"SERVICES PROVIDED TO RELATIVES OF PATIENTS ADMITTED TO A PSYCHIATRIC HOSPITAL: AN ASSESSMENT OF FAMILY SATISFACTION."

By

Magdaleen van Staden

DISsertation submitted in partial fulfillment of the requirements for the degree of master of social science in Clinical Social Work.

Supervisor: Lily Becker

University of Cape Town

December 1995
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.
ABSTRACT

This study explores family satisfaction with services provided to them on their relatives' admission to Valkenberg Psychiatric Hospital in Cape Town. The rationale for doing this research arose from the researcher's encounters with families of psychiatric patients and the perceived lack of involvement of the professionals with the families. In addition, a needs assessment was done to establish the need for family groups.

The literature review traced the psychiatric services from the earlier custodial orientation, the subsequent deinstitutionalisation of the services resulting in the families becoming the primary caregivers of their mentally ill relatives, to the emphasis of the biopsychosocial model in the recently established community services. Review of the treatment models indicated supportive family education as the primary form of intervention to ensure compliance, aid the recuperation process, enhance the quality of life for the patient and their families and to equip the families to cope with the illness.

A survey method was employed to gather quantitative and qualitative data via questionnaires and face-to-face interviews with 31 relatives of 24 patients who had been admitted during January, February, and in March 1995 to the male and female admission units (wards 9, 10, 14, 15 and 16) at Valkenberg psychiatric hospital in Cape Town. A non-probability convenience sampling procedure, based on the availability and accessibility of the relatives to attend an office interview, was used.

Findings from prior studies as well as from this current study have shown a lack of professional involvement with the families in relation to the treatment programme of their mentally ill relatives. The majority of the respondents were not informed about the implications of the illness and the effect of treatment and most of the respondents lacked
guidance on how to cope with their mentally ill relatives. Other findings indicated that families are the most concerned about the lack of supported housing, rehabilitation services, adequate financial assistance, day care centres, sheltered employment for their mentally ill relatives and difficulties in relation to admission procedures. More than three-quarters of the respondents were interested in family groups and there was a definite need for professional counselling for the parents and siblings.

In response to the findings a number of recommendations are made to improve services to families, including the formation of family groups where the relatives of mentally ill people can receive psychoeducation and practical guidance. The need for further research has been identified.
ACKNOWLEDGEMENTS

I would like to thank the following people:

The relatives of the patients who participated in this research,

My supervisor, Lily, for her support, guidance and understanding,

My colleagues, especially Lizette, for always standing in for me,

My consultant, Mike, for his encouragement,

The nursing staff and other team members of the male and female admission wards who facilitated with the data collection,

Shaun Kalisky, for his useful input on data analysis,

Cape Support Group for providing all their reading material,

My brother, Stals, for his computer expertise,

My family and friends for their support and encouragement.
DEDICATED TO:

MY MOTHER
"A PARABLE"

For many years there were thousands of families in the land who were hungry. They complained often to the king. They said, "We need relief from our hunger. Could you help us, please" (for they were very polite hungry families).

The king asked his advisors, "Why do these hungry families keep bothering me? What can I do about their hunger?" His advisors replied "Let us study these hungry families. Let us ask them questions in many ways and in many places to discover what they want."

So the royal advisors travelled across the land to speak to the families. And the hungry families answered their questions gladly, pleased to know the king was listening. They answered simply and clearly, "We're hungry because we have no food," they said. "If you give us food we will not be hungry."

The advisors returned to the castle and reported to the king: "We have listened to the hungry families. And we know what they need. They need to meet one another so that they will not feel alone. They will find comfort and understanding in one another. In fact, we will help them to form hungry family groups. These should not be large groups, however. It is better to have many small hungry families groups so that they do not become too powerful. And we must include some not-quite-so hungry families so they can moderate hungry families' demands.

They also need to learn how to manage their hunger," the advisors told the king. "We will send experts to teach them how to take their minds off their hunger: they could talk to friends; they could take long walks; they could learn yoga. We could help them to understand that it is not their fault they are hungry and they should not feel guilty. And if that doesn't work we could give them hungry family therapy."

And hungry families also need information on hunger. We can prepare booklets teaching them the nature of their discomfort. We can explain the reasons for their hunger pains and why their stomachs contract and cause them pain.

We can also teach them something called 'coping'. We'll show them that if they drink lots of water it will relieve their hunger pangs for a little while so that they can better endure the pain when it returns.

And we can give them something else called 'respite care'. We will give them food two weeks out of every year. They might not notice that they are hungry for the rest of the year. We will show that we are doing something to help them. They might then be too embarrassed to complain any more."

But when the hungry families heard the advisors' plan they shouted impatiently at them: "Why don't you just give us the food we need and take away our hunger forever?" (This time they were not so polite for they had formed a large hungry group on their own. They were beginning to feel powerful and very fed up with the king's advisors.)

The king's advisors sighed resignedly and grumbled among themselves, "What is wrong with hungry families? They are cranky and uncooperative. It's hard to tell what want. Why don't they just tell us?"

And then the advisors had an idea: "Let us study hungry families once more to find out what they really need."

Ontario Friends of Schizophrenics, Canada (WSF Newsletter : 1993 : 3)

(Prefacing a no-nonsense brief request on the provision of services for people with schizophrenia that was addressed to a government working group on mental health reform in Ontario.)
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>i</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>iii</td>
</tr>
<tr>
<td>DEDICATION</td>
<td>iv</td>
</tr>
<tr>
<td>EPIGRAPH</td>
<td>v</td>
</tr>
<tr>
<td><strong>CHAPTER 1 GENERAL INTRODUCTION</strong></td>
<td></td>
</tr>
<tr>
<td>1.1 INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>1.2 REASONS FOR THE IMPORTANCE OF THIS PROBLEM</td>
<td>2</td>
</tr>
<tr>
<td>1.3 POSSIBLE IMPLICATIONS OF THIS STUDY</td>
<td>3</td>
</tr>
<tr>
<td>1.4 RESEARCH QUESTIONS AND OBJECTIVES</td>
<td>4</td>
</tr>
<tr>
<td>1.5 SIGNIFICANCE OF THE STUDY TO SOCIAL WORK</td>
<td>5</td>
</tr>
<tr>
<td>1.6 ORGANISATION OF THE STUDY</td>
<td>6</td>
</tr>
<tr>
<td>1.7 PRESENTATION OF THE MATERIAL</td>
<td>6</td>
</tr>
<tr>
<td><strong>CHAPTER 2 HISTORICAL OVERVIEW OF PSYCHIATRIC SERVICES</strong></td>
<td></td>
</tr>
<tr>
<td>2.1 INTRODUCTION</td>
<td>8</td>
</tr>
<tr>
<td>2.2 PSYCHIATRIC CARE &amp; TREATMENT</td>
<td>8</td>
</tr>
<tr>
<td>2.3 MENTAL HOSPITALS</td>
<td>11</td>
</tr>
<tr>
<td>2.4 FAMILY INVOLVEMENT</td>
<td>12</td>
</tr>
<tr>
<td>2.5 THE LOCAL PERSPECTIVE IN RELATION TO VALKENBERG HOSPITAL</td>
<td>i4</td>
</tr>
<tr>
<td>2.6 CONCLUSION</td>
<td>16</td>
</tr>
<tr>
<td><strong>CHAPTER 3 LITERATURE REVIEW</strong></td>
<td></td>
</tr>
<tr>
<td>3.1 INTRODUCTION</td>
<td>17</td>
</tr>
<tr>
<td>3.2 THEORETICAL PERSPECTIVES ON PROBLEM</td>
<td>17</td>
</tr>
</tbody>
</table>
3.3 THE PROBLEM OF CARE FOR THE MENTALLY ILL PATIENT 24
3.4 TREATMENT MODELS 27
3.5 PRIOR WORK OF IMPORTANCE TO CURRENT STUDY 32
3.6 CONCLUSION 42

CHAPTER 4 RESEARCH DESIGN AND METHODOLOGY
4.1 RESEARCH DESIGN 44
4.2 POPULATION AND SAMPLE 45
4.3 DATA COLLECTION 46
4.4 MEASURING INSTRUMENTS 47

CHAPTER 5 RESULTS
5.1 IDENTIFYING DATA OF THE PATIENTS WHOSE FAMILIES WERE INTERVIEWED 48
5.2 PROFILE OF INTERVIEWEES 51
5.3 QUALITATIVE DATA 54

CHAPTER 6 DISCUSSION
6.1 GENERAL COMMENTS REGARDING THE INTERVIEWS 66
6.2 DEMOGRAPHIC DATA 66
6.3 DIAGNOSIS AND UNDERSTANDING OF THE ILLNESS 66
6.4 PROGNOSIS 68
6.5 SOCIO-ECONOMIC CONSIDERATIONS 69
6.6 CROSS-CULTURAL ISSUES 69
6.7 ADMISSION PROCEDURES 71
6.8 STAFF ATTITUDES 72
6.9 PSYCHIATRIC SERVICES 73
6.10 LIMITATIONS OF THE STUDY 74
CHAPTER 7 CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSIONS 78

6.2 RECOMMENDATIONS 79

BIBLIOGRAPHY 80

ANNEXURES

ANNEXURE 1: LETTER FOR APPOINTMENT 89

ANNEXURE 2: IDENTIFYING DATA WITH COVER LETTER 90

ANNEXURE 3: IDENTIFYING DATA OF PATIENT 92

ANNEXURE 4: PROFILE OF INTERVIEWEE 93

ANNEXURE 5: OPEN-ENDED QUESTIONS 95

ANNEXURE 6: FOLLOW-UP LETTER AND EVALUATION FORM 96

ANNEXURE 7: RELATIONS WITH HOSPITAL STAFF (WSF NEWSLETTER) 98

LIST OF TABLES

TABLE 1: AGE DISTRIBUTION 47

TABLE 2: DIAGNOSTIC CATEGORIES 49

TABLE 3: FAMILY CHARACTERISTICS 50

TABLE 4: MARITAL STATUS 51

TABLE 5: EDUCATIONAL QUALIFICATIONS 51
CHAPTER I

GENERAL INTRODUCTION

1.1 INTRODUCTION

As a social worker at Valkenberg Psychiatric Hospital in Cape Town, the researcher has often found families who were devastated by their experience of having a mentally ill relative admitted to a psychiatric hospital. Families of first-admission patients appear to be confused and desperately seek an explanation to help them understand their relative's behaviour. Families of multi-admission patients often have to battle with their relative's anger and abuse at having them locked up.

In terms of the systems theory, the individual must be treated in the context of his/her family and his/her broader eco-systems. The family, and therefore also the individual members, must be seen in the context of their social, economic, political, religious and cultural background. In the latter regard Ms Tiba (1991) emphasises the fact that mental illness is perceived and responded to in different ways by different people. She cautions that it is important to assess and appropriately accommodate these differences where West and Africa patients and professionals meet in psychiatric hospitals.

Ms Tiba also pointed out that the patient rarely makes the decision about the choice of treatment, e.g. hospitalisation or receiving treatment in the community. The family usually takes this responsibility. It is often also the family members who will seek professional help for their mentally ill relatives who claim not to be sick.

Webster's New Collegiate Dictionary defines asylum as an inviolable place of refuge and protection giving shelter, a place of retreat and security, and an institution for the relief or
care of the destitute or afflicted, especially the insane. However, professionals, parents, mentally ill people and the society at large have different views about the value of asylum (Wasow : 1993). In this study the researcher will therefore focus on family satisfaction regarding services provided with admission of their relatives to Valkenberg Hospital, in order to adapt the services to accommodate their needs.

1.2 REASONS FOR THE IMPORTANCE OF THIS PROBLEM

According to Everett et al (1994) mental health professionals have traditionally ignored clients' views of their own treatment. It was only when they began to define themselves as consumers rather than passive service recipients that discrepancies emerged between the intended purposes of various services and the results as described by consumers themselves. They believe that it is no longer acceptable to exclude consumers from mental health service planning, provision, or research. The researcher is of the opinion that the same principle applies to families with mentally ill relatives.

Research in the area of families' expectations of treatment has suggested that a link might exist between expectancy and outcome. The precise nature of this link is, however, uncertain. Regarding consumer satisfaction, Lebow (1982) found the following: "An important part of both relatives' and patients' education about schizophrenia may be the part it plays in decreasing expectations and making them more realistic, and is an area for further investigation" (in Atkinson : 1986 : 144).

Smith and Birchwood (1990) found families of especially first-admission patients to be more non-compliant with treatment than instances where patients have had numerous admissions. The researcher's experience has also been that these families and their mentally ill relatives deny the impact of the illness and prefer to regard it as a single episode. Some
families are also very anxious and angry because of the fact that this has happened to them and project these feelings onto the professionals. This attitude prevents them from engaging in a therapeutic programme with the professionals involved.

The researcher is therefore of the opinion that families must be actively involved in the assessment and treatment of their mentally ill relatives. This would also apply essential social work principles of respect and self determination. In addition the professionals need to acknowledge the difficulties that the families are facing, e.g. lack of transport, poverty and lack of support regarding the supervision of their mentally ill relative.

1.3 POSSIBLE IMPLICATIONS OF THIS STUDY

Nicholas Tarrier (1991) and other authors have underlined the importance of professionals needing to look at their attitudes towards families of mentally ill people. One way of doing this is by actually interacting and communicating with the families to reach a true and realistic understanding of their suffering. By doing this research and making the results available to the staff at Valkenberg hospital, the researcher is therefore hoping that this might inform, and therefore bring about a more positive attitude towards the families of patients admitted for treatment.

By having more regular contact with families, the researcher has found that she has changed her attitude towards them. Instead of, for instance, using terminology such as schizophrenics, she will talk about people suffering from schizophrenia. Instead of labelling families as exhibiting high expressed emotion, she would rather look at the reasons for their showing this behaviour and focus on helping them to develop better coping strategies. Thus a more empathic stance towards families has evolved.
Baker et al (1995) came to the same conclusion when they researched staff attitudes toward family involvement in residential treatment centres. Their survey ended with an item asking respondents whether completing the survey had affected their receptivity toward family involvement. A third of the respondents found themselves more receptive to family involvement after spending 45 minutes concentrating on the survey. They concluded that considering and expressing an opinion about family issues has an impact on staff attitude towards family members.

1.4 RESEARCH QUESTIONS AND OBJECTIVES

Firstly, the purpose of this study is to identify whether the professionals at Valkenberg Hospital are actually providing what the families really want. Research has highlighted various areas of dissatisfaction of families regarding psychiatric services worldwide, but there is little research done on families' expectations regarding their relatives' admission to a psychiatric hospital. While the majority of the previous studies relates to family satisfaction of community services, there has been no similar study done at Valkenberg hospital, and the psychiatric staff at the research institute at Valkenberg have indicated that such a study will be informative.

In this study it is hypothesised that the families whose mentally ill relatives have been admitted to Valkenberg hospital will indicate some dissatisfaction with the services provided to them. It is further assumed that one of the main reasons for this dissatisfaction will be the lack of involvement of the professionals with the families and the lack of sufficient information being imparted to the families regarding the diagnosis, treatment, side effects of the medication, prognosis of the illness and possible implications this will hold for the family. The research question is therefore: "What factors are most important
Secondly, the researcher wishes to explore families' beliefs concerning the reasons for their relatives' breakdown. "Psychiatrists have often disagreed sharply among themselves about the aetiology of mental illness and consequently the appropriate therapy, adopting themes from nonpsychiatrist critics or even giving ideas and perspectives to them" (Dain: 1994: 1011). By exploring alternative belief systems, the researcher has become aware of the diversity regarding the different explanatory models in relation to mental health and illness. For example, she has encountered people who believe that a mentally ill person is possessed by the devil or is bewitched. This prompted her to include the questions on explanation and causation of the patients' conditions. An overview of the explanatory models is included under the theoretical perspectives in chapter three.

Thirdly, an assessment will be made whether families express a need to be involved in family groups. "Earlier research has shown that psychoeducational programs for families, combined with treatment and antipsychotic medications for patients, significantly decreases patients' relapse rates and family members' distress and burden" (Lam: 1991 in Canive et al: 1993: 679). The researcher has had similar experiences while facilitating educational support groups for families. They noted that the support and better understanding they were receiving from the group helped them to feel more equipped and empowered to cope with life.

1.5 SIGNIFICANCE OF THE STUDY TO SOCIAL WORK.

As will be discussed under the literature review, family therapy is but one of various treatment modalities that is applied in hospital settings. By highlighting the role that
families fulfil in the lives of their mentally ill relatives and therefore proving the importance of the application of the systems theory in a predominantly medically oriented setting, the researcher is hopeful that more professionals of all categories will move towards a more systemic way of thinking. As social workers have traditionally been the main group of professionals to have direct dealings with the families, a secondary effect could be one of promoting the social work profession in a psychiatric setting.

According to Caplan (1961) the social worker's obvious role in the mental health team is that of being a specialist in assessing environmental phenomena. Kent et al (1994) found a substantial contribution of social factors to the readmission of patients to acute mental health services. A large number of these problems can only be dealt with by the clinical social worker who has a tremendous field of opportunity to use her traditional knowledge of environmental factors with her increased knowledge of the unconscious implications of overt behaviour (Caplan: 1961). The mental health system must hence provide appropriate, targeted, assertive and continuous case management to the psychiatric population to prevent social crises in their lives (Kent et al: 1994).

1.6 ORGANISATION OF THE STUDY

The researcher collected data on those families of patients who have been admitted to Valkenberg over a one month period. For the purpose of this study she did an interview schedule with individual members of the families. As far as possible the interviews were scheduled with the primary caretakers.

1.7 PRESENTATION OF THE MATERIAL

The research report consists of seven chapters with various sub-headings. The reasons for the importance of involving the families with the treatment of their mentally ill relatives are
accentuated in the first chapter. The significance of the study to the social work profession is also dealt with in chapter one.

In chapter two the researcher examines at the historical overview of psychiatric care and treatment in mental hospitals and to what extent families were involved. Chapter three reviews the literature in terms of the relationship between the relatives of mentally ill persons and professionals providing psychiatric services. The theoretical perspectives and treatment models are also highlighted in this chapter. Lastly attention is given to prior work of importance to the current study.

Chapters' four to six describes the research design and methodology applied in this study and discusses the results of the findings. Finally, chapter seven deals with the conclusions of the study and the researcher's recommendations.
CHAPTER II

HISTORICAL OVERVIEW OF PSYCHIATRIC SERVICES

2.1 INTRODUCTION

In this chapter an overview will be given of the development of psychiatric services internationally as well as locally. The first section explores the establishment of psychiatry within the medical model and the subsequent deinstitutionalisation of psychiatric services. The second section deals with the process of improving the conditions within the hospitals from being mere custodial in orientation. The third section examines the development of the family movement and the last section gives an overview of the establishment of Valkenberg as a psychiatric hospital.

2.2 PSYCHIATRIC CARE AND TREATMENT

In the Judaeo-Christian civilisation during the pre-renaissance period, it was believed that mentally ill persons were possessed by the devil. Prayer, cajoling, threats and even physical punishment were some of the methods used to exorcise the devil. The witch trials, involving mentally ill persons both as victims and as accusers, were monstrous examples of these efforts (Deutsch: 1949, Bell: 1980, Shryock: 1944 in Thompson: 1994)

Studies in anatomy and pathology led to a more humane approach. In the 17th and 18th century the mentally ill began to be seen as medical patients and for example treatments composed of bleeding, purging, and blistering when the underlying cause was regarded as excessive bile or disordered blood vessels. Some of the efforts to provide psychiatric services included boarding out patients with families. Most of the mentally ill persons were, however, kept at home, often in a locked room, were jailed if they were violent or
troublesome, or were treated as paupers if they were seen as harmless (Deutsch : 1949 : in Thompson : 1994).

With the rebirth of philosophy and psychology in the 18th and 19th century, a more scientific approach was developed. Asylums formed the primary psychiatric service and mental patients began to receive medical nursing and treatment. Most of the services in mental hospitals were custodial. Insulin shock, prefrontal lobotomy, and electroconvulsive therapy were among the new treatments developed, but questions about their effectiveness remained. Mesmer's discovery of hypnotism in the early 1800s introduced the importance of psychological therapy. Over the next hundred years the theories of psychopathology and psychodynamics were developed (Gillis : 1986, Thompson : 1994).

Alternatives to long-term hospitalisation only appeared in the late 19th and early 20th centuries. The importance of factual information about individuals in relation to their social circumstances in guiding interventions, and the interdependence of family and individual well-being was reflected in the work that social workers did in the early 20th century. This was a major contribution to the achievement of an integrated biopsychosocial view of the person with serious mental illness. In this integrated view the person's needs and capacities in the physical and social context of a family and community that provides (and require) support, resources, and opportunities could be adequately addressed. "In 1900, Miss Richmond laid out her conceptualisation of the social worker's field of action, which she represented as concentric circles symbolising family, neighbourhood, the civic arena, and private forces, with the family at the centre of the matrix " (Pittman-Munke : 1985 in Vourlekis et al : 1994).

The community mental health movement of the 1960s and 1970s both increased and introduced new types of services. This movement expanded the concept of mental health

"Within these changing parameters, both professions have struggled to achieve greater effectiveness and internal harmony by balancing the dialectical tension of psychogenic and social causation of mental illness with biological causation, individual treatment with social reform, care and custody with treatment, institutional approaches with community approaches, and public responsibility for services with private responsibility."


According to Sue Walrond-Skinner (1976) family therapy was initiated in the 1950s by the American psychiatric and social work professions. However, 1951 was important historically when Dr John Sutherland from the Tavistock Clinic in London and Dr John Bell from the Mental Research Institute in Palo Alto met and discussed the therapeutic possibilities of seeing whole families together. This reflected Dr John Bowlby's influence on the importance of family involvement. John Bell's early experimental work with family groups influenced other clinicians in the development of its practice (Bell : 1961 in Skinner : 1976).

Day treatment became widespread in the mid-1950s. Where psychiatric hospitalisations were once seen as the cure for mental illness, huge institutions, often housing as many as 5,000 or 6,000 patients, were thought to cause social breakdown syndrome (Bell : 1980, Bloom : 1984, Goffman : 1961, Gruenberg et al : 1962 in Thompson : 1994). With the improvement in patients' psychiatric state and their level of functioning resulting from the administration of antipsychotic drugs, people diagnosed as having a persistent mental illness did not have to live their lives in state hospitals. This resulted in a drastic reduction of the resident populations of large public mental hospitals and the closing of some hospitals (Baker et al : 1969). One of the consequences of treating psychiatric patients in
the community has been an increased understanding of the psychosocial factors and stresses associated with psychiatric illness.

2.3 MENTAL HOSPITALS

Up to the last two centuries, psychiatric services were based primarily within asylums. In the 15th century 'fools' towers for the mentally ill was constructed in Germany. Patients were chained in cells on bedding of loose straw sodden with urine and excrement (Gillis: 1986). There was high expectation that asylums could cure mental illness. In the 1880's institutionalisation itself was seen as the appropriate treatment. Although the asylums did improve the care of mentally ill patients, the patient population in the hospitals began to increase and took up more staff time. It became impossible to give the patients any personal attention and the hospitals became primarily custodial institutions, like the almshouses they had been created to replace (Deutsch: 1949, Grob: 1973 in Thompson: 1994).

The hospital authorities started improving the setting when it was realised that the environment of psychiatric patients influenced the outcome (Gillis: 1986). Heating and ventilation was added to hospital wards; violent patients were separated from those who were less violent; work, exercises, and amusement were introduced; better-trained staff were hired and no visitors were allowed who might disturb the patients (Binger: 1966, Rush: 1948, Alexander et al: 1966 in Thompson: 1994).

Former patients' exposés about the conditions in the hospitals contributed to the reform of psychiatric services (Grob: 1973 in Thompson: 1994). Attempts were made to design better hospitals. In America Dr. Thomas Kirkbride developed a practical, liveable architectural plan for hospitals, consisting of a central administration building with wings
on each side to house patients (Tomes : 1981 in Thompson : 1994). Later, hospitals were built on a plan that consisted of a central administration building surrounded by separate small buildings or cottages for patients. Reformers also suggested parole of patients with nonchronic conditions to work in the community (Grob : 1973 in Thompson : 1994).

The situation in the overcrowded mental hospitals began to deteriorate by the end of the 19th century. It was difficult to keep qualified staff, patient-abuse was common and the physical conditions of many hospitals were deteriorating (Grob : 1973 in Thompson : 1994). Dr. Adolf Meyer, a physician in the early 1890s, became committed to improving mental hospital life and developing programs for community care and prevention (Bell : 1980, Caplan : 1969, Grob : 1985 in Thompson : 1994). He instituted the policy of hospitals serving a limited geographic area and a defined population, in contrast to the norm of large, isolated hospitals serving a large portion of the state population. He also promoted clinics with outpatient, inpatient and social work services located in the communities they served (Meyer : 1912 in Thompson : 1994).

2.4 FAMILY INVOLVEMENT

According to Diane Froggatt (1995) the family movement got off the ground in the 70's when John Pringle, the father of a son with schizophrenia, posted a moving article about the plight of his family and son to the London Times in England. He was subsequently inundated with empathic responses. Families all around the world were released from their isolation, despair and the stigma that comes from being alone with serious mental illness.

Families around the world formed self-help groups to help them cope with the impact of mental illness within the family. Representatives from these organisations met at Toronto University in 1982 to form the World Schizophrenia Fellowship that acts as a channel for
information around the globe. Seventeen nations constitute the Voting Membership of the organisation and forty other countries have representation among the Associate Membership. The WSF is an entirely voluntary organisation, but have the commitment of volunteer professionals. The founding president, Arthur William Jefferies, was invested with the Order of Canada in 1991 for establishing this organisation (WSF Newsletter : 1993).

All member organisations are lobbyists for serious mental illness and have pushed for new types of comprehensive care for their relatives by urging reforms, drawing up proposals, gathering statistics, influencing public and government opinion and raising research funds. They are also doing a lot of work in providing housing, rehabilitation, recreation and a decent life for mentally ill people. A major task is supporting and educating the families who have an enormous and continuing burden to shoulder. The organisation is growing as more and more families and members of the caring professions seek their help (WSF Newsletter : 1993).

However, although the families of the mentally ill may have had significant information and experience to help with the management of their relatives, they were often not considered to be part of the hospital treatment team (Froggatt : 1995). This could be ascribed to the historical fact that the professionals blamed the families for causing the mental illness of their relatives and although these theories are not being adhered to anymore, Froggatt cautions that many of the offending text books have not been removed from library shelves of universities, schools of social work and departments of psychology.

Families were also excluded from the treatment and care of their loved ones as a result of the limited amount of funds made available for the appointment of doctors, nurses and other health care workers in the hospitals. Families are, however, involved and therefore
should be consulted. Wasow (1993), Froggatt (1995), Dain (1994) and others are of the opinion that the closure and reduction in size of mental hospitals have simply moved the problem elsewhere, into the streets and into the jails. Froggatt and other members of family self-help groups see it as the families' responsibility to come up with workable plans that will make new forms of institutional and community care and rehabilitation a working option for patients to lessen the burden on families.

2.5 THE LOCAL PERSPECTIVE IN RELATION TO VALKENBERG HOSPITAL

Psychiatry has been developed in a Western (Judeo-Christian) cultural framework by mainly white people (Fernando : 1988). There, however, existed a traditional health care system for the mentally ill in pre-colonial South Africa. Diviners diagnosed various kinds of mental affliction and, together with herbalists, they prescribed treatments including the taking of herbs and performing certain rituals. Today both systems are widely used in South Africa (Korber : 1990).

From 1658 Jan van Riebeeck sent those mentally ill persons who could not be cared for by their families with the convicts to Robben Island. The first mental hospital in Cape Town was founded on the island in 1846. In 1881 the government purchased Valkenberg property for the establishment of a reformatory. This was converted into a lunatic asylum in 1891 for the patients who were transferred from Robin Island. The total number of patients at Valkenberg rose steadily to a maximum of 2 353 in 1962. Since then the numbers declined to an average of 1 000 patients. During 1995 a mean of 800 patients have been admitted to Valkenberg Hospital.

The South African mental hospitals have not been affected by the community mental health movement of the 1950's, but have remained overcrowded. The exception has been
in the Orange Free State where community based psychiatric care was initiated in 1985. In this province the number of tertiary beds has been reduced to fewer than one tenth of its previous capacity by increasing the community services (Freeman : 1994 in Gericke : 1995).

With the previous political structure of apartheid, the South African health care system was divided on racial grounds. In the Western Cape, Stikland Hospital in the Belville area served mainly a white population, and Lentegeur Hospital in Mitchell's Plain served the local coloured population. More specifically, at Valkenberg all black and coloured patients were admitted to the Pinelands side of the hospital and all white patients to the Observatory side. The staff were also paid and administered by different structures, as each race group had its own health ministry (Kaliski & Zabow : 1994).

The first social worker at Valkenberg was appointed by the Department of Social Welfare and Pensions in 1966. Initially she worked on both the Pinelands and Observatory sides of the hospital, but later she was allowed to work only with the white patients and their families. In 1970 the first full time social worker for the Pinelands side was appointed by the Department of Coloured Affairs. In 1981 the white social work posts were transferred onto the hospital establishment (Department of National Health and Population Development).

Due to the change in state policy in 1990 it became possible to restructure the clinical services at Valkenberg, allowing for all population groups to be admitted according to clinical instead of racial requirements. The racial integration took place on both staff and patient levels. The social workers (from C.P.A. Community Services) for the black population groups were transferred onto the hospital establishment in 1991 and those for the coloured population (from the House of Representatives) in 1993.
In relation to family involvement, the Cape Support for Mental Health, a self-help group for relatives of people suffering from mainly schizophrenia and other mental illnesses, was formed in 1981. This organisation is affiliated to the Cape Mental Health Society and is based on the American NAMI family support group. The National Alliance for the Mentally Ill is one of the fastest growing pressure groups. This group was formed in 1979 and in 1986 it included 550 groups of every state with members from 30,000 households. NAMI's goals are emotional support, public education, advocacy of neglected programs and research of primarily schizophrenia (Eckholm: 1986).

The membership of Cape Support has grown to over 100 families. The group is actively involved in creating more community services to facilitate the patients' independence. They played an important role in providing accommodation by establishing the first group home in South Africa in 1986. Trust funds have also been formed to take over the management of the patients once the parents have passed away. Today their Comcare Trust manages 10 houses. Some of the members of the group homes are employed by the organisation. The group has representation on Valkenberg Public Relations and Mental Health Education Committee and grants annual psychiatric nursing awards for excellence to hospital staff.

2.6 CONCLUSION

Psychiatric services have evolved from being mainly custodial, with the mentally ill people being separated from the broader society, to becoming more community based. The social work profession was largely instrumental in initiating a more integrated psychiatric service, based on the biopsychosocial model and emphasising the involvement of the family in the treatment programme.
CHAPTER III

LITERATURE REVIEW

3.1 INTRODUCTION

In this chapter, a brief overview will be given of some explanatory models on mental health and illness, in particular in relation to the role of the family. Secondly, the literature will be reviewed in terms of how the families, as a result of the deinstitutionalisation of the psychiatric services, have been burdened by becoming the primary caregivers of their mentally ill relatives. Thirdly, a section relating to treatment models, indicates supportive family psychoeducation as the primary form of intervention. Finally, a summary is given of some previous research done in relation to the current study.

3.2 THEORETICAL PERSPECTIVES ON PROBLEM

In biblical times madness was seen as demonic possession and punishment for sin. Most psychiatrists rejected this viewpoint and stressed the physical and emotional nature of insanity. There are, however, still some of the more conservative Christians who adhere to this standpoint today (Dain : 1994). During the social upheavals of the 1960s and early 1970s, the psychoanalyst Thomas Szasz disputed the existence of insanity as a medical disorder in all but a minute number of cases (Szasz : 1984, 1979 in Dain : 1994).

The British psychoanalyst R.D. Laing saw mental illness as strength, not disease. He discredited the rationale for hospital psychiatry by questioning the reality of schizophrenia altogether. According to him schizophrenia was part of a process of potential human growth (Laing et al : 1964, Laing : 1968, Boyers : 1971, Ruitenbeek : 1972, Collier : 1977 in Dain : 1994). In this regard Vera Buhrmann (1982) describes the thwasa schizophrenia-like state occurring in African people when they are being called by the ancestors to have
treatment and training to enter their service by becoming an *igqira*. Some sociologists, on the other hand, viewed insanity as a response to the injustices of society. They accused psychiatry of using mental hospitals to control this disturbing group of the population by brainwashing the patients and thereby creating most of the symptoms characteristic of schizophrenia (Goffman: 1961, Scheff: 1984 in Dain: 1994).

In psychodynamic theories, psychoses are considered the severest form of psychopathology. Atkinson (1986) notes that Sigmund Freud's early viewpoint saw schizophrenia as a defence while his later formulations saw it as a deficit. Carl Jung (in Atkinson: 1986) was instrumental in developing the dynamic theory of schizophrenia and suggested that the deterioration of the patients in the latter stages of the illness was a psychosomatic expression of a pathological libidinal process.

In Fromm-Reichmann's concept of the *schizophrenogenic mother*, (in Atkinson: 1986) the mother was cold and withdrawn from the child and the father soft, indifferent and positive. In Bateson's *double bind* concept, (in Atkinson: 1986) paradoxical communication in the child-parent relationship, in which the child will always be in the wrong no matter what action he/she takes, was seen as a form of communication more often used by parents of schizophrenics than other parents.

In terms of learning theories, schizophrenia is seen as learned, adaptive behaviour. It is unclear, though, whether a lack of social skills, a specialised area of learning, pre-dates the schizophrenia, contributes to it or is a result of it. Snyder et al (1994) describes *expressed emotion* (critical, over involved and rejecting behaviour towards the mentally ill person) as a construct that reflects the level of stress and burden experienced by those who live with severely mentally ill patients. "Recent studies of expressed emotion have demonstrated the *interactional* nature of this construct, with the behaviours of patient and relatives..."
intertwined in a spiral of events that determine the quality of the emotional environment in the family" (Snyder et al: 1994: 1141).

The systems theory is based on the fact that no individual can be seen in isolation, but is viewed as interdependent with his social structure, and in particular his family (Gurman et al: 1983). The structural dimensions of the transactional pattern in families can be classified as returning to the boundaries, alignment or power-base in the family (Minuchin: 1974). In assessing the family pathology, therefore, the therapist looks at their functioning in relation to:

1. how clear the boundaries are amongst the subsystems along the continuum of enmeshment (diffuse boundaries) to disengagement (rigid boundaries);
2. what type of alignment pattern are evident in the relationship amongst the various subsystems (specifically looking at coalitions, triangulation and detouring); and
3. the distribution of power within the family (assessing the executive functioning of the parental subsystem and the power allowed to children in relation to their developmental stages)

Lidz's theory on the disordered marital relationship links up with the structural family therapy school where the entire family is seen as pathological, but primarily as a result of the disturbed triadic relationship of both the parents and the child (Atkinson: 1986). Lidz claims that he has never found a person suffering from schizophrenia who has come from a stable family. According to Atkinson (1986) though, there is little evidence to link a family's transactions with the development of schizophrenia.

Mara Palazzoli-Selvini and her associates in Milan, Italy, developed the Milan School of Family Therapy - also known as strategic family therapy (Gurman et al: 1983). They
started off working with anorexic families and expanded their work to include working with families with schizophrenic members.

There are many similarities between the strategic and structural approaches and both are based on the concept of systemic thinking. The therapist allies with all the family members, gets everybody's viewpoint of the problem and is therefore more likely to get their co-operation. Even when families, as a result of practical implications, cannot be involved in the management of their mentally ill relatives, the systemic way of thinking can still be applied when working with individuals. Regardless of whether the patient will return to the family or not, in most of the cases the patient will still have some form of contact with the family.

Caplan and Killilea's (1976) overview of the family as a support system emphasises the importance of including the family in the treatment programme. They described the following support system functions of the family:

1. *The Family as a Collector and Disseminator of Information About the World.*
   This function is essential in helping the mentally ill family member with his/her socialisation with the outside world.

   This enables the family members to adjust to other people's opinion regarding their behaviour.

   The family belief and value systems determine the individual's understanding of the nature and meaning of the universe and of how he will live his life.

   This often includes practical help in making the arrangements for the relevant caregivers, such as health and welfare agencies, to take action.
5. *The Family as a Source of Practical Service and Concrete Aid.*
Assistance includes financial aid, help with shopping, physical care, performing household tasks and practical assistance with hospitalisations. The fact that it is immediately available and often without having to be asked for, is a source of great strength at a time when people feel particularly weakened by their sense of vulnerability and increased dependency.

Within the boundary of privacy that surrounds a family group, the members feel themselves to be known and understood and therefore feel free to relax, to take a rest and to *be themselves.*

7. *The Family as a Reference and Control Group.*
Because an individual realises that his family knows him so well, he is more sensitive to their opinions of him; especially if he believes that they have his best interest at heart.

8. *The Family as Source and Validator of Identity.*
The family has a crucial role to play in validating an individual's precrisis self-image of competence by reminding him of his abilities and strengths, about which he is temporarily in doubt of.

The family supports a member's lack of capacity to tolerate negative emotions such as anxiety, depression, anger, shame and guilt by offering love, affection, comfort, guidance on the basis of past experience and by counteracting despair and feelings of helplessness through maintaining hope.

Dr. Kayla Bernheim (1988) traced the uneasy relationship that had existed between the two groups (families and professionals) from pre-deinstitutionalization days. Dr. Bernheim described two kinds of health care workers who still today minimise the importance of the
roles played by the family members of mentally ill people. The one group practises benign neglect and the other group follows the psychoanalytically-oriented model. In both these approaches, however, the professionals fail to adequately involve the families in the management programmes of the patients.

Bernheim advocates the bio-psycho-social approach where schizophrenia is recognised as a disease of the brain, but which has important psychosocial consequences for the patient and their relatives. In proposing the concept of a biopsychosocial treatment approach, Engel (Engel: 1977 in Bachrach: 1993: 523) wrote,

"To provide a basis for understanding the determinants of disease and arriving at rational treatment and patterns of health care, a medical model...must take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of illness."

The biopsychosocial approach, therefore, emphasises the interaction of biological, psychological, and sociological factors as they affect the course and outcome of mental illness.

Dr. Bernheim (1988: 3) further notes that families should be actively involved in the training of health care professionals. She outlined the following areas:

"1. Work towards attitude reorientation in health care professionals.  
2. Curriculum must be kept up-to-date.  
3. Professionals in training should have exposure to families through plenty of opportunity for dialogue with them."

One of the chief issues tackled by NAMI's Curriculum and Training Committee after its formation in 1981, was disproving the psychoanalytic, interpersonal, and family systems
theories being used to explain the aetiology of mental illnesses (Conn: 1995). Many of the parents of the NAMI self-support group had painful family therapy experiences; paying to be told that they had caused their child's illness. In fact, parents deserve credit for the major shift that has transformed the ways that professionals think about and work with families today; changing the family's image from *sick or toxic to families who shine with humanity in the face of an inhumane illness* (Bernheim, 1985). NAMI's research community also contributed to reducing the stigma by re-defining *mental illnesses* as *neurobiological disorders*.

Families whose relatives became ill 20 years ago are still carrying the scars caused by mental health professionals blaming them for causing the disease (Eckholm: 1986). Although a definite model regarding the aetiology of schizophrenia has yet to be proposed, there is a general agreement that both biochemical and environmental factors are likely to play a part. Regardless of whether they are a cause or an effect of schizophrenia though, families are involved and therefore should be involved.

According to Eckholm, activists are of the opinion that families *come out of their closets* as they learn more about the changing scientific understanding of schizophrenia. Families are being blamed less as the disease is seen to have a biological origin. As a result of this more sympathetic understanding towards families, a growing number of doctors are engaging with families.

There has thus been a major shift from initially attributing mental illness as being caused by family transactions to now understanding mental illness as having a biochemical basis, with environmental factors contributing both negatively and positively towards the mentally ill person's ability to cope with the illness. Both the mentally ill person and the family are in need of support and education about the illness to help them cope with the illness.
3.3 THE PROBLEM OF CARE FOR THE MENTALLY ILL PATIENT

Over the years, antipsychiatry groups including neurologists, social workers, new religions, consumers and psychiatrists have been competing for authority over the mentally ill. They objected to psychiatry as a hospital-centred medical speciality authorised to institutionalise and treat patients, and were of the opinion that treatment of hospitalised patients increased the stigma of mental illness. In the late 19th century, psychiatrists began to see heredity as the cause of mental illness and became pessimistic about restoring patients to sanity. Recent advances in biological treatments, however, have rekindled optimism about recovery that may go far in eliminating stigma (Dain: 1994).

In the pursuit of obtaining autonomy, independence and freedom for the mentally ill people by means of deinstitutionalising the psychiatric services, mental health agencies worldwide failed to establish adequate financial and institutional support for the discharged patients in the community. The result was that the public often saw highly disturbed persons acting out in the streets, which reinforced negative stereotypes, perpetuated and even increased the stigma associated with persons with mental illness (Bachrach: 1993, Dain: 1994). The concept of continuity of care was also not sufficiently taken into consideration by the deinstitutionalisation process. An integrated hospital and out-patient service is necessary so that mentally ill people, who may require lifelong intervention, can be cared for by the same people both in therapy and rehabilitation (EUFAMI: 1994, Bachrach: 1992 in Bachrach: 1993).

Many service planners believed that if the countertherapeutic practices, such as a primarily custodial approach to care that included use of physical restraints (that had been exposed in some mental hospitals) could be eliminated, the need for hospitals as such would be
eliminated altogether. This assumption, however, underestimated the reality of severe mental illness and the fact that access to hospital care for individuals who need it, for as long as they need it, is absolutely essential (Bachrach: 1993).

In this vein, Mona Wasow (1993), a professional teacher in the mental illness area and the parent of an adult son who has schizophrenia, expressed her concern regarding community care providing inadequate protection for many chronically mentally ill people. She emphasised the need for sanctuary for many patients that only permanent housing of some kind can provide. Towards this purpose she envisioned humane, unlocked hospitals that could provide shelter, food, and compassionate care and treatment.

Kent et al (1994) found that as a result of the deinstitutionalisation process, there was a reported rise in the rate of readmissions to psychiatric hospitals, particularly for short-stay patients. Others (Abramowitz et al: 1984, Gillis et al: 1985) were of the opinion, though, that appropriate non-hospital-based services could be developed by improving the knowledge of the factors that contribute to admissions and the breakdown of living arrangements in the community. This could lead to a reduction in the rate of revolving-door readmissions to acute services.

With the change in treatment policy and the consequent emphasis on deinstitutionalisation, mentally ill patients have become the burden of their families, who must, according to Dr. John Talbott (in Eckholm: 1986), fulfil the roles of doctors, nurses and social workers. The families have also become the victims of this devastating illness by being the main caretakers of their ill relatives. This is a mammoth undertaking from which the families get little respite. At times, family members must give up their work to become involved full-time in the management of their ill relatives.
Ms Wasow (1993) found that family members pay a heavy price for the freedom of their ill relatives. She questioned whether the freedom of one person in a family should not perhaps be sacrificed to preserve the well-being of the other family members. Adding to their burden, is the stigma of mental illness that these families are being subjected to that often leads to them living in isolation. Further, schizophrenia has taken its toll on marriages and has caused siblings in families of patients with this condition to feel neglected, angry and guilty (Eckholm: 1986).

The Federal Association of the Families of the Mentally Ill (EUFAMI: 1994) suggested that a joint effort be made by psychiatric practitioners, politicians and administrators with the families to provide services. They suggested further that a responsible health and welfare scheme must include co-operation between professionals in psychiatric institutions, patients and their relatives as a standard procedure.

Smith et al (1990) concludes that, while a lot of work has been done regarding family management of schizophrenia, these advances need to be integrated into routine clinical practice. The outputs of time, finance and manpower in family work need to be composed with possible savings from reducing readmissions. Hatfield (1987) discovered that: "Families themselves have voiced disquiet about the increased burden which the community movement is likely to place upon them. They fear that they might come to be regarded by managers simply as an inexpensive community resource" (Smith et al: 1990: 658).

In this regard, the New Zealand Fellowship group (WSF Newsletter: July: 1989: 3) submitted a brief to their government regarding the contents of their new Mental Health Act. They recommended that:
"1. families be involved;
2. adequately funded community services be in place before compulsory community treatment orders are made;
3. lines of accountability are clearly identified;
4. requests for assessments be responded to quickly."

The main goal of EUFAMI is that the findings of modern psychiatric science be applied to the practical work of care institutions. In this regard, they demand that, even with the present number of personnel, less intimidating admission wards be created so that the clients can meet their professional carers on a more equal basis and a climate of trust can be established. Counselling should consider the whole familial and social environment of the client, and relatives should be seen as fellow sufferers and not as the parties guilty of causing the illness (EUFAMI: 1994 in WSF Newsletter: 1994).

The families have therefore become part of the new multidisciplinary team. Victoria Conn (1992) from NAMI’s curriculum and training network committee, confirms that families have become cornerstones in the current community mental health system, and that families and professionals should jointly advocate for co-ordinated integrated services.

3.4 TREATMENT MODELS

Treatment models which involve the family, range from being supportive and crisis-oriented, to psycho-educational and task-oriented. Literature (Mollica: 1983, Brown: 1985, Mechanic et al: 1987 in Gericke: 1995) have indicated that the needs of families of psychiatric patients are mainly that of support and information about the nature of the illness, a likely prognosis and possible treatments. It is believed that the family itself is a resource for support and help to the individual (Butler et al 1983). Caplan et al (1976) urge caregivers to exploit the crisis situation, which naturally excites human interest and mobilises energy and motivation to help others, in order to promote family support
systems. According to Grinspoon et al (1990) the purpose of the family meetings is to lower the tension, encourage tolerance and to help the family learn to care for the patient. They enlist the family members as allies, asking them what they want, what most troubles them and what methods have been effective in the past.

Anderson (in Wessels: 1988) stresses that it is imperative to make contact with the family as soon as possible after the patient's admission to a psychiatric hospital. It is important to explain the hospital procedures, and to give attention to the experience that the family is going through during this time of crisis. The family may be concerned for their relative's safety within the psychiatric hospital and some members may develop doubts about their own state of mental health. The history taking should be handled with support and dignity, informing the family that this information is vital for working out a proper treatment programme for the patient.

Butler et al (1983) encourage the social worker to focus on the implications of the disorder upon the family. Relatives' feelings of frustration, anger and guilt are understandable in the light of their having endured a good deal of difficult behaviour from the patient. It is the social worker's task to disentangle these feelings, help the individuals to understand how they have arisen, enable them to come to some resolution and interpret these emotions to the other members of the professional team, thereby helping to soften entrenched attitudes and stereotyped views.

The early stages of the illness may exaggerate existing disharmony within the family and thereby contribute to distorted patterns of communication. Fleck (in Atkinson: 1986) sees the main aim of therapy to improve communication and helping the family to establish more workable boundaries. "Help in examining intra-family communication and pointing out possible distortions may allow the family to express more freely feelings and
emotions" (Butler et al 1983: 74). The members are taught how to express positive and negative feelings, to make requests for behaviour changes in others and to listen actively. By sharing experiences, personal feelings towards other members of the family become more open, and personal autonomy may be reasserted.

"The needs of the client and his family may be assigned to one of three broad categories: emotional, socio-economic and physical" (Butler et al 1983: 36). Socio-economic aspects are a major field for social work intervention. As part of the socio-economic needs, Butler et al highlighted that of employment, income maintenance and accommodation. At a meeting held on 1993.11.30 at the Cape Mental Health Society where "Equal Opportunities for People with Disability with Particular Reference to People with a Psychiatric Disability" was discussed, these same three areas as well as the need for transport and state subsidised services (e.g. day care facilities) were identified as primary needs.

One of the first steps in discharging a patient from hospital, is finding alternative accommodation. Many long-term psychiatric patients have either lost contact with their family or have no family. For many a return home may also not be the best answer. Available alternatives such as Salvation Army hostels and night-shelters are grim and in short supply. Group homes may begin to resemble the institutions they were designed to replace. Other alternatives are boarding-out ex-patients to live in ordinary domestic housing with a family to whom they are not related, and sheltered housing associated with the elderly. A number of voluntary organisations provide alternatives to hospital care. A social worker's task is to put people in touch with each other, providing accommodation and other assistance as required.
Studies such as that of Wansbrough and Cooper (1980 in Butler et al 1983) have indicated the importance of employment in the rehabilitation process of those who have suffered from a mental illness. Butler et al see employment as such an important factor for both client and family, that they recommend some specialisation within the social work team in order to attend to this factor. Furthermore, they are of the opinion that social workers are very effective at giving counsel with regard to the intricacies of the social security system.

An important contribution to psychiatric rehabilitation is the psychoeducation of families (Lamb : 1994). This task can be taken on by mental health professionals or by peers. The family members are informed, often in a small-group setting and with the help of visual aids and written handouts, about the cause, symptoms, treatment and prognosis of the illness and how to support the mentally ill relative. The family is given guidance regarding identifying and developing strategies in dealing with the problems that present a threat to their relative's current and future stability. The family members are also encouraged to lead independent lives and are told that being self-sacrificing is counterproductive in that it is likely to deplete family resources and make long-term support of their relative increasingly difficult.

The NAMI group (Hatfield : 1995 : 4, Griffin-Francell : 1993 : 6) developed the following guidelines for the provision of services to families with mentally ill relatives:

1 Families new to the mental health system need to know they are not alone. Inform the families about the self-help groups and other resources available in the community and work in coalition with families to create the necessary services.

2 Focus on the well-being of all the members of the family.
Be empathic of the way families experience mental illness by listening attentively and nonjudgmentally to what they say and by avoiding stereotyping families with such labels as dysfunctional, high EE, or co-dependent.

Stay abreast of advances in understanding mental illness, new treatments, and community care and share this information with the families so that they can be effective allies in treatment.

Encourage students to seek field placements not only in acute care settings, but also in community settings where psychiatric rehabilitation is practised. Encourage students to attend family self-help groups.

Acknowledge the difficulty of putting the ideas into practice in the home setting where attention cannot be focused exclusively on one individual or issue. Give advice on how to cope with the patient at home, such as effective communication skills, procedures for improving compliance with the prescribed medication, how to manage out-of-control behaviour and how to de-escalate high levels of anger.

Recognise that psychiatric services are required 24 hours a day.

Be clear about the model of intervention used and explain this to the families.

Do not allow the use of family education to perpetuate the idea that parents are destined to be caregivers to their adult mentally ill children indefinitely.

Recognise and respect the tremendous cost, both personal and financial, borne by families struggling with mental illness.

In conclusion, therefore, giving the necessary support and information about hospital procedures and the illness; attending to the families' feelings; facilitating intra-family communication and assisting families with accommodation, recreation and financial matters in relation to their mentally ill relatives, are aspects that should be taken into consideration when providing services to families of mentally ill people.
3.5 PRIOR WORK OF IMPORTANCE TO CURRENT STUDY

Falloon et al (1990) emphasise that psychiatric education needs to be extended to families and patients as well. Although this involvement will not result in a cure of the illness, research suggests that the quality of life for the patients and their families will be enhanced. The researcher, in her work with mentally ill patients and their families in Valkenberg, has found that family intervention improves the prognosis of psychiatric patients and enhances the quality of the family member's lives.

Families feel aggrieved when they are originally only contacted as a source for collateral from them, and then again when the patient needs to be discharged in their care. They want to be involved through all the phases of their relatives' treatment while they are being hospitalised. This could ensure that they have a better understanding of the illness and could also mean that they feel more equipped to deal with the situation back at home. Having been introduced to the management strategies while the patient was hospitalised, they will also be more motivated to participate in the after-care program.

Wilson et al (1983 : 320) describe the research done by Leavitt who had interviewed the families of 16 first-admission patients after their discharge from a psychiatric hospital. She identified the following possible contributory factors for the families' unpreparedness regarding the discharge of their ill relatives:

"1. Pessimism about the future related to their opinion that the patient had not recovered.
2. Lack of recognition of the hospital as a resource to the family.
3. Lack of instruction and anticipatory guidance how to respond to the patient's behaviour.
4. Failure to view themselves as a resource and part of the treatment team."
5. Limited communication with the staff concerning their perception of the patient's progress and inability to disagree with the staff's plan to discharge the patient."

Koch and Zabow (1992) reviewed all the patients (326, excluding forensic patients) who had been hospitalised in Valkenberg hospital for one year or longer, to identify those patients who no longer needed hospitalisation; but could not be discharged due to, inter alia, lack of adequate facilities in the community. Their work highlighted the opposite problem of the revolving door syndrome. When patients are hospitalised for too long periods of time, they can develop the so-called institutionalisation syndrome where they withdraw, become dependent and show decreased self-esteem and apathy. They became reluctant to be discharged, preferring the safe haven of their home that the hospital has become to them. It appears, therefore, that there needs to be a balance between too long and too short hospitalisation periods.

Further, they found that 28% of the patients remained in hospital because they had no suitable alternative accommodation. In 10% of the cases the family did not want the patient at home, despite the fact that 25% of the patients went out for weekend leave and 56% received visits from family or friends.

In a following study, Koch and Zabow (1992) investigated the home circumstances of all those patients (102) who no longer needed hospitalisation in order to identify who could possibly be discharged to their families. They found that in 19% of the cases there was no suitable accommodation, 24% of the families were not able to cope with the patient at home, 22% refused to have contact with the patient, 16% did not want the patient at home and 42% would not be able to provide adequate supervision. In only 15 of the 102 cases could they recommend possible discharge of the patients to their families. They found that
the higher socio-economic family groups (mostly white families) were more reluctant or unable to have their long-term mentally ill relatives discharged into their care.

In this study, the researchers recommended that the patient should remain in contact with the family during his/her hospitalisation and that the family should be more actively involved in the patient's treatment.

Hugh et al (1987) examined the effect that family involvement in discharge plans had on the readmission rates to a psychiatric unit. Patients were being hospitalised for a shorter period of time and they were concerned with the *revolving door syndrome*. The authors reviewed numerous previous studies (Rosenblatt et al: 1974, Byers et al: 1978, Francisco et al: 1980, Vitale et al: 1965, Tuckman et al: 1965) on the factors involving readmissions to psychiatric hospitals. The majority of these studies suggested that social processes, rather than diagnostic or psychopathological determinants, were the major factors in patient admission rates. The living situation of the patient may, for instance, be more important than receiving aftercare services. An increase in length of stay from 9 to 26 days was also associated with a 55% reduction in rapid readmission rates. The latter was attributed to more family involvement in the discharge plans.

Hugh et al (1987) further studied the records of all patients discharged from two 23-bedded adult inpatient psychiatric units over a period of one year, analysing these records in terms of "No Family Involvement", "Family Notified" and "Family Involved". Their findings suggested that family involvement had a small positive effect in preventing readmission and that the combination of no family involvement and a short length of stay in hospital contributed to the most rapid readmission rate.
Other variables also affect the patient's ability to remain in the community; e.g. "The quality of the social support system, the existence of appropriate employment opportunities, adequate financial support and the quality of accommodation...." (Hugh et al.: 1987: 12). Regarding the social support system, the New York Family Support Demonstration Project that was begun in 1984, compared a single-family psychoeducation model with a multiple-family group format. It was found that patients in the multiple-family format had substantially lower risk of relapse than patients in single-family treatment (McFarlane et al.: 1993).

Grella and Grusky (1989: 831) interviewed 56 family members of seriously ill persons to determine their satisfaction with services received through a country wide service system based on community support program (CSP) model developed by the National Institute of Mental Health. Their findings confirmed the results of previous research (Willis: 1982, Lombard et al.: 1978, Hatfield: 1983, Vine: 1982, Solomon et al.: 1988 in Grella et al.: 1989) regarding the dissatisfaction of families with the services available for them and their kin.

"First-person accounts by family members reveal hostility and resentment toward professionals who at best fail to perceive or address family needs and at worst may blame families for the illness of their relative. Family members typically report that they lack information about mental illness, are ignored by the mental health professionals, feel left out and uninvolved in the treatment process of their family member, are dissatisfied with the frequency of contact and quality of communication with professionals, and generally feel frustrated and powerless."

Grella and Grusky (1989) randomly selected four rural and four urban counties for investigation. Case managers at the designated core agency in each county recommended family members for interviews. Open-and-closed-ended questions were asked. They first examined family knowledge of the availability of 13 key services and then rated the quality and coverage of these services. They found that family members were more satisfied with
the service system after some time since the onset of the illness and when the age of onset was older. Providing information and supporting families were highly rated as indicators for satisfaction.

Dale Johnson (1994 : 26) researched families' satisfaction with services by sending out a survey questionnaire to 29 family support organisations around the world. Twenty-four responses were received. The results suggested that improvement of services for people with mental illnesses were needed everywhere. The problems cited in the various countries were:

"1. **Australia**: Poor care in the community, lack of supported accommodations, failure to involve families appropriately, and abysmal lack of resources - in all aspects.
2. **Bermuda**: Inadequate provision for community housing, what is available is too expensive, inadequate financial assistance, limited sheltered work opportunities, and few alternatives to hospital based services.
3. **Belgium**: Lack of financial support, no legal rights, poor housing, and social exclusion, e.g., work.
4. **Canada**: Inadequate housing, not being included in the community and the stigma surrounding mental illness, in particular, schizophrenia and, as a result, quality of care and continuum of care present a great challenge. Quality of care throughout the country is very uneven.
5. **Germany**: Care could be improved, especially for chronic patients as concerning housing and working facilities, day centres, etc. There are more and more problems due to difficulties with health care generally, but particularly in developing community care facilities for mentally ill persons.
6. **Holland**: Providing housing, work, proper professional care, especially in crisis, and needs of the family.
7. **India**: The stigma attached to the mental illness is too much. The State Government and Central Government do not even recognise this as a handicap and do not extend concessions in job, travel facilities, etc. The biggest question facing the families are what will happen to their wards after our demise.
8. **Ireland**: Social stigma, unemployment, lack of day activities, and shortage of public housing.
9. **Israel**: Not enough rehabilitation services available in the community enabling patients to receive treatment and becoming reintegrated into the community outside the hospital framework.
10. Japan: A shortage of housing and rehabilitation institutions so that most patients have to stay in hospital even if not necessary.

11. New Zealand: Lack of adequate community care, inadequate individualised treatment planning and case management, lack of government funding, improper use of the new Mental Health Act, difficulty in getting ill people into hospitals for stabilisation, lack of supervised housing, lack of sheltered employment places - like everywhere, it all comes down to government disinterest and underfunding in mental health.

12. Russia: The economic and political situation.

13. South Africa: (Cape Support for Mental Health) Lack of employment, housing and vocational rehabilitation. South Africa was one of the countries that were given highest overall ratings of satisfaction with services. Greatest satisfaction was reported for diagnostics and medications.

14. Spain: Lack of rehabilitation services, no working facilities, nearly no housing in the community, difficulty with laws.

15. Sweden: No proper housing, no work possibilities, stigma, and properly functioning community care is hard to find.

16. Switzerland: Having diagnosis in time, hospitalisation at the right time, emergency service, correct and continuous medication, lack of adequate housing, vocational rehabilitation, legislation, relations with psychiatric institutions and medical services, consequences of sectorization of enough aftercare, no leisure organisations or social integration, necessity to help families as they grow older, socially isolated, and tired.

17. Ukraine: Medication (there is virtually no anti-psychotic or anti-depressive medication in the Ukraine or Russia), absence of equal rights or social skills training, and it is very hard to find jobs.

18. United Kingdom: Difficulty in admission to hospital when necessary, inadequate resources for community care, too few staff to provide care plans effectively, countering public ignorance and social stigma.

19. United States: Problems vary greatly from one state to another with some providing quite good services and others that are distinctly limited.

20. Uruguay: No alternative besides hospital and the family and there is a lack of psychoeducational programs that could help the mentally ill persons to grow and rehabilitate.

Housing received the lowest rating of ratings."

The National Alliance for the Mentally Ill (NAMI) surveyed families about the adequacy of services for their mentally ill relative and found that families were particularly concerned about the limited availability of housing. "Families of persons with mental illness are deeply concerned about where and how their relatives are housed" (Hatfield : 1993 : 496). Paul Carling (1993) found a growing evidence that both consumers and their
families favour supported housing, based on principles of consumer choice, integrated community housing and flexible services.

Olga Gericke (1995) did a needs assessment in relation to emotional, educational and referral needs of 80 family members of psychiatric patients of the Dr. Abduragman psychiatric community clinic in Kewtown, Cape Town. As there were only few caregivers who responded to the request to attend the clinic for an interview, another sample was selected by doing home-visits.

The study indicated that the majority of the caregivers had little knowledge about their relative's illness. Only 22.5% of the families complained that their relative was a burden to them and just 11.11% reported having difficulties referring their relatives to the clinic or hospital or getting help from the police. Although 90% reported satisfaction with the clinic's support for the patient, 61% requested provision of more information on the patient's illness, 38.8% requested home-visits, 35% were interested in family support groups and 27.5% wanted educational groups for families.

In her study on "Living with Mental Illness: Effects of Professional Support and Personal Control on Caregiver Burden", Susan Reinhard (1994 in WSF Newsletter : 1995) found that care-givers who lived with and apart from their relatives reported similar levels of burden and psychological distress. She concluded that this was an important area for further study since the support needs of families who live apart but remain involved are not well known.

"The few existing studies concerning victims of violent psychiatric patients suggest that about half of those victims are family members" (Binder et al : 1986, Gondolf et al : 1989, Tardiff : 1984 in Straznickas et al : 1993 : 385). It was found that most of the patients
were younger, had schizophrenic disorders with psychotic symptoms such as paranoid delusions involving the family caregiver, abused drugs or alcohol and lived in the family home. Straznickas et al (1993) recommended that hospital staff should therefore be prepared to provide support, respite, and education about early warning signs of psychiatric decompensation by patients who become assaultive during episodes of acute mental illness. Families might also learn how to deal with aggressive behaviour in ways that can lead to better adjustment through peer support groups. It was further recommended that involvement of the criminal justice system might in some circumstances be a viable option for managing violence.

Clark's (1994) research on "Family Costs Associated with Severe Mental Illness and Substance Use" showed that parents of adults with dual disorders gave significantly more money and time to the adult child than did parents of adults with no chronic illnesses. This extra burden prevented the families from providing for retirement or leisure activities, for unexpected expenses or for financial support to other relatives. Clark recommended that policymakers should therefore remember that independent living usually does not mean financial independence from families and should explore better ways of supporting families.

The study of Greenberg et al (1994), on the other hand, highlighted that persons with serious mental illness living in the community provide substantial amounts of help to their families, particularly when they live in the same household. The aids include household tasks such as meal preparation, shopping, interpersonal support such as companionship, and financial support. Because of the often debilitating effects of mental illness, not all clients with mental illness are however able to make contributions to their families. Notwithstanding this, these findings may help mental health providers, researchers, clients,
and their families recognise the positive roles that persons with mental illness can play in the family and community.

Glass (1995) notes the importance of ongoing assessment of consumer satisfaction to improve the quality of services. Patient responses to satisfaction questionnaires are summarised monthly and shared with all staff. The results of these questionnaires indicated that caring staff, explanations of treatment, family involvement in treatment and involvement in groups and classes were considered most important by patients.

Polowczyk et al (1993 : 590) compared patient and staff surveys of consumer satisfaction to determine whether psychiatric patients would respond differently to other patients than to staff when surveyed about the care they received. The patients reported general satisfaction with the psychiatric services provided, but those surveyed by patients reported significantly less satisfaction. "Patients surveyed by other patients may have felt more free to reveal their dissatisfaction. On the other hand, among peers a socially desirable response set may have been to report more dissatisfaction than was actually felt."

Packer et al (1994 : 1117) examined "Psychiatric Residents' Attitudes Toward Patients with Chronic Mental Illness." They found significant positive correlations between the residents' attitudes and their training in settings where patients were considered to receive high-quality care and supervisors were good role models. They concluded that constructive training experiences during residency can have a positive influence on residents' attitudes toward patients with chronic mental illness.

In another study, in which professionals' attitudes toward patients were researched, Snyder et al (1994) investigated non-familial caregivers and the relationship of expressed emotion to relapse of persons with severe mental illness. It was found that residential care
operators in this study made fewer critical and positive remarks during the Camberwell Family Interview than family members in an earlier study and were rated as less hostile and overinvolved. Unlike the study of family members though, the residential care operators were not interviewed when their residents were having acute problems. It was, however, found that the effects of operators' expressed emotion on their residents were similar to those of family members on their adult offspring. The residents reported poorer quality of their residential care environment and showed an increase in their hostility-suspiciousness during the follow-up when the emotional climate was more critical. The attitudes of the caregivers toward the mentally ill persons were also affected by the severity of the disorder. The findings, therefore, supported the interactional nature of the construct of expressed emotion, with reciprocal contributions by both mentally ill individuals and their caregivers.

3.6 CONCLUSION

Prior studies have highlighted the importance of educating and involving the family in all the treatment phases of their mentally ill relative to ensure compliance, aid the recuperation process, enhance the quality of life for the patient and their families and to equip the families to cope with the illness. The research has also shown that families are the most concerned about the lack of supported housing, rehabilitation services, adequate financial assistance, day care centres and sheltered employment for their mentally ill relatives.

In terms of the systemic school of thought, an individual's psychiatric problem is positively or negatively affected by the family's transactions. Family interference or support, therefore, exacerbates or alleviates the symptoms, but does not cause the illness. Overall systems therapy is a useful model to apply. In a setting like a hospital where the researcher
works, however, patients are sometimes admitted from other provinces or countries and it
is therefore not always possible to involve all the families. The families from the township
areas often don't have transport to enable them to attend family meetings. With the
psychiatrically ill person being labelled the index patient, it is sometimes difficult to
persuade the other family members to get involved in the treatment programme. The
urgency of the problem has disappeared with the patient being hospitalised and the family
can now relax.

Research has been focusing too much on expressed emotion and has subsequently been
overlooking valuable work that can be done with families. Unfortunately the concept of
high-EE families has acquired a connotation of problem families as it focused on the
negative interactions within the family. These studies also focused on reducing the risk of
relapse of the mentally ill person and did not give enough attention to family needs,
anxieties and support in adjusting to the emergence of mental illness (Smith et al : 1990).
CHAPTER IV

RESEARCH DESIGN AND METHODOLOGY

4.1 RESEARCH DESIGN

Due to the fact that very little previous research has been done regarding family satisfaction with psychiatric services, an exploratory-descriptive design was used to explore the possible factors influencing consumer satisfaction (Arkava et al : 1983). A qualitative research method was applied to "unlock the wealth of knowledge concerning human beings with social problems" (Schurink et al : 1988 : 99). Using qualitative methodologies alone within health settings, can lead to charges of nonobjectivity (Everett et al : 1994). Richer data will be produced by combining qualitative and quantitative methodologies through triangulation (Daly et al : 1992).

It is hypothesised that families will be dissatisfied with psychiatric services when there is limited professional involvement with the families in the treatment programme of their mentally ill relatives. This study is based on the premise that the families' dissatisfaction with the services is positively related to:

1. difficulties experienced with admission procedures,
2. a perceived negative attitude towards families from the staff,
3. lack of sufficient information about the illness and treatment thereof,
4. lack of guidance on how to respond to the patient.

Furthermore, it is hypothesised that families will vary quite widely in terms of their understanding of the aetiology of mental illness and that professionals don't always take these factors into account.
The research objective is therefore to test these hypotheses in the interest of improving the psychiatric services offered to the families of psychiatric patients at Valkenberg Hospital. A further objective is to answer the research question, namely: "What factors are most important in explaining consumer satisfaction with psychiatric services provided to families with their relatives' admission to Valkenberg Hospital?"

Finally, a needs assessment will also be done to establish the need for family groups.

4.2 POPULATION AND SAMPLE

The subjects for this research comprised 31 relatives of 24 patients who had been admitted to the male and female admission units (wards 9, 10, 14, 15 and 16) at Valkenberg psychiatric hospital in Cape Town. A non-probability convenience sampling procedure, based on the availability and accessibility of the relatives to attend an office interview (the exception being one telephonic interview with a father who would not come in for an office interview, but proceeded to talk over the phone), was used. The probability of inclusion in the sample is therefore unknown and no indication can be given of the reliability of the results obtained (Grinnell : 1988).

During 1994, a pilot study was done on 10 selected patients of which only 2 families could be interviewed. An attempt was also made to make appointments with the families via a call-in letter (see Annexure 1), but families did not respond to the letters. Forty-eight copies of section one of the questionnaire were then distributed amongst the twelve case managers in the three male and two female admission wards, with the request to complete the identifying data of the patients (see Annexure 2). Only seven of the questionnaires were returned and none of the relatives could be interviewed. As there were no major
problems with the questionnaire, only a few changes were made to the final measuring instrument.

Subsequently, 114 patients, of which only 22 families could be interviewed, were selected during January, February, and the majority in March 1995. The total number of admissions to these acute wards during the three month period were 448. The main reasons why some of the selected subjects could not be interviewed were: misunderstandings regarding the time and venue of the scheduled interviews; family members not able (primarily due to lack of transport), or not willing (wanting nothing to do with the patient) to attend an office interview; failing to keep the appointments; family members not responding to messages left; wrong telephone numbers, or getting no responses and in two instances the family members were not able to speak either English or Afrikaans. The hospital had only one official interpreter employed at that time, and due to his high work load, it was not possible to involve him with the research.

4.3 DATA COLLECTION

A survey method was employed in this study to gather quantitative and qualitative data. Questionnaires and face-to-face interviews of one hour duration were used, in which families' satisfaction regarding services provided during their relatives' admission to a psychiatric hospital, was assessed. The researcher conducted interviews with individual members of the families on the basis of a semi-structured interview schedule "directed toward understanding informants' perspectives on their lives, experiences, or situations as expressed in their own words" (Taylor et al :1984 in Schurink et al : 1988 : 99).

The interviewees were informed about the researcher's profession and experience at Valkenberg hospital, and that the research would form part of a dissertation to obtain a Masters Degree at the University of Cape Town. With every interview, their permission
was asked to tape record the interview and they were given the assurance that they would remain anonymous. The importance of their participation in the study was emphasised in the light of the psychiatric services needing to incorporate the families' needs.

The researcher collected the data every Thursday afternoon at the five admission units. She completed the section of the identifying data of all the patients who had been admitted to Valkenberg during the preceding week. This information was obtained from the folders. The data from the semi-structured interviews were collected via tape recordings that was transcribed, analysed descriptively and tables have been used for further illustration.

4.4 MEASURING INSTRUMENTS

An interview schedule, designed by the researcher, was used to measure family satisfaction. For the purposes of this study, satisfaction was defined as adequately meeting the subjects' needs and expectations regarding the services provided. The questionnaire, comprising three sections, recorded the demographic data of the patients and of the interviewees, and a section of open-ended questions (see Annexures 3, 4 and 5).

Section One (Identifying Data of Patient) and Section Two (Profile of Interviewee) of the questionnaire consisted of structured multiple choice questions where provision was made for three or more categories of responses (CSD : 1993). These two sections of the questionnaire were devised from examples of other questionnaires utilising similar research methods. Section Three constituted unstructured open-ended questions to encourage unrestricted responses. The researcher constructed this section by drawing from her experience in practice and from the literature review, working mainly from research done by Atkinson (1986).
CHAPTER V

RESULTS

5.1 IDENTIFYING DATA OF THE PATIENTS WHOSE FAMILIES WERE INTERVIEWED

Allocated therapists: (n=24)

Seven (29.2%) of the patients were allocated to social workers, fourteen (58.3%) to the registrars and three (12.5%) to psychologists.

Demographic data: (n=24)

Fifteen (62.5%) patients were male and nine (37.5%) were female.

Age distribution:

Most of the patients (25%) were between 19 and 24 years of age. There was only one patient each in the age groups 37 to 42 and 49 to 54 (see table 1).

<table>
<thead>
<tr>
<th>Age distribution (n=24)</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>19-24</td>
<td>6</td>
<td>(25%)</td>
</tr>
<tr>
<td>25-30</td>
<td>5</td>
<td>(20.8%)</td>
</tr>
<tr>
<td>31-36</td>
<td>4</td>
<td>(16.7%)</td>
</tr>
<tr>
<td>37-42</td>
<td>1</td>
<td>(4.2%)</td>
</tr>
<tr>
<td>43-48</td>
<td>5</td>
<td>(20.8%)</td>
</tr>
<tr>
<td>49-54</td>
<td>1</td>
<td>(4.2%)</td>
</tr>
<tr>
<td>55-60</td>
<td>2</td>
<td>(8.3%)</td>
</tr>
</tbody>
</table>

Marital status: (n=24)

The majority (sixteen=66.7%) of the patients were single. Two (8.3%) were married and six (25%) were divorced.
Population groups: (n=24)
The majority of the patients were from the Coloured population group: sixteen (66.7 %), while four (16.7 %) were Black and four (16.7 %) were White.

Religious affiliation: (n=24)
Seventeen (70.8 %) of the patients were from the Christian religion. Four (16.7 %) were Muslim and no information was available regarding the rest (three=12.5 %).

Admission pattern: (n=24)
Only eight (33.3 %) of the patients were admitted to a psychiatric hospital for the first time. The rest (16=66.7 %) had been hospitalised before. Of the latter, one had received treatment in Britain and another one had been admitted to Kenilworth Clinic on two previous occasions.

Section of the Mental Health Act: (n=24)
Most of the patients (17=70.8 %) were admitted in terms of section four (as patients by consent) of the Mental Health Act. Five (20.8 %) needed certification (section 9) and two (8.3 %) had to be admitted via section twelve (as urgencies).

Ward distribution: (n=24)
Only two (8.3 %) of the patients in the sample were from the closed male high care unit (ward 15). Four (16.7 %) and nine (37.5 %) patients were from the other two male admission units (wards 14 and 16). Three (12.5 %) patients were from the closed female admission unit (ward 9), and six (25.%) were from the other female admission unit (ward 10).
Diagnosis:

Twenty-one of the twenty-four patients had a psychotic disorder. Of these, nine had a dual diagnoses of which two had a dual psychotic diagnoses. The dual diagnoses of the other seven patients were a psychotic diagnoses with:

* dementia
* epilepsy
* histrionic personality traits
* substance abuse (two)
* substance abuse and anti-social personality traits
* substance abuse, anti-social and borderline personality traits

Most of the patients (12=23.53 %) had at some stage been diagnosed as having schizophrenia and the second largest group (9=17.65 %) had been diagnosed with a bipolar affective disorder. Seven (13.73 %) of the patients had a diagnosis of substance abuse and three (5.88 %) displayed personality disorder traits. The patient with a diagnosis of malingering also had a diagnosis of substance abuse (see table 2).

Table 2: Diagnostic categories (n=51)

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia (3 as previous diagnoses + 2 as dual diagnoses)</td>
<td>12</td>
<td>23.53 %</td>
</tr>
<tr>
<td>Bipolar (3 had previous diag. of schitz. + 5 as dual diagnoses)</td>
<td>9</td>
<td>17.65 %</td>
</tr>
<tr>
<td>Substance abuse (6 as dual diagnoses)</td>
<td>7</td>
<td>13.73 %</td>
</tr>
<tr>
<td>Personality disorder traits (all dual diagnoses)</td>
<td>3</td>
<td>5.88 %</td>
</tr>
<tr>
<td>(i) Histrionic</td>
<td>1</td>
<td>1.96 %</td>
</tr>
<tr>
<td>(ii) Anti-social</td>
<td>2</td>
<td>3.92 %</td>
</tr>
<tr>
<td>(iii) Borderline</td>
<td>1</td>
<td>1.96 %</td>
</tr>
<tr>
<td>Other (6 as dual diagnoses)</td>
<td>8</td>
<td>15.69 %</td>
</tr>
<tr>
<td>1 Schizophreniform</td>
<td>1</td>
<td>1.96 %</td>
</tr>
<tr>
<td>2 Schizoaffective</td>
<td>2</td>
<td>3.92 %</td>
</tr>
<tr>
<td>3 Epilepsy</td>
<td>1</td>
<td>1.96 %</td>
</tr>
<tr>
<td>4 Malingering (pseudoseizures)</td>
<td>1</td>
<td>1.96 %</td>
</tr>
<tr>
<td>5 Brief psychotic episode</td>
<td>1</td>
<td>1.96 %</td>
</tr>
<tr>
<td>6 Dementia</td>
<td>2</td>
<td>3.92 %</td>
</tr>
</tbody>
</table>
5.2 PROFILE OF INTERVIEWEES

Time of interview: (n=24)

Sixteen (66.7 %) of the interviews were conducted during office hours and eight (33.3 %) after hours. The interviews took place between 5 and 39 days after the admissions of the patients.

Family characteristics:

More than one family member was present at five of the 24 interviews. Most of the interviews (14=45.2 %) were conducted with the mothers of the patients. In three of the instances the fathers were also present and in one case a brother and a sister accompanied the mother. Two of the three wives of patients who were interviewed, were divorced from their husbands. Twenty-three (74.1%) of the interviewees were female (see table 3).

<table>
<thead>
<tr>
<th>Table 3: Family characteristics (n=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father</td>
</tr>
<tr>
<td>Mother</td>
</tr>
<tr>
<td>Daughter</td>
</tr>
<tr>
<td>Brother</td>
</tr>
<tr>
<td>Sister</td>
</tr>
<tr>
<td>Grandmother</td>
</tr>
<tr>
<td>Aunt</td>
</tr>
<tr>
<td>Wife (2=ex)</td>
</tr>
<tr>
<td>Other (brother-in-law + his mother)</td>
</tr>
</tbody>
</table>

Age distribution: (n=31)

Thirteen (42 %) of the interviewees were between the ages of 35 and 55 years, thirteen were older than 55 years and four (13 %) were between 21 and 35 years of age. It is uncertain what the age of the father is who was interviewed telephonically.
Marital status:

More than half (16=51.6%) of the interviewees were married. Seven (22.6 %) were divorced, three (9.7 %) were widowed and two (6.4 %) were single (see table 4).

Table 4: Marital status (n=31)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>2 (6.4 %)</td>
</tr>
<tr>
<td>Married (1=living together)</td>
<td>14 (45.2 %)</td>
</tr>
<tr>
<td>Divorced</td>
<td>7 (22.6 %)</td>
</tr>
<tr>
<td>Widowed</td>
<td>3 (9.7 %)</td>
</tr>
<tr>
<td>Remarried</td>
<td>2 (6.4 %)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>3 (9.7 %)</td>
</tr>
</tbody>
</table>

Family composition: (n=24)

Thirteen (54.1 %) of the interviewees came from extended families, ten (41.6) were nuclear families and one mother lived in an old age home.

Educational qualifications

The majority (12=38.7 %) of the interviewees had only primary school education. Two (6.4 %) had a degree, one (3.2 %) had a diploma and four (13 %) had obtained other post-school qualifications (see table 5).

Table 5: Educational qualifications (n=31)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary school</td>
<td>12 (38.7 %)</td>
</tr>
<tr>
<td>High school</td>
<td>8 (25.8 %)</td>
</tr>
<tr>
<td>Diploma</td>
<td>1 (3.2 %)</td>
</tr>
<tr>
<td>Degree</td>
<td>2 (6.4 %)</td>
</tr>
<tr>
<td>Other post-school qualification</td>
<td>4 (13 %)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>4 (13 %)</td>
</tr>
</tbody>
</table>
**Occupation:** \( n=31 \)

Ten (32.2%) of the interviewees had white collar occupations, eight (25.8%) blue collar occupations, ten were housewives and one (3.2%) was a male patient who has never worked. It is not certain what the vocations of two (6.4%) of the interviewees were.

**Employment:** \( n=31 \)

More than half (16=51.6%) of the interviewees were not employed in the open labour market. Thirteen (42%) were employed and the employment situation of two (6.4%) was uncertain.

**Economic situation:** \( n=31 \)

Thirteen (42%) of the interviewees earned a salary, thirteen were pensioners, two (6.4%) received maintenance from their husbands and the financial situation of three (9.7%) was not known.

**Religious affiliation:** \( n=31 \)

The interviewees were mainly from the Christian religion (24=77.4%) and seven (22.6%) were Muslim.

**Home language:** \( n=31 \)

The interviewees were chiefly Afrikaans speaking (19=61.2%). In addition, eight (25.8%) were English speaking and four (13%) interviewees were Xhosa speaking.

**Area:** \( n=31 \)

The majority (24=77.4%) of the interviewees lived in the city area, five (16.1%) lived in the townships and a married couple (6.4%) came from the rural area.
Psychiatric illness in the family: \(n=24\)

In more than half \(15=62.5\%\) of the instances, there was a history of psychiatric illness in the family (including two of the interviewees). It is not certain if there is any psychiatric illness in the family of the father who was interviewed over the telephone.

5.3 QUALITATIVE DATA

Question 1  How do you feel about your relative's admission to Valkenberg hospital?

Emotional response to hospitalisation: \(n=28\)

Seventeen \(60.71\%\) of the interviewees felt positive about their relatives' admission to Valkenberg hospital. Their responses varied from feeling "okay" \(2=7.14\%\), "relieved" \(3=10.71\%\), "at peace" \(1=3.57\%\), "thankful" \(5=17.86\%\) to believing the hospitalisation to be in the best interest of the patients \(6=21.43\%\). One respondent had no real feelings about his son's admission and examples of the other answers are: feeling "sad" \(3=10.71\%\), "disappointed" \(2=7.14\%\), "upset" \(3=10.71\%\) and feeling "guilty" \(2=7.14\%\).

Two of the respondents, expressing feelings of sadness and being upset, were at the same time thankful to have their relatives admitted and felt that it was in the best interest of the patient to receive treatment in hospital; as illustrated by the following two examples:

A daughter's response in relation to her mother's admission:

"Oh, very sad, but I'm also glad. You know, she's been in and out of clinics; Kenilworth clinic - that didn't do her any good. It just reoccurred again the next year, you know, and here I feel that she's getting the attention she needs. In the private clinics, they weren't, agh you know, they did, they looked after her, but not much interest, you know. It wasn't as good as, I mean, here I feel that they really do take care of her and they're interested in her. You know, I'm getting a lot of calls from everyone, telling me how she is."
A father's response to his daughter's admission:

"We were sort of upset, you know, because when it started to happen it was very traumatic for the family......, it came unexpectedly on us, you know. Well, mostly, most of the people, I mean the general public, when it goes to Valkenberg, it's sort of asylum......, but in her own interest, we thought that these people working here will help her, because these people here in this hospital understands the problem more than we do, you know."

**Question 2.1 Did you experience any difficulty to have your relative admitted?**

**2.2 What did you experience the most difficulty with regarding your relative's admission?**

**Difficulties experienced with admission: (n=25)**

Nine (36 %) families experienced no major problems in having their relatives admitted to Valkenberg hospital. Three (12 %) interviewees had no specific comments to make. One respondent was a mother who was more upset about the stigma related to Valkenberg hospital, and for another respondent it re-evoked negative experiences in relation to another relative's admission.

The greatest difficulties experienced by the other families were:

* Not being informed about the patient's transfer from Tygerberg hospital to Valkenberg 1 (4 %)
* Difficulty finding the ward 1 (4 %)
* Having no private transport 2 (8 %)
* Having to lie to the patient 1 (4 %)
* Having to resort to getting help from the police 6 (24 %)
* Having to have the patient certified 2 (8 %)

**Question 3 How do you feel about your relative's treatment on admission?**

**Treatment on admission: (n=24)**

More than half (15= 62.5 %) of the interviewees were satisfied with their relatives' treatment on admission. Two (8.33 %) interviewees had no comments to make and the father, who was interviewed over the phone, was unhappy about having to take his son
back to the hospital after he had absconded and about the fact that the staff had not been aware of his son's disappearance from the hospital. A mother's account (her son had been treated at Valkenberg since 1973) highlights the communication problems that she had experienced:

"Well this time, one never quite knows what's happening, where he's going on admission. What happened this time was, you see, the thing is that he's not under the Wynberg clinic anymore, he's under the outpatient's here at Valkenberg. So that there's been good continuity. Our social worker had phoned dr. X. He knew he was coming in, that we were getting him committed. He agreed that he should be committed. But then I phoned in the afternoon at about 15h45, because in the end the police didn't bring him in till about 14h00. I phoned admissions and they said yes, he's just been admitted, that he'd been sent to ward 15, I think. So I said I wondered if I could not speak to dr. X? The person at admissions said: "O no, you certainly could not speak to dr. X." I can't imagine why, I was so taken aback. She said: "No you certainly can't." So I presumed that they would let dr. X. I mean, I don't know why she wouldn't let me speak to him. Because I said he knew he was coming. So then there was a proper muddle. So then I phoned the next morning and ward 15 had sent him to ward 14. So I went to ward 14 and the sister there said no, she didn't know what firm he was under, she'd sent him back to ward 15. So then I went back to ward 15 and ward 15 said they sent him to ward 16, because they couldn't let him go out because he was completely psychotic and he told me he had to go to my funeral. So they got him locked up in ward 16 and he spent the weekend there. So then I phoned on Monday to find out how he was and I, Oh, I never had a problem getting dr. X, he's very accessible, and I got through to him and he hadn't even known Y was in the hospital. But I think there was a bit of confusion there, because when I phoned ward 16 on Sunday, they said Y had settled, he was fine and I asked what dr. he was under and the nurse said that dr. Z was away so he was under dr. X. But when I phoned on Monday they said dr. Z was back. So I don't know. So then dr. X looked him up in ward 16 and sent him to ward 14. So I think there's a bit of a problem with communication sometimes. I was a fool, I should have insisted on getting dr. Z on, it was all Friday afternoon too you see. I assumed he was busy or he'd left or something, so I just left it. I mean, I didn't think it was important. He was there and it would all get sorted out."

Five (20.83 %) respondents complained about the medication having negative effects on the patients. The following are two examples of a daughter reporting about her mother's treatment and an ex-wife's account regarding her ex-husband's condition.
"I was worried when she was admitted first to ward 9. I saw her face was really in and she looked rather pale. I was really scared, because I told my husband I don't like the way she's looking. But then they explained to me she went for a lumbar punch and she had a few headaches and so on. I think the medication that she was on made her vomit and she refused to eat. That is why she was looking not like the way I know she should be looking. But she is looking normal now again. Her face is full again now."

"Maar vir my was dit "quite fine" gewees. Is nou net wat ek hom kom besoek, toe was hy soos 'n "zombie" gewees. So stil, was soos 'n "zombie", so. Toe sê hy, want sy suster het vir my gesê, moenie dat hy "shock treatment" kry, want ek het mos nie kennis nie. Hulle weet dan nie eens nie. Hulle sê altyd net ek moenie dat hy "shock treatment" kry nie. Ek moet sê dat hulle vir hom met die pille moet "treat". En so het ek dit nou gesê vir hulle, moet hom pille gee maar nie "shock treatment" nie."

**Question 4**  How did you experience the health care professional's attitude towards you?

*Comments regarding professionals' attitudes: (n=28)*

Most (20=71.43 %) of the families had positive encounters with the hospital staff. Two (7.14 %) respondents had no complaints, and others described the professionals' attitudes towards them as "good" (7=25 %), "considerate and kind" (2=7.14 %), "sympathetic" (1=3.57 %), "polite and helpful" (4=14.29 %) and being "nice" (4=14.29 %). Two (7.14 %) interviewees had had no contact with hospital staff and one (3.57 %) respondent had no comments.

The following negative reports were received regarding hospital staff:

* being uninformative 1 (3.57 %)
* being judgmental 1 (3.57 %)
* being rude 1 (3.57 %)
* not understanding 2 (7.14 %)
Question 5  What is your understanding of/how do you explain your relative's condition?

Understanding of the illness: (n=25)

Six (24 %) interviewees found it difficult or were unable to explain their relatives' conditions. Their diagnoses were:

* schizophreniform psychosis
* schizophrenia (disorganized type)
* schizoaffective
* malingering, pseudoseizures, alcohol and cannabis abuse
* bipolar affective disorder [manic] (previously schizophrenia)
* toxic psychosis with cannabis abuse and dependence

In the instance of the two (8 %) respondents who related their relatives' conditions to substance abuse, the actual diagnoses were that of bipolar affective disorder and schizophrenia with substance abuse. Where another two (8 %) interviewees were of the opinion that their relatives' "minds were not right", the diagnoses were brief psychotic episode (mania) with alcohol abuse and substance abuse with dementia due to alcohol. In the case of a patient's aunt who believed that her nephew was malingering, his diagnosis was psychosubstance abuse, bipolar affective disorder [manic] and anti-social traits.

Only six (24 %) of the respondents believed that their relatives had an illness. These patients' diagnoses were:

* psychosis due to epilepsy (epilepsy with mood disorder [manic] on admission)
* bipolar affective disorder with histrionic traits (previously schizophrenia)
* schizophrenia with mood component
* schizophrenia with substance abuse
  (same respondent mentioned above who related the diagnosis to substance abuse)
* bipolar affective disorder
* paranoid schizophrenia

In the example of the father who was interviewed over the phone who was of the opinion that his son was possessed by evil spirits, his son's diagnosis was schizophrenia. According
to the answers of seven (28%) respondents, their relatives' conditions was a direct result of their inability to cope with life.

<table>
<thead>
<tr>
<th><strong>Explanations:</strong></th>
<th><strong>Diagnoses:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>* being frustrated</td>
<td>* bipolar affective disorder [manic]</td>
</tr>
<tr>
<td>* can't take pressure (two)</td>
<td>(previously schizophrenia/mood disorder)</td>
</tr>
<tr>
<td>* stress-related</td>
<td>* schizophrenia (both)</td>
</tr>
<tr>
<td>* not dealing with problems</td>
<td>* schizophrenia</td>
</tr>
<tr>
<td>* keeping feelings bottled up and then exploding</td>
<td>* organic induced disorder, manic psychosis</td>
</tr>
<tr>
<td>* nervous breakdown</td>
<td>(? underlying B.A.D.), substance abuse, borderline and antisocial traits</td>
</tr>
</tbody>
</table>

**Question 6  What caused your relative's condition?**

**Cause of illness: (n=29)**

Three (10.34 %) interviewees did not know what had caused their relatives' illness. Two (6.9 %) respondents understood the illness to be as a result of a genetic pre-disposition, the parents of one patient thought that their daughter's condition might be the result of the patient being too intelligent, two (6.9 %) interviewees thought that head injuries had caused the condition and in three (10.34 %) instances the family was of the opinion that the abuse of substances was the cause. Three (10.34 %) interviewees attributed their relatives' conditions to supernatural causes (possessed by evil spirits, involvement in the occult and the possibility of the patient being poisoned), another three (10.34 %) related it to a deprived and abused childhood and in twelve (41.38 %) cases the family connected it to stress-related events:
Unemployment  1 (3.45 %)
Labour-related action  1 (3.45 %)
Losing all possessions  1 (3.45 %)
Having an unplanned pregnancy  1 (3.45 %)
Getting a girl pregnant  1 (3.45 %)
Removal of children in terms of the Children's act  1 (3.45 %)
Due to sibling's death  1 (3.45 %)
Twin of opposite sex getting married  1 (3.45 %)
Break-up of relationship  2 (6.9 %)
Marital problems  2 (6.9 %)

**Question 7.1**  *Were you told what your relative's illness is?*

**7.2  How did you feel/what did you think when you were first told about your relative's diagnosis?*

*Emotional response to the diagnosis:* (n=26)

Just under half (12=46.15 %) of the interviewees were not informed about their relatives' diagnosis. Two mothers who were not informed, read the diagnosis on their sons' medical certificates. The father who was interviewed over the telephone, gave no comments in this regard. Four (15.38 %) respondents (one being the mother who read about her son's diagnosis on his medical certificate) felt sad, two (7.69 %) were shocked and a mother reported feeling bad after being told about her son's diagnosis. Another mother expressed herself as follows:

"It is difficult, because actually I refused him being diagnosed as a schizophrenic. But when doctor explained it to me - then I had no other choice but to accept it. Because I mean, this is a medical doctor - if it would have been somebody else, I would have said no, I refuse to accept it. But I mean, it's from his doctor himself."

The mother, brother and sister of a male patient who had been admitted for the first time, did not really understand their relative's condition of schizophrenia (disorganised type). Two (7.69 %) interviewees (one being the other mother who had read about her son's diagnosis on his medical certificate) were not surprised about their relatives' diagnosis, an
aunt initially accepted her nephew's diagnosis, but then years later felt that he was malingering and a mother could not care less, but just wanted a break from her daughter (The daughter had a previous diagnosis of schizophrenia, but on her last admission her diagnosis was bipolar affective disorder with histrionic traits). She described her feeling as follows:

"I couldn't care less. I just felt that she must, I just want to be away for a while. The way I felt was very cruel and that's not my nature to hate a person. I hated her very very much. I even slapped her sometimes and she sat still. I wanted her to fight back, so I could do something severe to her, but she didn't fight back. She just sat there, because deep down in her mind she knew she was wrong. What she did was wrong, I started feeling sorry for her. I loved her more then. I loved her like I saw her as my little baby. She was for ever crying. We couldn't go anywhere, nobody can come visit, she was for ever crying. It's hard to say, I just wanted my X back. I got half of my X back and I was satisfied with that, because I knew then, like they explained to me, I knew then getting half of her back is more than enough I thank God for that, that I got half of her back. Because when I look out through the window, I see this guy walking up and down the road and I look at her and I would kiss her and I would sometimes just hug her with my heart, but not physically. I would say thank God that she is not so far away from me, that I have to force her to do that."

**Question 8**  
**Were you told about the implications this illness and the treatment thereof would have on your relative and the family?**

**Implications of illness and treatment thereof on relative and family: (n=24)**

More than half (15=62.5 %) of the interviewees were not informed about the implications the illness and the treatment thereof would have on their relatives and on the family. Two (8.33 %) were given a pamphlet in this regard, but didn't really understand the situation fully. A mother reported that she were only given limited information, four (16.67 %) respondents said that they were informed and two (8.33 %) had no comments.
Question 9  Were you given any guidance as to how you should respond to your relative's behaviour?

Guidance how to respond to relative's behaviour: (n=24)

Half (12=50 %) of the interviewees were not given any guidance as to how they should respond to their relatives' behaviour. One was a mother, who was not given information about her son, but years ago, was given advice in relation to her first husband (father of patient) who had the same diagnosis of schizophrenia. Seven (29.17 %) respondents reported that they were given only limited information, e.g. that the patients must not use substances, that the patients must find employment and that the family should be more strict with the patients. Only three (12.5 %) respondents were given guidance and two (8.33 %) had no comments.

Question 10  How do you think this condition should be managed?

How the families felt their relatives should be managed: (n=28)

<table>
<thead>
<tr>
<th>Option</th>
<th>Count (n)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>By professionals</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>To be kept at a place until completely recovered</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>Drive evil spirits out</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>Combine western and traditional healing</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>Treated as normal</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>Treated with respect</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>Listen to them, love and give them attention</td>
<td>2</td>
<td>(7.14 %)</td>
</tr>
<tr>
<td>Pacify/soothe the patient</td>
<td>2</td>
<td>(7.14 %)</td>
</tr>
<tr>
<td>Treated firmly</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>To be given some responsibility</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>Help patient to obtain qualifications for employment</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>To be kept busy/given employment</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>Give the patient space to be alone</td>
<td>2</td>
<td>(7.14 %)</td>
</tr>
<tr>
<td>To be kept in an institution</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>To have alternative supported housing for the patient</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>At home on out-patient basis</td>
<td>3</td>
<td>(10.71 %)</td>
</tr>
<tr>
<td>Give financial support</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>To be compliant on medication</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
<tr>
<td>Don't know</td>
<td>4</td>
<td>(14.29 %)</td>
</tr>
<tr>
<td>Family can't cope being part of it anymore</td>
<td>1</td>
<td>(3.57 %)</td>
</tr>
</tbody>
</table>
Question 11  Would you find it helpful to have contact with somebody who also has a relative with a similar condition to your relative?

Contact with other relatives: (n=24)

Nineteen (79.17 %) interviewees confirmed that they would find it helpful to have contact with other families of mentally ill people. Only one mother was already a member of the Cape Support Group. A mother thought that she might find it supportive and an ex-wife of a patient was uncertain in this regard. The one respondent who was not interested in support from other families, was a female patient's brother who also had a diagnosis of schizophrenia. Two (8.33 %) interviewees had no comments.

Question 12.1 Do you from your side have any suggestions you would like to make that might help other families in similar circumstances?

12.2  What suggestions would you like to make?

Suggestions given for other families in similar circumstances: (n=31)

*  Not to worry as patient is in good care 2 (6.45 %)
*  To give support to other families 6 (19.35 %)
*  The importance of open communication 1 (3.23 %)
*  Regular contact, listen, comfort patient and try to understand 1 (3.23 %)
*  Be tolerant with patient 2 (6.45 %)
*  Give patient lots of love 2 (6.45 %)
*  Care/support the patient 3 (9.68 %)
*  To keep faith that the patient will recover 1 (3.23 %)
*  Pray for patient 2 (6.45 %)
*  Pacify/soothe the patient 1 (3.23 %)
*  Set limits for the patient 1 (3.23 %)
*  Don't confront a potential violent patient 2 (6.45 %)
*  Enlist help from the police 1 (3.23 %)
*  Early treatment to prevent condition deteriorating 1 (3.23 %)
*  Important that patient remain compliant on medication 2 (6.45 %)
*  Siblings should be counselled 1 (3.23 %)
*  No comments 2 (6.45 %)
Question 13  What would help you most?

What would help families most: (n=30)

For all of the family members to support the patient (not for only one member to be burdened with the responsibility) 1 (3.33 %)
To be educated about the illness 2 (6.67 %)
To have the patient treated at home 1 (3.33 %)
For the patient to be well enough to be home again 1 (3.33 %)
To have the patient in a more manageable state 2 (6.67 %)
Help for patient to obtain qualifications for employment 1 (3.33 %)
For the patient to find employment or to be occupied 2 (6.67 %)
Club for psychiatric patients 1 (3.33 %)
Financial support (D.G.) 2 (6.67 %)
Hospitalisation when required 3 (10 %)
Closer hospital to have regular contact 1 (3.33 %)
For patient to remain in hospital 1 (3.33 %)
To be admitted to a place until completely recovered 1 (3.33 %)
For the patient to stop drinking alcohol 2 (6.67 %)
To have alternative supported housing for the patient 2 (6.67 %)
Care for the patient when family is not able anymore 2 (6.67 %)
Combined Western and Traditional treatment 1 (3.33 %)
For the patient to undergo his initiation 1 (3.33 %)
Prayer and faith that caregiver will not become ill 1 (3.33 %)
To have peace and quiet 1 (3.33 %)
No expectations regarding psychiatric services 1 (3.33 %)

Usually there was quite a long pause before answering this question. The respondents' first reaction were to answer what they thought would be most helpful for the patient.

Question 14  Is there anything else you would like to add?

What families had to add:

When asked whether they would like to add anything, most of the interviewees repeated themselves and ventilated about the difficulties they were experiencing. They also had numerous questions about mental illness, the management thereof and what resources were available. One mother expressed the desire to see her daughter married and a wife of a patient was unhappy about the "pornographic" magazines that her husband had obtained while in hospital.
The following requests were added: (11)

* Support when admission is required 1 (9.09 %)
* To be oriented regarding hospital procedures 1 (9.09 %)
* To be kept up to date with patient's progress 1 (9.09 %)
* Individual counselling for parents by hospital staff 1 (9.09 %)
  (as not all parents go to Cape Support and not all
  the members of Cape Support are qualified to give counselling)
* Longer hospitalisation in open wards 2 (18.18 %)
* For patient to be institutionalised 1 (9.09 %)
* Organised transport to visit patient during hospitalisation 1 (9.09 %)
* For patients to be kept occupied while hospitalised 1 (9.09 %)
* Improvement of the physical appearance of the wards 1 (9.09 %)
* Home visits 1 (9.09 %)
* Peer-support for patients 1 (9.09 %)
CHAPTER VI

DISCUSSION

6.1 GENERAL COMMENTS REGARDING THE INTERVIEWS

For most of the interviewees it was quite painful to talk about their experiences. They often became emotional during the interviews and it was difficult not to get drawn into a therapy session with them. The families also had a lot of questions about their relatives' conditions and their general progress. In every instance they were referred back to their relatives' therapists and encouraged to discuss their problems openly.

6.2 DEMOGRAPHIC DATA

More than half of the patients in the sample were single males under the age of 37 years from mainly Coloured Christian population groups. This sample is a good representation of the distribution of age, gender, marital status, population groups and religious affiliation of the patients in the male and female admission wards at Valkenberg hospital. With regard to the interviewees, 74.1% of the sample were female of which 45.2% were the mothers of the patients. These figures correlate positively with previous studies where it was found that the majority of caregivers are female (Chafetz et al. 1989, Winefield 1994 in Gericke 1995, Gericke 1995).

6.3 DIAGNOSIS AND UNDERSTANDING OF THE ILLNESS

The majority (87.5%) of the patients had a psychotic disorder, nevertheless, although 46.15% of the interviewees claimed to have been informed about their relatives' diagnosis, only 24% believed that their relatives had an illness. This confirmed the results of Grella et al (1989) and Gericke (1995) which noted that families were poorly informed about
their relatives' illnesses. When asked what would help them most, only two respondents requested more education about the illness, a contrast to Gericke's study where two-thirds wanted more information about the patients' illnesses.

To an extent though, the families' lack of understanding regarding their relatives' conditions is comprehensible in the light of 45.83% of the patients presenting a dual diagnoses. The unsophisticated explanations given by the respondents for their relatives' psychiatric conditions, could also be positively related to the fact that 38.7% of the interviewees had only primary school education and although a further 25.8% attended high school, not all of them matriculated.

Although more than half of the interviewees were not informed about the implications of the illness and the effect of treatment nor were given any guidance as to how they should respond to their mentally ill relatives, none of them seemed to have made any requests in this regard to their therapists. However, this could be attributed to the fact that most of the interviewees were married and came from extended families where they may have received the necessary support to cope with the mentally ill relative. The role of the family as a support system in being a source of concrete aid and a haven for rest and recuperation is highlighted in the literature (Caplan et al: 1976).

On the other hand, the families may have been shy or cautious not to appear being demanding, and this could explain their lack of requests in relation to information about the implications and management of the illness. In her study, Gericke (1995) for instance found that the caregivers were reluctant to state that the patients were a burden to them and only admitted to it after some prompting. In this current study, however, nearly all of the respondents indicated that they would find it helpful to have contact with other families of mentally ill people. The following three examples highlight the families' need in
requiring guidance with the management of their relatives, even though they did not specifically request it:

A daughter's response in relation to her mother:
"Yes, I can learn from them. It will tell me also how to handle the patient."

A brother's comment in relation to a male patient:
"Hang af as dit dieselfde probleem is. Maar ek dink sy probleem is uniek. Ek het nog nie 'n probleem gesien soos sy probleem nie. Ek sal wil ondersoek instel, om meer uit te vind hoe om vir hom te hanteer. En om, soos ek sê op 'n gelyke vlak met hom te wees waar mens kan verstaan vir mekaar en praat met mekaar."

An ex-wife commenting on her husband (they are still living in the same house):
"Ja, ek sal, om op 'n manier oor hoe ons te werke moet gaan om, as 'n mens so 'n persoon in jou huis het en die familie, hoe jy met hom te werke moet gaan."

Although only 6.67 % of the respondents indicated that being educated about their relatives' illnesses would help them most, there seemed to have been a greater need in terms of the management of the mentally ill person; which confirms what the researcher has experienced in practice, regarding both patients and their families wanting to know how to cope with the situation, and not necessarily wanting to have theoretical knowledge about mental illnesses.

6.4 PROGNOSIS

The interviewees' 60.71 % positive emotional response regarding their relatives' admission to Valkenberg hospital, could be positively related to the fact that the majority of the patients had long psychiatric histories with numerous hospitalisations, that 70.8 % of the patients could be admitted as patients by consent and that only five (20.83 %) of the
patients had to be admitted to the closed high care admission units. Grella and Grusky's (1989) study shows similar results regarding families being more satisfied with the service system after some time since the onset of the illness. The families could therefore have become more familiar with the hospital procedures and, in the words of a mother in relation to her son:

".....the only thing I know is that when he's sick, I go to the police station and the police take him through to the hospital. There I get help."

6.5 SOCIO-ECONOMIC CONSIDERATIONS

Just over half of the interviewees were not employed in the open labour market and 42 % of them were pensioners. A number of needs verbalised, related to difficulties experienced with admission, comments on how their relatives should be managed, what would help them most and what they had to add. These needs could be subsumed under the socio-economic needs of families of patients as also highlighted by Butler et al (1983).

<table>
<thead>
<tr>
<th>Socio-economic needs</th>
<th>Citations</th>
</tr>
</thead>
<tbody>
<tr>
<td>* private transport when hospitalisation is required and for visitation</td>
<td>2</td>
</tr>
<tr>
<td>* employment for the patient</td>
<td>4</td>
</tr>
<tr>
<td>* financial support</td>
<td>3</td>
</tr>
<tr>
<td>* alternative accommodation</td>
<td>6</td>
</tr>
<tr>
<td>* to care for the patient when the family is not able anymore</td>
<td>2</td>
</tr>
</tbody>
</table>

6.6 CROSS-CULTURAL ISSUES

While the researcher did not ask specific questions related to cultural issues, the results of this study indicated that quite a few of the interviewees' responses considered cultural aspects, e.g.:
attributing supernatural causes to the illness, i.e. being possessed by evil spirits,
being of the opinion that western and traditional healing should be combined in the management of the patients, i.e. the importance of a patient needing to undergo his initiation,
emphasising the importance of keeping faith and praying for the patients' recovery,

The majority of the interviewees, however, were Afrikaans speaking Christians from the Coloured communities in the city. The Western Cape has historically always had a large Coloured community. In the researcher's experience, it has only been during the last ten to fifteen years that large groups of Black people, mainly from Transkei, have been settling down the Cape. Even if the two family members who could not be interviewed due to a language problem, were included in the study, the above-mentioned results could still have been the same as their responses would still be a minority.

However, the literature has emphasised the importance of taking various cultural aspects into consideration. "Daily contact with patients often demands an appreciation of personal meanings that transcend established clinical knowledge. For example, Xhosa patients occasionally display distress, acting out behaviour, or symptoms of a known disorder because these behaviours are in themselves symptomatic of a failure to fulfil particular cultural rituals, including adult circumcision, death rites, or rites for appeasement of ancestors" (Kaliski & Zabow: 1993: 1192).

In Swartz's (1986) experience, the therapist-patient relationship is further complicated by political events and a suspicion by the patient that the therapist, even with good intentions, is patronising him. Swartz is of the opinion that cross-cultural workshops between mental health professionals and traditional healers have been moderately successful in improving communication and lessening distrust and he foresees that traditional healers will eventually become legitimate members of multidisciplinary treatment teams.
Waldfogel et al (1993: 476) emphasises the importance of understanding a patient as a biopsychosocial-spiritual whole. "The stresses and confusions of the illness experience can be mitigated by the certainties of religious belief, and patients' (the same applies for their families) understanding of their illness and emotional responses to it are often filtered through their religious belief system." The role of the therapist is therefore not to judge these religious claims, but to seek to understand their clinical impact and to use the religious resources available to patients and their families to help them cope with the illness.

6.7 ADMISSION PROCEDURES

Most of the 52% respondents who had reported experiencing difficulties with their relatives' admissions to Valkenberg hospital, noted mainly practical problems in this regard, particularly having to resort to getting help from the police. These aspects correspond with the literature which highlights the increased burden and exposure to violent psychiatric patients, which the community movement has placed on the families (Smith et al: 1990, Bachrach: 1993, Eckholm: 1986, Straznickas et al: 1993).

In Gericke's (1995) study, though, only 12.5% of the caregivers had to resort to the police for help. She was, however, surprised with the results of her findings in which only 11.3% of the caregivers experienced problems in referring their relatives. Difficulties experienced were particularly in relation to psychotic and potentially aggressive male patients refusing hospitalisation. As illuminated by the following examples, families in this current study reported similar problems:

A mother describing the difficulties regarding her son's admission:

"As ek vir hom sê jy moet dokter toe gaan, dan sê hy vir my: "Are you sick?, then you go to the doctor." So het die tyd aan gegaan en die tyd het aan gegaan
en ons het toe nooit so, was mos nou een oggend toe wat ek nou sien, want ek sien, nee, die kind makeer behandeling. En toe bel ek mos, toe bel ek 'n verkeerde dokter. Sy sê. "van waar is jy?", sy sê waar wil ek eintlik wees. Toe vertel ek nou van die seun van my, toe gee sy vir my die nommer van Lentegeur. Toe bel ek vir hulle, toe gee hulle vir my 'n ander nommer, ek weet nie of dit "Life Line" is nie. Toe sê hulle vir my ek moet die polies bel dan sal die polies kom. So het dit mos nou gekom dat die polies nou bring vir hom deur."

A wife describing the difficulties regarding her husband's admission:

"Kyk, ons het al gesien die Maandag, wat ons gesien het, toe sê ons: "gaan sien die dokter, jy moet dokter toe gaan, want jy begin siek raak." Dan was dit nou nie nodig dat hy nou erger geword het nie, as hy gegaan het nie, maar hy wil niks verstaan nie. Hy wil net doen wat hy wil doen. Toe'et ons die blitspolisie gekry om hulp te leen en dit het lank gevat, want hulle wou hom nie met "force" gevat nie. Maar toe Dinsdag, toe ontslaan die dokter hom weer en hy was nie gesond nie, want hy's baie "aggressive" en "abusive". As mens miskien vir hom iets sê wat hy nie "like" nie, sal hy, hoe sê mens, "violent" word."

A mother describing the problems she had experienced in relation to her son's admission:

"Sorry ma'm, I asked the police to take him in. He was quiet and he didn't want to go to the van. He was so difficult. It was very very difficult. He wanted to go back. He was carrying a knife on him to the police station, because I was there, waiting for the van, to go home. As I was standing there, the police said I must wait at the gate. He was coming, but he didn't know I was there, in the police station. He was walking with friends. As soon as he saw me ma'm, he took a knife from the pocket, a big knife, and then he said: "if you don't run inside the police station, and the police car, bring me the key." I think some of the friends took the knife from him."

6.8 STAFF ATTITUDES

Only five of the thirty-one interviewees complained about the hospital staff's attitude towards them. They were:

* a patient's brother-in-law and his mother (patient = male schizophrenic)
* the father who was interviewed over the phone (patient = male schizophrenic)
* a mother (patient = female B.A.D. with histrionic traits/previously schizophrenia)
* an ex-wife (substance abuse with dementia due to alcohol)
In three of the above instances, one being the ex-wife, there was a history of psychiatric illness in the family. It is not certain what the family situation of the father is. The one common factor might thus be that, where there is a history of psychiatric illnesses in the family, the families are more inclined to complain about the staff's attitude towards them. No other commonalities regarding allocated therapists; demographic, cultural or socio-economic data of the patients or the interviewees; or the patients' admission patterns, could be found. The majority of the respondents, as noted in the previous chapter, reported favourably on staff attitudes.

6.9 PSYCHIATRIC SERVICES

The families' requirements regarding psychiatric services for them and their mentally ill relatives, can be summarised as follows:

* professional input (including counselling for parents and siblings)
* hospitalisation when requested and longer hospitalisation periods in open wards
* support when admission is required (including orientation re. hospital procedures)
* improvement of the physical appearance of the wards
* orientation re. hospital procedures and kept up to date with the patients' progress
* psychoeducation and practical guidance (including family groups)
* acknowledgement of spiritual and cultural needs
* emotional support (in the context of a relationship characterised by mutual respect)
* some form of occupation/employment (including a club for psychiatric patients)
* financial support (including organised transport)
* community psychiatric services
  (including home visits and hospitals in the rural areas)
* alternative supported housing (including institutionalisation for the severely ill)
* guardians for the patients once the parents are frail or deceased
The findings above correspond with the research done by Johnson (1994), Hatfield (1993), Carling (1993) and Clark (1994) in relation to families' needs. The request for counselling and explanation of the hospital procedures is supported by the work of Anderson (in Wessels : 1988) and Butler (1983). The comment by one of the mothers in the example below, emphasises the need for counselling by professional staff:

"The Parent Support Group tried to meet individual needs, but I'm not sure myself that all the parents are qualified. I mean, some of them are, but I think it ought to be sort of built into the hospital structure, because I mean not all parents go to the support group and they don't all have enough confidence in the support group to speak to another parent. I do feel that the hospital, the clinics, if they had somebody like yourself for parents to speak to, because I don't think they always realise that they need to speak to somebody. But make them come, because in the early stages you just don't realise what the problems are going to be or the implications, how you're dealing with crises. You could not really realise your own underlying attitudes are possibly wrong."

The following examples corresponds with Leavitt's (in Wilson et al : 1983) findings in relation to families being dissatisfied with patients' being discharged when they have not recovered:

"he'd said X was discharged and I must phone the doctor. I phoned the doctor, but then I couldn't get hold of the doctor that was X's doctor and I spoke to another doctor. She said that, she asked me how, what do I think how is X. So I said to her that I don't think that X is really well enough to come home yet, but then she said that X will still have to attend. I said okay, but please make it like the soonest after he was discharged."

"Toe die Dinsdag, toe die Woensdag ontslaan hulle vir hom en hy was nog nie gesond gewees nie, want toe ons hier weg gaan van die hospitaal, toe begint hy al in die kar en toet. Ek en my dogter het hom kom haal, toe begint hy al en heel middag het hy aan gegaan by die huis, dieselfde dinge gedoen en gesê toe ons hom hier laat kom het hiernatoe."
6.10 LIMITATIONS OF THE STUDY

The study has a number of limitations which need to be noted, and the results need to be viewed in the light of these.

The study was limited by the dearth of available literature and previous studies on family satisfaction regarding inpatient treatment for their mentally ill relatives in the South African context, which restricts the comparing of the findings of this study.

Most of the previous research and literature deals with the implications of schizophrenia. The researcher, however, interviewed families of mentally ill relatives with schizophrenia as well as other psychiatric diagnoses. This aspect again limits the comparative dimensions of the study.

The fact that the study was limited to only one psychiatric hospital in South Africa, may have consequences for generalizability. The population sample was too small to gain statistical significance, and does not provide a basis for generalising beyond this study.

The population used in the study was limited to only those families who have had relatives admitted to the acute admission wards. The relief of having their mentally ill relatives off their hands, may have clouded or influenced their responses. They may have reported less satisfaction if the interviews had been conducted while the patients were at home where they were experiencing problems in managing their psychotic relatives.

Further, if the families of the patients had been surveyed by other family members instead of the researcher, who is an employee of Valkenberg, it is possible that the families in the
study could have reported less general satisfaction. In this respect, Polowczyk et al (1993) noted the comparison between patient and staff surveys, where more satisfaction was expressed to staff than to other consumers.

The respondents may also not always have been totally honest when answering the questions; or interpersonal dynamics could have played a role in response to questions in the in-depth interviews.

The overall response rate might have been less positive if the researcher had interviewed at home those families who were not able or not willing to attend office interviews. Their lack of motivation to attend office interviews, could be an indication of their being less satisfied with the psychiatric services.

The reliability and internal validity of the questionnaire is uncertain. The researcher found that she had to rephrase her questions and that she often had to repeat the questions, as the respondents were not answering to the point. However, by using open-ended questions, she obtained valuable additional information, often tailored to the respondents replies.

It has been recognised that it is important to integrate hospital and community psychiatry into the main stream of general health services to ensure that a comprehensive mental health care system evolves (Oberholzer: 1985). Further, that a continuum of care (Wasow: 1993) that accepts the dependency of mentally ill people, their various levels of functioning, as well as the progress, deterioration, and inevitable fluctuations that occur, is essential. To this end, this research needed to tap into the families of the patients in order to assess their responses to the services which are offered in the psychiatric hospital which
ultimately serves as a springboard from which other services into the community can be offered.

Despite the limitations of this study, as noted above, in the areas of sampling, instrumentation and response sets, a broad and general baseline impression of the families' responses was obtained, which could motivate further research in this area.
CHAPTER VII

CONCLUSIONS AND RECOMMENDATIONS

7.1 CONCLUSIONS

The research has highlighted a number of issues and insights into family satisfaction with services offered to them on their relatives' admission to a psychiatric hospital.

The research findings indicated that:

* there was limited professional involvement with the families in relation to the treatment programme of their mentally ill relatives,
* more than half of the respondents reported experiencing difficulties with admission procedures,
* most of the respondents felt positive about staff attitudes,
* the majority of the respondents were not informed about the implications of the illness and the effect of treatment,
* most of the respondents lacked guidance on how to cope with their mentally ill relatives,
* the respondents varied quite widely in terms of their understanding of mental illness,
* more than three-quarters of the respondents were interested in family groups,
* there was a definite need for professional counselling for the parents and siblings.

Psychoeducation of families and practical guidance are therefore important areas to consider in order to improve psychiatric services to families of patients.
Besides the families' needs for psychoeducation, practical guidance, family groups and counselling as mentioned above, the other aspects summarised under families' requirements regarding psychiatric services (pp. 73), must also be included in policy making.

7.2 RECOMMENDATIONS

In response to the findings, the following recommendations are made:

1. Psychoeducation of families and practical guidance regarding socio-economic issues
2. Professional counselling of families which will include parents and siblings
3. A psychiatric service which will take the various cultural aspects into consideration
4. Exploration of ways to improve admission procedures
5. Support groups for families
6. Increased professional involvement as an overall aim.

Additional recommendations are as follows:

i A more structured survey with a larger sample of families of psychiatric patients, and a further study at Lentegeur and Stikland, the two other psychiatric hospitals in the Western Cape are recommended.

ii Ongoing assessment of consumer satisfaction to improve the quality of services is recommended. The researcher recommends, and has drawn up a follow-up letter to be posted to the families a week after their relatives have been discharged from the hospital, with the request to complete a brief evaluation form regarding the services (see Annexure 6). The results of these questionnaires would be summarised monthly and the contents would be shared with all staff.
iii Pending on the response to attend family groups at Valkenberg Hospital, the researcher plans to facilitate psychoeducation and support groups for families of patients.

iv It is also recommended that all the families of psychiatric patients be referred to Cape Support for Mental Health where they can receive the necessary peer support and guidance.

v Finally it is recommended that the results of the current study be made available to hospital authorities to ensure the inclusion thereof in policy making.
BIBLIOGRAPHY


Bakker, T.M. "Family Therapy with an Individual", Family Therapy in South Africa Today.


Centre for Science Development (1993) *Questionnaire Construction Workbook*, Winter School, Pretoria, HSRC

Clark, R.E. (1994) "Family Costs Associated with Severe Mental Illness and Substance Use", *Hospital and Community Psychiatry*, August, Vol. 45, No. 8, 808 - 813


Daly, J. & McDonald, J. (1992) "Covering Your Back: Strategies for Qualitative Research in Clinical Settings", Qualitative Health Research, 2, 416 - 438

European Federation of Families (1994) "From the Policy Statement of the German Association of Families of the Mentally Ill", World Schizophrenia Fellowship Newsletter, Third Quarter, p 9


Hatfield, A.B. (1993) "A Family Perspective on Supported Housing", Hospital and Community Psychiatry, May, Vol.44, No. 5, 496 - 497


Oberholzer, D.J. (1985) The Development and Comparison of Community Psychiatric Services in two Geographically Defined and District Communities in Southern Africa, Department of Psychiatry, Medical University of Southern Africa, October


Wessels, M. (1988) The Role of the Clinical Social Worker in a Treatment and Rehabilitation Programme for Schizophrenic Patients and Their Families, School of Social Work, University of Cape Town


WSF (1993) "Information About the W.S.F.", World Schizophrenia Fellowship Newsletter, Special Congress Edition, August/September, 5 - 6
Dear Daleen van Staden,

Social Work Department
Valkenberg Hospital
Telephone no.: 470050
19....../....../…….

I am a social worker employed at Valkenberg Hospital since 1986.

I am presently registered as a postgraduate student at the University of Cape Town. I am undertaking to do a study on family's satisfaction regarding services provided with their relatives admission to a psychiatric hospital. I would like to include you in this study that I will be doing at Valkenberg Hospital. The results of the research will form part of a dissertation that is a prerequisite to obtaining my Masters Degree in Clinical Social Work.

Please contact me for an appointment to interview you if you should agree to participate in this research. With your permission I would like to tape record the interview to ensure accurate transcribing of our communication. Your responses will be incorporated into the thesis in such a manner that you will remain completely anonymous.

Without the participation of people like yourself it will not be possible for me to do this kind of research. It is very important for the clinical staff of Valkenberg to form an opinion of how you feel about our services to yourself and your relative who is presently receiving treatment at the hospital. Your co-operation in this regard will therefore be greatly appreciated.

Yours sincerely

Daleen van Staden
ANNEXURE 2

Daleen van Staden
Social Work Department
Education Centre
Valkenberg Hospital
Telephone ext. 177/185
19...../......../......

Dear Colleague

RESEARCH: AN ASSESSMENT OF FAMILY'S SATISFACTION REGARDING SERVICES PROVIDED WITH THEIR RELATIVES FIRST ADMISSION TO A PSYCHIATRIC HOSPITAL

Your co-operation in completing the attached form will be greatly appreciated.

This research has been approved by Prof. Zabow and your consultant.

Please complete the identifying data of those patients who have been admitted to the male and female admission wards (wards 9, 10, 13, 15 and 16) for the first time. Those patients who have been previously admitted to other psychiatric hospitals and all forensic patients are excluded from this study.

The data must be collected between the second and fourth week of the patient's admission to Valkenberg or as soon as the therapist or hospital staff member has interviewed the relative.

Please forward the forms to me as soon as they have been completed.

Thank you

Daleen van Staden
INTERVIEW SCHEDULE

SECTION ONE: IDENTIFYING DATA OF PATIENT (information obtained from folders)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Research number: ..........................................................</td>
</tr>
<tr>
<td>2.</td>
<td>Therapist: .................................................................</td>
</tr>
<tr>
<td>3.</td>
<td>Folder number: ............................................................</td>
</tr>
<tr>
<td>4.</td>
<td>Name: .................................................................</td>
</tr>
<tr>
<td>5.</td>
<td>Age/D.O.B: ..................................................................</td>
</tr>
<tr>
<td>6.</td>
<td>Marital status:</td>
</tr>
<tr>
<td>6.1</td>
<td>Single</td>
</tr>
<tr>
<td>6.2</td>
<td>Married</td>
</tr>
<tr>
<td>6.3</td>
<td>Divorced</td>
</tr>
<tr>
<td>6.4</td>
<td>Widowed</td>
</tr>
<tr>
<td>6.5</td>
<td>Remarried</td>
</tr>
<tr>
<td>7.</td>
<td>Population group:</td>
</tr>
<tr>
<td>7.1</td>
<td>One</td>
</tr>
<tr>
<td>7.2</td>
<td>Two</td>
</tr>
<tr>
<td>7.3</td>
<td>Three</td>
</tr>
<tr>
<td>8.</td>
<td>Religious affiliation:</td>
</tr>
<tr>
<td>8.1</td>
<td>Christian</td>
</tr>
<tr>
<td>8.2</td>
<td>Muslim</td>
</tr>
<tr>
<td>8.3</td>
<td>Jewish</td>
</tr>
<tr>
<td>8.4</td>
<td>Other</td>
</tr>
<tr>
<td>9.</td>
<td>Date of admission: ..........................................................</td>
</tr>
<tr>
<td>10.</td>
<td>Previous admissions: ..........................................................</td>
</tr>
<tr>
<td>11.</td>
<td>Section: ..................................................................</td>
</tr>
<tr>
<td>12.</td>
<td>Ward: ..................................................................</td>
</tr>
<tr>
<td>13.</td>
<td>Diagnosis: ..................................................................</td>
</tr>
<tr>
<td>14.</td>
<td>Name of relative who had contact with the hospital staff: ..................................................................</td>
</tr>
<tr>
<td>15.</td>
<td>Address of relative: ..........................................................</td>
</tr>
<tr>
<td>16.</td>
<td>Telephone number of relative:</td>
</tr>
<tr>
<td>16.1</td>
<td>Home: ..................................................................</td>
</tr>
<tr>
<td>16.2</td>
<td>Work: ..................................................................</td>
</tr>
</tbody>
</table>

Completed by: ..................................................................

Date: ..................................................................

Please forward completed form to Daleen van Staden, Education Centre

Thank you

Daleen van Staden
ANNEXURE 3

INTERVIEW SCHEDULE

SECTION ONE: IDENTIFYING DATA OF PATIENT (information obtained from folders)

1. Research number: .................................................................
2. Therapist: .............................................................................
3. Folder number: .................................................................
4. Name: ..............................................................................
5. Age/D.O.B: ...........................................................................
6. Marital status:
   6.1 Single
   6.2 Married
   6.3 Divorced
   6.4 Widowed
   6.5 Remarried
7. Population group:
   7.1 One
   7.2 Two
   7.3 Three
8. Religious affiliation:
   8.1 Christian
   8.2 Muslim
   8.3 Jewish
   8.4 Other
9. Date of admission: ..............................................................
10. Previous admissions: ...........................................................
11. Section: ............................................................................
12. Ward: ............................................................................... 
13. Diagnosis: .........................................................................
14. Name of relative who had contact with the hospital staff: ...
15. Address of relative: ............................................................
16. Telephone number of relative:
   16.1 Home: ............................................................................
   16.2 Work: ............................................................................

Date: ........................................................................................
ANNEXURE 4

Interview with: ...........................................................................................................................................

Date: ..........................................................................................................................................................

Time: ..........................................................................................................................................................

SECTION TWO: PROFILE OF INTERVIEWEE

1. Relation to patient:
   1.1 Father
   1.2 Mother
   1.3 Son
   1.4 Daughter
   1.5 Brother
   1.6 Sister
   1.7 Grandfather
   1.8 Grandmother
   1.9 Uncle
   1.10 Aunt
   1.11 Cousin
   1.12 Niece
   1.13 Nephew
   1.14 Husband
   1.15 Wife
   1.16 Other

2. Age in Years:
   2.1 15-21
   2.2 21-35
   2.3 35-55
   2.4 55 and over

3. Marital Status:
   3.1 Single
   3.2 Married
   3.3 Divorced
   3.4 Widowed
   3.5 Remarried

4. Family Composition:
   4.1 Nuclear
   4.2 Extended
   4.3 Single Parent
   4.4 Reconstituted
   4.5 Other
5. Educational Qualifications:
5.1 No schooling
5.2 Primary school
5.3 High school
5.4 Diploma
5.5 Degree
5.6 Other post-school qualification

6. Occupation: ..................................................................................................................................
6.1 Employed
6.2 Unemployed

7. Economic Situation:
7.1 Earns a salary
7.2 Income from investments
7.3 Pensioner
7.4 No income

8. Religious Affiliation:
8.1 Christian
8.2 Muslim
8.3 Jewish
8.4 Other

9. Home Language:
9.1 English
9.2 Xhosa
9.3 Afrikaans
9.4 Other

10. Area:
10.1 City
10.2 Township
10.3 Rural

11. Psychiatric illness in the family:
11.1 Family member
11.2 Diagnosis
11.3 Treatment
11.4 By whom?
11.5 Where?
11.1 Family member
11.2 Diagnosis
11.3 Treatment
11.4 By whom?
11.5 Where?
ANNEXURE 5

SECTION THREE: OPEN-ENDED QUESTIONS

1. How do you feel about your relative's admission to Valkenberg hospital?

2.1 Did you experience any difficulty to have your relative admitted?

2.2 What did you experience the most difficulty with regarding your relative's admission?

3. How do you feel about your relative's treatment on admission?

4. How did you experience the health care professional's attitude towards you?

5. What is your understanding of/how do you explain your relative's condition?

6. What caused your relative's condition?

7.1 Were you told what your relative's illness is?

7.2 How did you feel/what did you think when you were first told about your relative's diagnosis?

8. Were you told about the implications this illness and the treatment thereof would have on your relative and the family?

9. Were you given any guidance as to how you should respond to your relative's behavior?

10. How do you think this condition should be managed?

11. Would you find it helpful to have contact with somebody who also has a relative with a similar condition to your relative?

12.1 Do you from your side have any suggestions you would like to make that might help other families in similar circumstances?

12.2 What suggestions would you like to make?

13. What would help you most?

14. Is there anything else you would like to add?
Dear

It has been a week since your relative's/friend's discharge from Valkenberg Hospital. We hope that all is well.

It would assist us greatly if you would please answer the questions on the attached brief evaluation form and return it to us. This will help us in assessing our services.

Thank you,
Yours sincerely,

pp Senior Medical Superintendent

Beste

Dit is 'n week sedert u familielid/vriend/vriendin se ontslag van Valkenberg Hospitaal. Ons hoop dit gaan goed.

Ons sal dit baie waardeer indien u asseblief die vrae op die bygaande kort evaluasie vorm sal beantwoord en die vorm aan ons terugstuur. U inseette sal ons help om ons dienste te evalueer.

Baie dankie,
Vriendelike groete,

pp Senior Mediese Superentendent
A. Please tick yes or no (questions 1-4)

1) I was informed about my relative's/friend's illness: YES NO
2) I was informed about his/her treatment: YES NO
3) I was given guidance on how to cope with the situation and how to respond to my relative/friend: YES NO
4) I am interested in attending family groups at Valkenberg Hospital: YES NO

B. Any further comments?

A. Merk asb. ja of nee (vrae 1-4)

1) Ek was ingelig omtrent my familielid/vriend/vriendin se siekte: JA NEE
2) Ek was ingelig oor sy/haar behandeling: JA NEE
3) Ek was leiding gegee oor hoe om die situasie te hanteer en hoe om te tree: JA NEE
4) Ek stel belang om familiegroepe by Valkenberg Hospitaal by te woon: JA NEE

B. Enige verdere kommentaar?

A. Nceda ufake unontshabalaza kwimpendelo ethi ewe okanye hayi

1) Ndaziswa ngesigulo sesihlobo/sizalwana sam: EWE HAYI
2) Ndaziswa ngamayeza/ipilisi azisebenzisayo: EWE HAYI
3) Ndafundiswa indlela emandi phile ngayo nendlela yokuphendula izizalwana/izihlobo ngesisi gulo: EWE HAYI
4) Ndinomdla wokuthabatha inxaxheba kwizifu ezinikwa izihlobo/izizalwana apha esibhedelele (Valkenberg Hospital): EWE HAYI

B. Ingaba ikhona enye into onokuvibhala?
ANNEXURE 7

RELATIONS WITH HOSPITAL STAFF (WSF Newsletter: 1993: 9)

(From Schizophrenia: A Handbook for Families, published by Health and Welfare Canada in co-operation with the Schizophrenia Society of Canada)

Suggestions by "experienced" families to help families new to coping with this brain disorder.

1. "Keep a record of everything while you still remember. List the questions you ask, the responses you're given, the names and phone numbers of the staff attending your relative. Keep a record of the treatment given, including dates and times. Keep copies of everything you mail, and all notices and letters you receive from the hospital.

2. Recognise that hospital staff (and other health care professionals) are there to help your relative. Make it clear that you understand this is their prime responsibility and that you are ready to do all you can to help them. See if you can establish a 'partnership' relationship between the psychiatrist, your relative and yourself.

3. Find out the names of the assigned psychiatrist, psychiatric nurse, and social worker. These are the people responsible for the treatment of your relative. You should be able to phone and speak with them if you have any questions and concerns. Remember that the amount of information you are given may be limited by the constraints of confidentiality.

4. Be polite and assertive when talking to hospital staff. Use sentences such as, 'Please help me,' 'Please tell me where I can get information about.....'

5. Ask for a meeting with the assigned psychiatrist and social worker. Try to get to know them at the first meeting. At later meetings come prepared with a list of questions
written down. Let them know of your willingness to provide them with information about the patient.

6. Keep all conversations to the point. Ask for specific information. Some sample questions: What are the specific symptoms you are most concerned about? What do these indicate? How do you monitor them? What is the medication being given? How often? How much? Have there been side effects? What is being done about them?

7. Ask for clarification of all answers. Do not settle for jargon and vague information.

8. If the psychiatrist is too busy to talk to you, write out what you want to ask or say (in point form), and deliver the letter to his or her office.

9. If you phone to speak to someone who is not available, leave your name, your relative's name, and your number. Then stay home and keep your line as clear as you can so that the member can return your call.

10. Consider having a friend or relative who is less directly involved come with you to meetings at the hospital. This person can be a calm and reasonable presence should you be overwhelmed by emotion and frustration.

11. Write letters of appreciation or criticism, and send them to the head of the hospital and the ward of the unit. Consider sending copies to the College of Physicians, Nursing, etc., if you think it appropriate. Be specific and brief in your letters.

12. Be a member of SSOC. When all else fails, help from the chapter or group may possibly allow you to cut through hospital "red tape" and get answers.