information and education on schizophrenia and time to ask and discuss all their questions and concerns.
- ❖ Support for their relatives with schizophrenia from Cape Mental Health Society's psycho-social groups including meeting other people with schizophrenia and an opportunity to socialise with other people.
- ❖ Fountain House which offers work rehabilitation and social support for people with schizophrenia.
- ❖ Assistancess from extended family.
- ❖ Support and help from two nursing sisters at Valkenberg Hospital.
- ❖ A support group in Wynberg for families providing support in the form of connecting with other families with a relative with schizophrenia. This group no longer exists.
- ❖ The Disability Grant Administration Programme at Cape Mental Health Society, in particular one consistent person who administers the disability grants. This was helpful as it meant that the interviewee did not have to deal with her son's money, which had become a problematic issue for them.

## **4.4 INTERVIEWS**

### **4.4.1 The Experience of Conducting the Interviews**

The writer became very aware of how emotional it was for the interviewee to be interviewed. The majority of the interviewees cried during the interview and the writer needed to contain them. The emotional climate of the interviews was highly charged. Despite the distress that many of the interviewees felt during the interview each interviewee thanked the writer for allowing them to talk. This gives evidence of how little time and support families get from professionals. The need for these families to talk about their experience was great. This was very evident during the interviews.

One particular interview will always stay with me. The interview was with a mother whose daughter suffered from schizophrenia. This mother spoke often during the interview of feeling alone and having to carry the burden of her daughter's illness by

herself. After the last questions she told a story which she had never told anyone. It was a traumatic event that had happened to her daughter and the mother had to do a very painful and difficult thing in order to protect her daughter. This mother felt tremendous guilt and shame even though she knew it was the right thing. She was offered follow-up counselling sessions directly after the interview.

#### **4.4.2 Climate of the Interviews**

The predominant climate of the interviews was sadness. Families felt sad when they recalled the painful and traumatic events which had occurred during their relatives' illness. At times during the interviews families expressed anger towards doctors and hospitals. However under this anger was also a deep sadness, which the writer had to contain. I believe this sadness is linked to loss. These families have in many ways lost a relative they once knew. One interviewee did describe going through a period of mourning. They need to mourn for the relative they once had but also for the expectations and future plans they may have had for their relative which now have to change. Terkelsen (1987) describes how families mourn the loss of expectations they once had for their relative with schizophrenia. Hatfield (1987b) also refers to the mourning families go through when a relative is diagnosed with schizophrenia.

A feeling often referred to throughout the interviews was guilt, which did influence the climate of the interviews. Families' guilt may be due to the theories that schizophrenia is due to the way parents raise children, such as the "Schizophrenogenic mother" theory developed by Fromm-Reichmann (Hatfield, 1987a). Interviewees did not discuss this directly.

## CHAPTER FIVE

### CONCLUSION AND RECOMMENDATIONS

#### 5.1 CONCLUSION

The purpose of the research was to identify the needs of families with a relative with schizophrenia utilising services at Cape Mental Health Society. The aim of this research is to better equip social workers to meet the needs of families with a relative with schizophrenia. In order to identify these needs the writer developed three research questions. As a way of concluding this dissertation the research questions will be answered using the results from the research.

##### **5.1.1 Question one: What is the experience for the family when one of its members is diagnosed with schizophrenia?**

Guilt was one of the most common feelings experienced by the families. The families gave different reasons for feeling guilty. Other common feelings experienced were fear, helplessness, shock, sadness, pain, anger, disappointment and worry. The families experienced feeling out of control and feelings of being overwhelmed by the illness schizophrenia. Families felt very alone with the burden of schizophrenia.

What was also identified was that the families felt traumatised by the diagnosis. The families often described symptoms of trauma. Some families denied the initial symptoms of schizophrenia. This indicated the family feeling so traumatised by the symptoms that they avoided them through denying their existence. Another example of how the families felt traumatised was the assumption that the families had blocked out initial diagnoses made by doctors. The difficulty families had in describing their own emotions during the initial stage of their relative's illness also suggests that they blocked out certain events in the process of their relative's illness as they were too traumatised to deal with them at the time. The families' desperate need to talk to the writer during the interviews demonstrates how they need to express the trauma they felt

during the process and, in a sense, debrief from it. Hatfield (1987b) confirms that having a relative with schizophrenia is traumatic for the family.

### **5.1.2 Question two: What does the family need?**

The needs expressed by the families have been categorised into three main needs: support, education and practical needs. These will be dealt with each of these separately.

#### **5.1.2.1 Support**

The need for support was very apparent during this research. The families throughout the different stages of their relative's illness identified this need for support. Support was indicated in the form of wanting to meet other families who have a relative with schizophrenia. This is a very powerful tool in healing, as meeting with others who have similar experiences offers therapy through factors such as:

- ❖ Instillation of hope – occurs by the families being able to see and hear the successes other families have had when dealing with their relative with schizophrenia.
- ❖ Universality – when a family meets other families with a relative with schizophrenia they realise that they are not alone in their experiences.
- ❖ Imparting of information – this occurs when families share their experience and knowledge on schizophrenia with other families. (Yalom, 1985)

Families also needed support from mental health professionals such as a social worker and doctors. Support was needed in the form of being given enough time to ask questions and to relay their experience of living with their relative with schizophrenia to a professional who would be empathetic, containing, respectful and sensitive. This type of support is necessary for the families to be able to cope. What needs to be pointed out here once again is that if the family feels able to cope with their relative's illness, this has many benefits for their relative's prognosis. This is because when the family copes they can act as a support system, and would then play a role in

maintaining the psychological well being of their relative with schizophrenia (Greenblatt *et al* 1982).

#### **5.1.2.2 Education**

The extent to which families need information on schizophrenia was striking. Information is needed on all aspects of schizophrenia. As discussed in the previous chapter, information is an important tool in empowering the family. This counteracts the ways in which a diagnosis of schizophrenia can disempower the family.

Education on schizophrenia using a psychoeducation model is important. The goals of psychoeducation include:

- ❖ Educating the family about schizophrenia and medication,
- ❖ Facilitating an understanding of schizophrenia,
- ❖ Giving information on community resources,
- ❖ Encouraging the establishment of a support network and
- ❖ Improving family functioning. (Anderson *et al* 1986)

Through this type of education the family also feels supported, and, in this way, family members become effective and constructive caregivers for their relative with schizophrenia.

#### **5.1.2.3 Practical Needs**

Practical needs were also identified as being important for the family. Needs such as long-term residential care and longer admissions to hospital were described by the family. Residential facilities for people with schizophrenia are needed. Families also said that the hospitals did not keep their relatives long enough. Another extremely important need families have is for a sense of security that there would be a safe place for their relative to go when the caregiver is no longer alive.

### **5.1.3 Question Three: What are the factors which make the experience of schizophrenia easier for the family?**

These factors have been described and discussed in detail in the results and discussion of results section of this dissertation. To answer this question the factors will just be listed:

- ❖ Contact with support group for families with relative's with schizophrenia
- ❖ Contact with mental health organisations such as Cape Mental Health Society
- ❖ Education on schizophrenia
- ❖ Assigned social workers to offer case management services
- ❖ Supportive and understanding doctors and staff in psychiatric hospitals
- ❖ People with schizophrenia to be admitted for longer periods of time to psychiatric hospitals
- ❖ Support and social groups for their people with schizophrenia
- ❖ Consistency in the doctor people with schizophrenia consult with at the clinic/day hospital
- ❖ Available and affordable residential facilities for people with schizophrenia
- ❖ Psychiatric medication to be more effective for symptoms of schizophrenia
- ❖ People with schizophrenia to be compliant with their medication.

## **5.2 RECOMMENDATIONS**

The following are recommended to ensure that the experience of schizophrenia is made easier for the family.

### **5.2.1 Recommendations for the person diagnosing schizophrenia:**

- ❖ At the time of diagnosis the needs and feelings of the family are taken into consideration and dealt with by the person disclosing the information.
- ❖ If the doctor disclosing the information is not able to spend time addressing the family's issues and needs, then the family should be handed over to another professional who is able to spend more time with the family.
- ❖ The person disclosing the diagnosis should be careful when disclosing information to a relative or the patient on his or her own. It may be helpful to the patient or relative to have another family member there for support.
- ❖ The person disclosing the information should ensure that the family understands all the terminology used.
- ❖ When the diagnosis is made doctors dispel any myth that the family may be in any way to blame for the diagnosis of schizophrenia.

### **5.2.2 Recommendations for all mental health professionals**

- ❖ At the time of diagnosis the families are given an opportunity to ask any questions they may have.
- ❖ Education on schizophrenia should be provided to the family preferably using a psychoeducational model.

- ❖ Counselling should be offered to families immediately after the diagnosis has been made to provide support and to deal with further questions the families have.
- ❖ Families are put in contact with support groups and mental health organisations at the time of diagnosis.
- ❖ Families are assigned social workers to offer social work services.
- ❖ Families feel very emotional and are traumatised and therefore need at all times to be dealt with in a sensitive and caring manner.

### **5.2.3 Recommendations for mental health policy makers**

- ❖ The process of certification is dealt with by all involved in a sensitive and caring manner to make it less traumatic for the patient and their family. This would involve educating all the people involved in the certification process including the police and the district surgeon.
- ❖ More residential facilities should be established for people with schizophrenia.

### **5.2.4 Recommended Research**

While undertaking this research possibilities for further research emerged. The following areas are recommended to be explored further:

- ⊠ The hypothesis could be tested that people with schizophrenia are abandoned by friends and relatives who were close to them prior to the diagnosis of schizophrenia being made.
- ⊠ The effect of trauma experienced by the family at the time the diagnosis of schizophrenia is made.

- ☒ The extent, if any, to which families block memories of parts of the experience of schizophrenia when it is initially diagnosed in a relative - as a way of protecting themselves from the painful reality.
  
- ☒ A long-term study on the effect on a person with schizophrenia when their family's needs are met.

## REFERENCE LIST

Anderson, CM; Reiss, DJ & Hogarty, GE 1986. **Schizophrenia and the family**. New York: Guilford Press.

Bachrach, LL 1997. Lessons from the American experience in providing community-based services. In: Leff, J (Ed) **Care in the Community Illusion or Reality?** Chichester: John Wiley & Sons.

Barrowclough, C; Tarrier, N; Watts, S; Vaughn, C; Bamrah, JS & Freeman, HL 1987. Assessing the functional value of relatives' knowledge about schizophrenia: A preliminary report. **British Journal of Psychiatry**, 151:1-8.

Beels, CC 1981. Social support and schizophrenia. **Schizophrenia Bulletin**, 7(1):58-70.

Beiser, M; Erickson, D; Fleming, J & Iacono, W 1993. Establishing the onset of psychotic illness. **American Journal of Psychiatry**, 150(9):1349-1354.

Bergman, RL & Goldstein, MJ 1993. Short-Term stability of task-generated, interactional patterns in families of schizophrenic patients. **Family Process**, 32:105-115.

Brown, S & Birtwistle, J 1998. People with schizophrenia and their families: fifteen-year outcome. **British Journal of Psychiatry**, 173:139-144.

Carrier, J & Kendall, I 1997. Evolution of policy. In: Leff, J (Ed) **Care in the Community Illusion or Reality?** Chichester: John Wiley & Sons.

De Vos, AS & Strydom, H 1998. Sampling and sampling methods. In: de Vos, AS (Ed) **Research at Grass Roots. A primer for the caring professions**. Pretoria: Van Schaik Publishers.

- Dixon, LB & Lehman, AF 1995. Family interventions for schizophrenia. **Schizophrenia Bulletin**, 21 (4):631-641.
- Erickson, DH; Beiser, M & Iacono, WG 1998. Social support predicts 5-year outcome in first-episode schizophrenia. **Journal of Abnormal Psychology**, 107(4):681-685.
- Eli Lilly (SA). **Schizophrenia**. Pamphlet.
- Fadden, G; Bebbington, P & Kuipers, L 1987. The burden of care: the impact of functional psychiatric illness on the patient's family. **British Journal of Psychiatry**, 150:285-292.
- Finestone, S & Kahn, AJ 1975. The design of research. In: Polansky, NA (Ed) **Social Work Research, methods for the helping profession**. Chicago: The University Press.
- Friedmann, MS & Goldstein, MJ 1993. Relatives' awareness of their own expressed emotion as measured by a self-report adjective checklist. **Family Process**, 32:459-471.
- Gibbons, JS; Horn, SH; Powell, JM & Gibbons, JL 1984. Schizophrenic patients and their families. A survey in a psychiatric service based on a DGH unit. **British Journal of Psychiatry**, 144:70-77.
- Gillis, LS 1986. **Guidelines in Psychiatry**. Wetton: Juta & Co.
- Gochros, H.L. 1988. Research Interviewing In: Grinnell, RM (Ed) **Social Work Research and Evaluation**. Illinois: Peacock Publishers.
- Greenblatt, M; Rosina, MD; Becerra M & Serafetinides EA 1982. Social networks and mental health: An overview. **American Journal of Psychiatry**, 139:8, 977-983.
- Grinnell, RM 1988. Utilizing Research Designs In: Grinnell, RM (Ed) **Social Work Research and Evaluation**. Illinois: Peacock Publishers.

Hammer, M 1981. Social supports, social networks and schizophrenia. **Schizophrenia Bulletin**, 7(1)45-55.

Harrison, G 2001. Association between schizophrenia and social inequality at birth: case – control study. **British Journal of Psychiatry**, 179:346-350.

Hatfield, A 1987a. Families as caregivers: A historical perspective. In: Hatfield, A (Ed) **Families of the Mentally Ill: Coping and Adaptation**. London: Cassell.

Hatfield, A 1987b. Coping and adaptation: A conceptual framework for understanding families. In: Hatfield, A (Ed) **Families of the Mentally Ill: Coping and Adaptation**. London: Cassell.

Hinsie, LE & Campbell, MD 1970. **Psychiatric Dictionary**. New York: Oxford University Press.

Johnson, JT 1994. **Hidden Victims Hidden Healers: An eight-stage healing process for families and friends of the mentally ill**. USA: Doubleday

Kaplan, HI; Sadock, BJ & Grebb, JA 1994. **Synopsis of Psychiatry**. Baltimore: Williams & Wilkins.

Keith, SJ & Matthews, SM 1991. The diagnosis of schizophrenia: A review of onset and duration issues. **Schizophrenia Bulletin**, 17(1):51-64.

Lawrie, S; Whalley, H; Abukmeil, S; Kestelman, J; Miller, P; Best, J; Owens, D & Johnstone, E 2002. Temporal lobe volume changes in people at high risk of schizophrenia with psychotic symptoms. **The British Journal of Psychiatry**, 181:138-143.

Lipton, FR; Cohen, CI; Fischer, E & Katz, SE 1981. Schizophrenia: A Network Crisis. **Schizophrenia Bulletin**, 7(1):144-151.

Leff, J. & Vaughn, C. 1985. **Expressed Emotion in Families Its Significance for Mental Illness**. New York: The Guilford Press.

Leff, J; Wig, N; Ghosh, A; Bedi, H; Menon, D.K; Kuipers, L; Korten, A; Ernberg, G; Day, R; Sartorius, N & Jablensky, A 1987. Influences of relatives' expressed emotion on the course of schizophrenia in Chandigarh. **British Journal of Psychiatry**, 151: 166-173.

Lenior, M.E; Peter, MA; Dingemans, AJ; Linszen, DH; Lieuwer; De Haan & Schene, AH 2001. Social functioning and the course of early onset schizophrenia. **British Journal of Psychiatry**, 179:53-58.

Macmillan, JF; Crow, TJ; Johnson, AL & Johnson, EC 1987. Expressed emotion and relapse in first episodes of schizophrenia. **British Journal of Psychiatry**, 151:320-323.

Makikyro, T; Sauvola, A; Moring, J; Veijola, J; Nieminen, P; Jarvelin, M & Isohanni, M 1998. Hospital-treated psychiatric disorders in adults with single-parent and two-parent family background: A 28-year follow-up of the 1966 Northern Finland birth cohort. **Family Process**, 37(3)335-343.

McCreadie, RG; Phillips, K; Harvey, JA; Waldron, G; Stewart, M & Baird, D 1991. The Nithsdale schizophrenia surveys. VIII: Do relatives want family intervention – and does it help? **British Journal of Psychiatry**, 158:110-113.

McElroy, EM 1987. The beat of a different drummer. In: Hatfield, A (Ed) **Families of the Mentally Ill: Coping and Adaptation**. London: Cassell.

Mindel, CH & McDonald, L 1988. Survey Research In: Grinnell, RM (Ed) **Social Work Research and Evaluation**. Illinois: Peacock Publishers.

Mintz, J; Mintz, L & Goldstein, M 1987. Expressed emotion and relapse in first episodes of Schizophrenia a rejoinder to Macmillan *et al* (1986). **British Journal of Psychiatry**, 151:314-320.

Mouton, J 2001. **How to succeed in your master's and doctoral studies. A South African guide and resource book.** Pretoria: Van Schaik.

Oldridge, ML & Hughes, ICT 1992. Psychological well-being in families with a member suffering from Schizophrenia. **British Journal of Psychiatry**, 161:249-251.

Pedersen, CB & Mortensen, PB 2001. Family history place and season of birth as risk factors for schizophrenia in Denmark: a replication and reanalysis. **British Journal of Psychiatry**, 179:46-52.

Salokangas, R C *et al* 2002. Structural magnetic resonance imaging in patients with first-episode schizophrenia, psychotic and severe non-psychotic depression and healthy controls. **The British Journal of Psychiatry**. 181:s58-s65.

Seaburg, JR 1988. Utilizing Sampling Procedures. In: Grinnell, RM (Ed) **Social Work Research and Evaluation.** Illinois: Peacock Publishers.

Spaniol, L; Zipple, AM & Lockwood, D 1992. The role of the family in psychiatry rehabilitation. **Schizophrenia Bullentin**, 18(3):341-347.

Spaniol, L; Jung, H; Zipple, AM & Fitzgerald, S 1987. Families as a resource in the rehabilitation of the severely psychiatrically disabled. In: Hatfield, A (Ed) **Families of the Mentally Ill: Coping and Adaptation.** London: Cassell.

Suvisaari, J; Haukka, J; Tanskanen, A & Lönnqvist, K 1998. Age at onset and outcome in schizophrenia are related to the degree of familial loading. **British Journal of Psychiatry**, 173:494-500.

Szmuker, GI; Berkowitz, R; Eisler, I; Leff, J & Dare, C 1987. Expressed emotion in individual and family settings: a comparative study. **British Journal of Psychiatry**, 151:174-178.

Tarrier, N; Barrowclough, C; Porceddu, K & Fitzpatrick, E 1994. The Salford family intervention project: relapse rates of schizophrenia at five and eight years. **British Journal of Psychiatry**, 165:829-832.

Terkelsen, KG 1987 The Meaning of Mental Illness to the Family In: Hatfield, A (Ed) **Families of the Mentally Ill: Coping and Adaptation**. London: Cassell.

Van Staden, M 1995. **Services provided to relative of patients admitted to a psychiatric hospital: an assessment of family satisfaction**. University of Cape Town: Unpublished manuscript.

Verdoux, H; Van Os, J; Sham, P; Jones, P; Gilvarry, K & Murray, R 1996. Does familiarity predispose to both emergence and persistence of psychosis? A follow-up study. **British Journal of Psychiatry**, 168:620-626.

Vostanis, P; Burnham, J & Harris, Q 1992. Changes of expressed emotion in systemic family therapy. **Journal of Family Therapy**, 14:15-27.

Wig, N; Leff, J; Ghosh, A; Bedi, H; Menon, DK; Kuipers, L; Korten, A; Ernberg, G; Day, R; Sartorius, N & Jablensky, A 1987. Expressed emotion and schizophrenia in North India 1. Cross-cultural transfer of ratings of relatives' expressed emotion. **British Journal of Psychiatry**, 151: 156-173.

Yalom, ID 1985. **The Theory and Practice of Group Psychotherapy**. New York: Basic Books Inc.

York, R 1998. **Conducting Social Work Research: An Experiential Approach**. United States of America: Allyn & Bacon.

## **ANNEXURE ONE**

### **INTERVIEW SCHEDULE**

1. How are you related to your relative with schizophrenia?
2. What is your relative with schizophrenia's gender?
3. What is your first language?
4. When was your relative diagnosed with schizophrenia?
5. What was your relatives' age at the time of diagnosis?
6. Who diagnosed your relative with schizophrenia?
7. What happened when your relative first started experience the symptoms of schizophrenia before a diagnosis was made? What was this experience like for you?
8. Who told you about the diagnosis?
9. Was your relative present when the diagnosis was disclosed to you?
10. If not, was your relative aware that the information was being disclosed to you?
11. Who was present when the diagnosis was disclosed to you?
12. Tell me how the information was disclosed to you? i.e. what did he/she say, how did you feel about the person disclosing the information?

13. Was the diagnosis and the implications of the diagnosis explained fully to you and your relative?
14. Do you think the diagnosis was explained in a sensitive manner to you?
15. What was your experience when the diagnosis was disclosed?
16. How has your relative's illness affected your life?
17. What could have happened at the time of diagnosis which would have made the experience easier for you?
18. What could have happened at the time of diagnosis, which would have made the experience easier for your relative with schizophrenia, and the rest of your family?
19. What were your immediate needs when the diagnosis was being disclosed?
20. What needs did you have shortly after diagnosis was disclosed? i.e when you got home/ a couple of days later.
21. What needs do you have currently?
22. Do you feel your needs would have been different if the way the diagnosis had been handled had been different?
23. What assistance (psychiatry, educational, support groups, counselling etc) have you received since the diagnosis was made?