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**FACTORS CAUSING THE REJECTION OF STATE PATIENTS BY THEIR
FAMILIES AND RELATIVES AND THE EFFECTS OF THE REJECTION ON
THE PATIENT**

BY

SIVIWE MDUNYELWA

**A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTERS IN SOCIAL WORK
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SUPERVISOR: SHONA STURGEON

**DEPARTMENT OF SOCIAL DEVELOPMENT
UNIVERSITY OF CAPE TOWN
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ABSTRACT

The process of rehabilitating State Patients requires that they go out on leave of absence (LOA), once their psychiatric condition has settled to spend time with their families away from the hospital environment. The cooperation of the family or relatives is crucial as the patient is going to need supervision while he is at home. The family therefore should be prepared to accept him.

The research was conducted at Valkenberg Hospital in the Western Cape. A qualitative approach was used to explore and describe the factors that cause the rejection of State Patients by their families and relatives and the effects of the rejection on the patient. A random sample was drawn from patients who are currently occupying beds in the forensic wards at Valkenberg Hospital, and have not been out on leave for at least one year and above. Ten patients were selected and relatives of these patients were interviewed.

Emergent findings were that relatives were not willing to accept the patients because of lack of knowledge and understanding of the illness and also out of the fear of not knowing if and when the patient will re-offend. Substance abuse and aggression emerged as the main factors that families were struggling with and a high percentage of the respondents mentioned these as major difficulties for them.

The patients who were interviewed appeared to be struggling with expressing their feelings, and could not articulate how the rejection affected their mental state or whether it affected them at all.

DECLARATION

I declare that this is my own work, and that it has not been previously submitted in whole or in part for the award of any degree. Each significant contribution to, and quotation in this dissertation from the work or works of other people has been attributed, and has been cited and referenced.

Signature:

Signed by candidate

Date: 29/01/2009

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University of Cape Town

CHAPTER 1

1.1 INTRODUCTION

Valkenberg is one of two psychiatric hospitals in the Western Cape which have a forensic unit. The other unit is housed at Lentegeur Hospital and only caters for chronic forensic patients and also has a small section that accommodates 30 women. The unit at Valkenberg only accommodates male patients, and has a capacity of 140 inpatients. Fifteen of the 140 beds are for Observation patients and the rest are for State Patients. There are more than 500 State Patients on the hospital records, which means therefore that most of these State Patients have to be managed in the community. This is also in line with the new comprehensive health care system which is being established in South Africa. The new Healthcare 2010 plan for the Western Cape involves a shift in focus from tertiary or hospital care to primary care. This means therefore that most patients should be managed in the community. (Department of Health Western Cape, 2003)

For a person to be declared a State Patient they need to have committed an offence which led to an arrest. The court then sends the person to a psychiatric hospital for psychiatric observation, which will then determine if the person is mentally ill and whether they are fit or unfit to stand trial. This is in terms of Section 79 (2) of the Criminal Procedures Act (Act 51 of 1977). If the person is then found to be mentally ill and unfit to stand trial he is then classified in terms of Section 41 of the Mental Health Care Act No. 17 of 2002 as a State Patient and is sent to a Forensic Unit for an example at Valkenberg Hospital for an indefinite period.

While in the unit the patients are engaged in a rehabilitation program and this includes a process of gradual reintegration to the family and the community at

large. Once a patient's psychosis has settled and the patient is considered by the multidisciplinary team to be doing well in the unit's rehabilitation program, he is allowed Leave of Absence (LOA), away from the hospital to spend some time with his family or relatives. There is great concern about the deinstitutionalisation of patients in state hospitals and the ability of the community to cope with these patients in a home environment. Caring for a mentally ill relative demands a lot of the family's resources, be it human, emotional and/or financial. The scarcity of resources in the community makes the burden to be even heavier on the caregivers.

Leave of Absence may in terms of section 45 of the Mental Health Care Act (Act 17 of 2002), be granted in writing by the head of the health establishment. The written notice of Leave of Absence must state the commencement date and the return date of the State Patient to the health establishment and must be submitted to the head of the National Department. It must also state terms and conditions to be complied with during the period of leave. One of the conditions for the granting of Leave of Absence is that the State Patient be under supervision of an employer, or a specified next of kin, an acquaintance, escort or custodian, while he is out on leave. A clinical report on the patient's condition should be provided together with a social work report on the proposed custodian with special reference to any social problems that might exist in that household and which may have played an active role in the cause of the patient's mental illness.

Family members are usually the first to be considered when looking for custodians for the State Patients during their periods of leave. The cooperation of the family or relatives is therefore very important in this regard as the patient will need to be supervised while he is at home especially during his initial leave. Some families engage with the team and the patient's rehabilitation process from the onset of admission. They get involved in the treatment process and visit the

patient regularly in the hospital. These families are usually keen to take the patient out as soon as he is allowed leave from the hospital. There are however those families who do not become involved at all and would refuse to take the patient out when he is allowed to have leave.

1.2 Problem definition

The rehabilitation process of state patients requires that they spend time with their families during their period of hospitalization. Some of the families of these patients are willing to accept the patients back to their homes, while there are those who refuse to accept them. The staff in the forensic wards is faced with a number of patients who cannot be sent out on leave because their relatives will not accept them. Many of these State Patients consequently become disillusioned and are reluctant to become involved in the rehabilitation programmes, which often results in relapse. These State Patients have now formed an ever increasing pool of undischageable patients and when the constant stream of newly certified and admitted state patients is added, the reality is that the Forensic Unit finds itself in an ever growing crisis of lack of beds and resources.

To add to this problem there is also a long waiting list of people waiting to come into the hospital for observation but due to the lack of beds people remain in prison for long periods before they are seen in the unit for assessment. Some of these people are mentally ill people who will eventually be declared State Patients therefore adding to the crisis of lack of beds.

It therefore becomes important for the Unit to be able to send out some of the stable patients so as to accommodate the new admissions. This however becomes difficult when there is no cooperation from the patients' families. It also puts a lot of pressure on those families who are cooperative and willing to accommodate the patients at home as they often have to take the patient even when they feel that they need a break from him sometimes.

Patient records in the forensic unit at Valkenberg Hospital show that state patients predominantly have the following diagnoses: schizophrenia, schizoaffective disorder, bipolar affective disorder, dementia, mental handicap and substance or alcohol abuse disorders. Most have associated personality disorders, especially antisocial and borderline personality disorders.

1.3 Purpose of the study

The purpose of this study was to investigate the factors that caused families to accept or reject state patients that were entrusted into their care during periods of leave from the hospital. As a social worker working in the Forensic Unit at Valkenberg Hospital and therefore involved with these State Patients and their families, I have always been curious about the reasons why it was so difficult for some families to accept their relatives back into the family after they had been declared State Patients. It was also important for the continuation of social work services in the unit to find out about these families' difficulties so as to be able to work out a strategy to assist them or to determine alternative care for these patients.

Factors that were considered included the characteristics of the families, the nature of the index crime (that resulted in the certification), the impact that the families' rejection may have had on the State Patients, and the role of their social networks in the reintegration process. It is hoped that these insights will assist the Forensic Mental Health Team in finding alternate placements for those State Patients who are rejected by close family.

1.4 Research Topic

Factors causing the rejection of State Patients by their families and relatives and the effects of the rejection on the patient.

1.7 Definition of Terms

1.7.1 Rejection

For the purpose of this study, "rejection" refers to the family's refusal to accept the patient back into their lives by refusing to take them out when they have been granted leave.

1.7.2 State Patient

A State Patient is a person who has been classified as such by a court directive in terms of section 77(6) or 78(6) of the Criminal Procedure Act and admitted at a psychiatric hospital for mental health care, treatment and rehabilitation services as stipulated in section 42 of the Mental Health Care Act No. 17, 2002 (The Mental Health Care Act, Act 17 of 2002).

1.7.3 Relative

For the purposes of this study "relative" refers to someone who is in the same family as the State Patient in most cases who is also the caregiver. This term has also been used in the text to refer to the patient where it says the mentally ill relative.

1.7.4 Caregiver

The "caregiver" refers to someone who looks after the patient at home, whether it is a parent, sibling or other relatives.

1.7.5 Leave of absence (LOA)

Leave of Absence refers to a specified period of time during which the State Patient is allowed to be absent from the hospital grounds to promote the rehabilitation of the patient. Leave of Absence is granted to patients whose mental state has improved to an extent that they can be involved in a program for re-integration into the community (The Mental Health Care Act, Act 17 of 2002)

1.8 Ethical Considerations

A copy of the research proposal and the interview schedule were submitted to the Head of the Forensic Unit at Valkenberg Hospital and to the Head of the Social Work Department, with a letter to the hospital management requesting permission to undertake the research at the hospital. The research was approved by all concerned and the researcher was given permission to proceed.

The purpose of the study was explained verbally to all the participants and each person was given a choice to participate or not if they did not wish to do so. Thus no one was forced to participate. There was provision made at the bottom of the interview schedule for the participants to sign stating that they were giving permission for the information to be used for the purpose of this study. Consent was therefore given in writing.

Issues of confidentiality were discussed with the participants before they become involved in the study. They were also assured that their names would not be used in the research and that the information that they gave was solely for the purpose of the study and will not be recorded in their hospital files. The respondents were also made aware that the findings of the study would be shared with the team that works in the forensic unit at Valkenberg Hospital as this would assist them in making future plans for the unit.

It was also acknowledged to the participants that the interview was a sensitive process and might evoke some feelings within the participants. The researcher therefore informed participants that she would be available for consultation should such a need arise, or she would be willing to refer the participants should she be unable to assist.

1.9 Reflexivity

The nature of some research topics can evoke emotions that may affect the researcher's objectivity. Researchers could therefore, led by their emotions, give priority to their own self-interests and not the interests of the research subjects. De Vos, (2002:369) describes reflexivity as "the ability to formulate an integrated understanding of one's own cognitive world, especially understanding one's influence or role in a set of human relations. It is a quality of metacognition, thinking about one's perceptions and ideas." He also states that these characteristics are related to the widely supported social work qualities of empathy and self-awareness.

Tripodi and Tripodi, (1999:89) describe reflexive practice as "a practice that is capable of learning from experience and adapting itself to the lessons learned. It is a seductive concept, easier to proclaim than to substantiate." Tripodi and Tripodi (1999:89) also state that practitioners bring certain advantages to the research task and they also need to overcome certain difficulties. They state that the advantages include an overlap in professional skills, and argue that research-minded practitioners are well placed to inform research agendas, as they know better than most what questions could be addressed to increase understanding of the circumstances and problems of communities and service users, and to improve the effectiveness of services.

Tripodi and Tripodi, (1999:90) further state that practitioner researchers possess skills that are well developed in problem analysis, interviewing, recording, and in filtering out the irrelevant. They also have better access to data than external researchers. However they need to distance themselves from many of their day-to-day assumptions, to seek help in the formulation of questions and to realize that the researcher's relationship with a client has a different focus than that of a social worker. These authors also argue that practitioners need to be prepared for the conflicts of allegiance and responsibility to colleagues and the agency that

can come from switching between the roles of the researcher and the practitioner.

During the research process therefore I had to be aware of my role as a practitioner in this field and currently working with the research subjects. It was at times difficult to switch from the role of practitioner working in the unit to that of a researcher. This was especially difficult with the patients' interviews as they also struggled to understand the difference and therefore wanted to speak to me as their social worker and not as some researcher.

1.10 Conclusion

This chapter presented the introduction to the study and the setting where the research was conducted. It gave a definition of the problem and the purpose of the study. The chapter also described the objectives of the study and the research questions. A brief definition of terms that are used in the study, ethical considerations and reflexivity were also described.

The next chapter (chapter 2) will present the literature review.

CHAPTER 2

LITERATURE REVIEW

Introduction

There seems to be very little research that investigates the relationship between mentally ill offenders and their families. The review of literature has however revealed studies that have been conducted on the relationship between families and relatives with general mental illness but are not necessarily offenders. Generally what comes up in these studies is the difficulties in the relationships between mentally ill persons and their families and the difficulties that the family members face when caring for their mentally ill relatives.

The literature has also shown a link between mental illness, violent behaviour and substance abuse. These factors have also been linked with offending within the community of mentally ill persons. In this chapter therefore special attention will be given to the effects of substance abuse on the relationship between the mentally ill person and his relatives and also whether there is a relationship between mental illness and violence and how this affects the mentally ill person's relationship with his family. This chapter will also look at the nature of the relationship between the patient and his family, with special emphasis on expressed emotions. Attention will also be given to social networks and support.

The chapter will cover the following topics and at the end of the chapter there will be a concluding summary.

- The family as care givers
- Expressed emotion
- Social networks and support
- Mental illness and violence
- Mental illness and substance abuse

The era of de-institutionalization resulted in many mentally ill persons being discharged from institutions and placed in the community with their families. The focus of this process was on closing buildings, ending practices of patient restraint and on freeing people. Patients were discharged from institutions and given their medication and often had to find their own way of surviving in the community with the help of family members. Often family members and the general community did not know how to deal with people who are mentally ill. Anthony *et al.* (2002:1) felt that society's attitude prior to de-institutionalization was that mentally ill people are locked up in institutions and that is where they remain for the rest of their lives.

In North America particularly, the 1980's was a decade of transition between the former era of de-institutionalization and the era of rehabilitation. In the 1990's psychiatric rehabilitation assumed its place as one of the triumvirate of mental health initiatives, concentrating on prevention, treatment and rehabilitation (Anthony *et al.* 2002). These authors describe the mission of psychiatric rehabilitation as "to help persons with long-term psychiatric disabilities increase their functioning so that they are successful and satisfied in the environments of their choice, with the least amount of ongoing professional intervention". Rehabilitation focuses on enhancing their quality of life by providing personal support, so that those with psychiatric disorders are able to lead full independent lives.

Interestingly, the goal of de-institutionalization was lessening the number of people in institutions as well as lessening their length of stay. Very little, if any, consideration was made in terms of what would then happen to the patients once they were out in the community. This goal can also be realized through rehabilitation and its focus on the quality of life. Psycho-social rehabilitation has become policy in South Africa as well since the early 1990's. It has become a

credible service in the field of mental health and could become more viable with the provision of relevant community resources.

2.1 The Family as Caregivers

The movement away from institutional care to providing care in the community has resulted in families becoming more involved in the lives of their mentally ill relatives and are often themselves in the role of primary caregiver (Hatfield and Lefley, 1987:3). For most families this role is something new as mentally ill people were in the past removed from society and placed in mental institutions. The role played by families in the rehabilitation of their mentally ill relatives has become very important in the field of mental health. Community mental health care relies on families, partners and friends as important sources of informal care and support for persons experiencing mental ill health (Chaffey and Fossey, 2004:199). Families are increasingly having to take on this role, and most have found their new caregiver roles to be difficult and stressful.

In studies conducted by various authors, described by Hatfield and Lefley (1987:16) there was an indication of what the families found most burdensome in living with their mentally ill relatives. "Bizarre symptoms" were found to be problematic, and for male patients hitting and hurting others, damaging property and drinking were also behaviours which families found to be problematic. Uncertainty as to how to deal with the patient's inactivity, confusion about the unpredictability of behavior, and long-term worries about the patient's future in the light of his inability to cope with life and to manage independently were also difficulties faced by the family. Another factor was that often parents are afraid of their disturbed adult child.

These authors found that families came across as ambivalent in their feelings, having a sense of concern and caring mixed with resentment and anger. There

were also feelings of helplessness and entrapment. There was a general feeling among these authors that the burdens of caring for the mentally ill are universal, with no respect for differences in social class, education, age or the sex of the carer.

Chaffey and Fossey (2004:200) emphasize the stressful nature of informal care, often termed "caregiver burden". They argue that carers experience objective and subjective difficulties in caring for their mentally ill relatives. The objective burdens include the tangible stressors encountered when providing care such as the stressors associated with the symptoms and behaviours of the person experiencing mental illness, dealing with the mental health system and health professionals. Other stressors included the disruption of practical activities and the associated social costs to their daily lives.

"The subjective burden, in contrast, refers to the perceived stress, distress and emotional costs of caring. These include feelings of being overloaded, powerless and entrapped by the demands of care giving and a chronic sense of loss of previous familial relationships and aspirations for a loved one." Chaffey and Fossey (2004:201) also state that in previous research where the stresses for families caring for persons with mental illness were examined it was found that mothers were more affected than other family members.

Ohaeri (2002:457) argues that the most important predictors of burden are problematical behaviour, disability and the severity of symptoms. In his study on the subject of family burden, Ohaeri (2002:459) found that the effects of caring are noticeable on family functioning, on the children and the family finances, as well as the pervasive sense of stigma by association. Some of his noteworthy findings are that caregivers encounter many problems communicating with professionals and the prominence of grief in the care giving experience.

In a one year follow-up study of 681 caregivers, it was found that the physical health of former care givers (those who were no longer providing care for at least six months because of the death or institutionalization of patients) improved significantly once they stopped providing home care. In another study of vulnerable caregivers (i.e. those with poor health), the conclusions were that reliance on caregivers without considering their ability to provide care can create a stressful and potentially unsafe environment for the caregiver and the recipient of care (Ohaeri, 2002:459).

Another mediator of burden is the family's social support network, which can provide emotional, task and instrumental support (Solomon and Draine, 1995:420). These authors felt that personal and social resources influence family members' perceptions of the amount of burden they experience. They also found that family characteristics, including the relationship of the family member to the ill relative, did not really contribute to the explanatory power of subjective burden. The amount of subjective burden therefore was always felt whether the family had resources or not, or the family members had a close relationship with the ill relative or not.

Clark (1994:808) in his study of family costs associated with severe mental illness and substance use, found that parents of adult children with a mental illness gave significantly more money and time to their adult children than did parents of adult children with no chronic mental illness. Clark (1994:809) argues that this is an area that is not always seen as a problem but should actually be considered carefully in treatment planning as relatives usually spend time which they could spend earning money, looking after their mentally ill relatives. He states that "time spent helping a relative is not always thought of as economic assistance because it is not a cash transaction, but time contributions involve tradeoffs or opportunity costs, that is loss of opportunities to earn".

Ohaeri (2002:459) has also recognized this as an important factor in providing care to mentally ill relatives. He states that in the area of economics, the field has been advanced by the development of methodologies for assessing the market value of the care provided by unpaid family members so that using national data it should be possible to develop a league table comparing care giver costs across illness groups in the style of the World Health Organisation global burden of disease. He further asserts that these results should help the policy makers to appreciate the informal economic contribution of families, and offer a strong argument to include caregiver costs in economic evaluations of national healthcare costs.

2.2 Expressed Emotion

According to Hooley (2004:202) the clinical course of most psychiatric patients is determined by the nature of their family environments. She describes some characteristics of families that make it difficult for patients to stay at home. She talks about a measure of the family environment called "expressed emotion" (EE). According to Kuipers *et al.* (2002:3) Brown and Rutter (1966) coined the term "expressed emotion" to describe the families who are critical or over-involved with the patient.

Kuipers *et al.* (2002:3) argue that expressed emotion is a clinical term. They maintain that "it contributes very little to our understanding of the etiology of schizophrenia, but is a robust predictor of its course when someone with the illness lives with relatives." It is also argued by Butzlaff *et al.* (1998:547) that "EE is a measure of the family environment that has been demonstrated to be a reliable psychosocial predictor of relapse in schizophrenia." Patients who live in high EE family environments therefore are more likely to relapse than those in low EE family environments.

Butzlaff *et al.* (1998:551) have also examined the validity of the EE construct for mood disorders and eating disorders and concluded that there is an association between EE and relapse in a wide range of psychopathological conditions. Ball *et al.*, (in Kuipers *et al.*, 2002:3) state that research on EE has been extended to professional carers, who have been found sometimes to develop critical attitudes towards patients with schizophrenia which are comparable to those expressed by some family members.

Hooley (2004:202) mentions three key elements of EE: criticism, hostility and emotional over-involvement. According to Kuipers *et al.* (2002:4) "criticism is a direct expression of anger, and the number of critical comments made during an interview indicates how angry the carer is with the patient." "Hostility is an extreme form of criticism and represents a high intensity of anger, which may be accompanied by the rejection of the patient." Various authors, Brewin *et al.* 1991, Weisman *et al.* 1998, Boye *et al.* 1999, King *et al.* 2003 (in Patterson *et al.* 2005:59) argue that higher levels of criticism have been associated with relatives' perceptions that the cause of patients' behaviours and symptoms are more personal to and controllable by the patient, and that more troublesome behaviours in patients are as a result of failure to engage in productive activity. Barrowclough and Tarrier (1992) (also in Patterson *et al.*, 2005:) suggest that relatives high in critical relationships may be displaying coercive attempts to restore good behaviour in the patient because they believe that by being in control they may be able to influence the patient's behaviour.

Over-involvement is fueled by a mixture of anxiety and guilt. Guilt stems from feeling responsible for the patient's illness and is much more common in parents than other relatives or professional carers. The sense of guilt may impel relatives to try to do everything possible for patients to make up for the impact of illness on their life. Unfortunately this results in the patients becoming increasingly dependent on their relative and anxious about their ability to function on their

own (Kuipers, 2002). Bensten *et al.* (1996, 1998 in Patterson *et al.*, 2005) argue that emotional over-involvement is linked to more anxious and depressive symptoms and less aggressive and also uncritical behaviour perceived by relatives especially single mothers.

Expressed emotion is measured in terms of high and low EE. Low EE families are usually more accepting of the patient while high EE families are more critical and hostile and often have their own ideas of what the patient should or could do. High EE relatives will try to help the patient by making direct suggestions, offering ideas, or in more extreme cases, applying coercion (Hooley, 2004:203). This could make it difficult for the patient to live at home with his family or may cause the patient to relapse more often. The family also finds it difficult to stay with the patient because they feel they cannot get through to him and are therefore unable to help him.

Kuipers *et al.* (2002) argue that the term "high EE" is somewhat misleading. It is often interpreted to mean that it is preferable for family members to suppress all emotions in the presence of the patient. They state that there is strong evidence that the negative emotions of criticism, hostility and over-involvement tend to worsen the outcome for people with schizophrenia and should be avoided if possible. However they suggest that high levels of warmth improve the course of the condition and one of the aims of family work should be to increase the expression of warmth by relatives.

2.3 Social Networks and Support

There is a general belief that social support plays a major role in modifying or mitigating the deleterious effects of stress on health. Of key importance in determining the outcome of a crisis is the absence or availability of social supports in the environment. People depend on others for justification and affirmation; few can survive without the support of some segment of their fellow

humans. How well families do in the face of a severe mental illness may depend to a significant extent on how well their needs for support are met (Hatfield, 1987:191). Estroff *et al.*, (1994) state that social support includes the affective or emotional and instrumental or helping qualities of relationships. They further state that people with major mental illness are characterized as having relationships that are less intimate, reciprocal, symmetrical and durable than those of the general population, due either to the pragmatic contingencies of life as a mentally ill person or to the interpersonal styles associated with their clinical conditions.

Caplan (1974 in Hatfield, 1987:191) defines social support systems as "attachments between individuals and groups of individuals that promote mastery of emotions, offer guidance, provide feedback, validate identity and foster competence". Hatfield (1987:191) argues that people help by sharing tasks; supplying extra resources, such as money, material and tools; and they give practical advice and information. She argues that almost every social relationship has a potential for giving emotional support. There is potential support based on attachment, such as in the family; through shared interests and similarity of circumstances in the community; or through bonds of loyalty or through other kinds of investment in another's well-being.

Kaplan *et al.* (1994:199) describe the term "social network" as referring to a network of persons to whom someone relates, and the term "social support" refers to the mechanism by which interpersonal relationships protect people from the deleterious effects of stress. These authors argue that when someone has a strong support system, the vulnerability to mental illness is low, and the chance of recovery should a disorder develop is high.

They state that research comparing the social networks of psychiatric patients and normal persons has shown that schizophrenic patients have a much smaller

social network than do controls and that neurotic patients have a loose or sparse network. They also argue that similarly a stable support system can ameliorate the effects of physical illness on the person for example, that in obstetrical and asthmatic patients those with low social support have an increased incidence of complications.

The demanding experience of caring for a family member with a severe mental disorder has been extensively described since the 1950's. Constraints of social and leisure activities, neglect of other family members and feelings of sadness and loss are the difficulties most frequently reported by patient's relatives (Magliano *et al.*, 2002:291). These authors also state that research on social support has suggested that in addition to professionals, friends often function as a source of information, support and assistance to families during time of stress.

Raymond *et al.* (in Talbott 1984:309) argue that for many families the diagnosis of a mental illness, particularly schizophrenia, can be as tragic as the announcement of impending death. They likened the stages of reaching emotional adjustment to that of the stages of adjustment to death, a predictable cycle of denial, anger, and mourning. Some families, they note, cope well or even rise to a new level of adjustment while others cannot come to terms and are left with lasting scars. Doll *et al.* also (in Talbott 1984:309) found that families often were in an emotionally untenable and highly demanding situation, which they feared could go on forever. They found that the burden was especially heavy when a single parent was coping alone. In their concluding statements these researchers observed that there are forces that are pervasively, silently, corroding the stability of these families and that by neglecting these forces the whole community- centered mental health treatment experiment may be threatened.

Talbott (1984:316) adds that these cycles of denial, the mourning, anger and anxiety are usually the family's efforts to solve problems that are highly complex and also highly relevant to the family's well being and are taxing to the family's adaptive capacities. He sees these as normal and expected reactions rather than an indication of pathology. He suggests that what these families need is information, problem solving skills, and support; they need the help of someone who will focus on their competencies and coping skills who knows how to deal with tangible problems in a realistic way and who recognizes and respects the family as the expert on its own member.

Riebschleger (1991:1) also supports this view. In her study on siblings of mentally ill patients she found that siblings also experience grief and loss similar to that experienced by families in confronting other traumatic events such as death, disability or serious physical illness. She argues that siblings also move through phases of denial, anger and depression. They have at times also blamed themselves for or felt cheated by the mental illness. She however feels that little attention has been given to siblings of adult chronically mentally ill persons and siblings particularly adults often become care takers of the identified patient.

Torey (1983 in Riebschleger 1991:4) reported that siblings experience a survivor's syndrome in which they blamed themselves for being free of the devastating illness that affected their brother or sister. They blamed themselves for the situation yet simultaneously felt that it was not their fault. They felt drawn to help the ill family member and at the same time were repulsed by their brother or sister's bizarre behaviour and lack of impulse control. They hoped for a cure but feared there was none. They worried about their own sanity but assured themselves that they were sane. Cole and Cole 1987 (also in Riebschleger, 1991:4) argue that the normal ambivalence of sibling rivalry might have been exacerbated when family energy and resources flowed to the mentally ill member of the family.

Although several studies have documented the positive effects of psychological and practical support on the levels of stress the families are exposed to, little is known about the amount and quality of support that families of mentally ill persons receive from professionals and social networks in their every day encounters (Magliano *et al.*, 2002: 291). Talbott (1984:318) argues that a major issue for families is their sense of alienation from providers of services in mental health.

In a study exploring systematically the situation of families of patients with schizophrenia in Italy, Magliano and his colleagues (2002) found that the family burden is significantly related to patient's disability and unemployment. This suggests that rehabilitative interventions such as the patients' vocational skills training may have a positive impact on family burden. In addition, the involvement of patients in daily programs may enable relatives to preserve independent activities and avoid social isolation. These authors also found significant relationships between the family burden and professional and social network support. They also suggested that in addition to psycho-educational family interventions, relatives could benefit from self-help groups. This can provide a setting where they can share experiences and coping strategies with other families (Magliano *et al.*, 2002:297).

Estroff *et al.* (1994:677) in their study on *The Influence of Social networks and Social Support on Violence by Persons With Serious Mental Illness*, found that individuals who listed mental health professionals in their social networks were less likely to be violent.

2.4 Mental Illness and violence

State Patients or patients who come through the forensics system are often perceived as being aggressive or violent. This perception may be true for some

patients and not for others. Estroff *et al* (1994:669) argue that the risk for violence is best assessed by investigating what kinds of people in what kind of situations and social networks, with what qualities of social relations, and at what phase of their lives and illness are likely to engage in dangerous behaviours toward whom.

These authors further argue that persons with persistent psychiatric disorders may be at increased risk of committing violence because of socioeconomic factors and because of how, where, and with whom they live, rather than because of their psychiatric disorders. They state that the combination of having a major mental illness and leaving in meager, stressful circumstances may be much more predictive of the characteristics of social networks, relationships and risk of violence than any clinical factor alone (Estroff *et al.*, 1994:670).

Serper and Bergman (2003:40), state that the impact of caring on the carers of persons experiencing mental illness may be affected by whether the mentally ill person is violent or aggressive. They describe violence as yet another devastating aspect of mental illness that can have an overwhelming impact on the family particularly in these days of limited hospitalizations due to Managed Care, and the reduced availability of special programs for the mentally ill.

Serper and Bergman (2003:40) state that the patient's primary care giver is the family member most likely to be victimized. They state that parents are the most likely victims of younger, schizophrenic patients who live in the family home. This may be a result of the high level of contact that caregivers have with patients, affording more opportunities for attacks as well as attempts by caregivers to place limits on patients, a situation that often seems to precede violent incidents. Estroff *et al.* (1994:670) support this view. They also state that mothers are the most common targets of violence and most of the perpetrators are their sons or spouses.

Serper and Bergman (2003:41) also argue that of all the family members at risk, it seems that single mothers of adult children with mental illness are often the targets of violence. They state that a study of family members who belong to the National Alliance for the Mentally Ill (NAMI) found single parents, especially single female parents, were vulnerable caregivers and more than one third of the single parents feared violence from their mentally ill relatives.

According to Hyde and Forsyth (1991:88) schizophrenia is the most chronic and disabling of the mental illnesses. It afflicts about one percent of the adult population. These authors state that one form of schizophrenia, paranoid schizophrenia, is most frequently associated with violence. Hearing voices that usually consist of derogatory remarks about the patient is characteristic of this form of illness. In other cases the voices give orders that involve acts of violence. For example Hyde and Forsyth (1991:88) write about a patient who heard voices that ordered him to kill people in order to prevent earthquakes in San Francisco. This patient's voices made him believe that committing a murder would protect human beings from earthquakes and in less than a year he had killed thirteen people.

Beels (1981 in Estroff *et al.* 1994) observed that persons with schizophrenia have a deficit of initiative and fail to pursue or maintain relations with individuals other than those with whom they have easy access, such as family members. As a result individuals with severe and persistent mental illness may be more likely to direct violence towards parents and siblings, with whom they may have their most intimate relationships.

Hyde and Forsyth (1991:89) also mention another mental disorder, which is usually associated with violence and aggressive behaviour. They argue that some violent individuals fit the diagnosis of the antisocial personality, a character

disorder characterized by frequent rule violations and aggressive behaviour that begins in childhood or early adolescence. They state that these people are also called psychopaths. Psychopaths are mentally abnormal in the sense that they have no compassion or true feeling for others and since they have no conscience they take what they want without feeling guilt or remorse. Family members are often easy victims for this subgroup as well.

Coid *et al.* (2006:16) in their study "*Violence and psychiatric morbidity in the national household population of Britain: public health implications*", found that persons with antisocial personality disorder and substance dependence were more likely to report involvement in violent incidents. They are also more likely to inflict injuries on their victims, receive injuries themselves and be involved in multiple incidents, thereby increasing the burden of care upon healthcare services. They also reported that antisocial personality disorder (APD) and alcohol dependency also increase the risk of multiple victim types. In contrast, these authors felt that the contribution to violence at the population level from persons screening positive for psychosis was very small, and that the largest public health impact on serious and repetitive violence, was exerted by hazardous drinking.

Joyal *et al.* (2004:433) conducted a study on the characteristics and circumstances of homicidal acts committed by offenders with schizophrenia. They found that even for such extreme acts as homicides, the circumstances affecting the occurrence of violence among offenders with schizophrenia may differ when an additional antisocial personality disorder diagnosis is present, which would have important implications for prevention and treatment programs. They argue that although most violence in the community is not attributable to schizophrenia and the vast majority of individuals with schizophrenia do not pose a risk of violence, the odd ratio for homicide are remarkably elevated among subgroups of patients with schizophrenia.

Also in this study by (Joyal *et al.*, 2004:433) a significant majority of homicides were considered as a consequence of psychotic symptoms; they mostly involved someone who knew the offender; and they usually occurred in a private residence. However the subgroup of offenders with both schizophrenia and antisocial personality disorder (APD) were less likely to be judged as responding to psychotic symptoms; they assaulted a non – relative more frequently, and they were more likely to have used alcohol and to be involved in an altercation with the victim prior to the incident than offenders without an antisocial personality disorder.

Joyal *et al.* (2004:438) argue that APD is intimately associated with several risk factors for violence (e.g. substance abuse, low educational levels, behavioural impulsivity, poor familial and socio-economic background), so that origins of violence committed by persons with APD is multidimensional, based on intricate factors that are difficult to untangle. Determining the effect of each related factor on aggressive behaviour among persons with a personality disorder is very difficult, all the more so when a severe mental illness is present. These authors felt that although their findings did not allow for evaluation of the relative impact of these antisocial factors, they suggested that for a significant portion of offenders with schizophrenia, violence is not necessarily the consequence of psychotic symptoms, and might occur in closer association with circumstantial factors traditionally observed among persons with a personality disorder.

The idea that some individuals with serious mental illness may become violent was prevalent throughout the nineteenth century (Torrey, 1994:653). Torrey states that stereotypes have been created around mental illness. In movies for instance, the stereotype of the mentally ill individual as a homicidal maniac can be found as early as "The Maniac Cook" in 1909. He further states that a 1987 study of the residents of Ohio revealed that perceived dangerousness was the

single most important factor contributing to the stigma of mental illness. Torrey (1994) conducted a study in which the perceived association between violent behavior and serious mental illness was explored to determine the validity of claims by mental health advocates that individuals with serious mental illness are no more dangerous than members of the general population.

He found that although the vast majority of individuals with serious mental illness are not more dangerous than members of the general population, recent findings suggest the existence of a subgroup that is more dangerous. A history of violent behavior, noncompliance with medications and substance abuse are important predictors of violent behavior in this subgroup. Torrey (1994:656) mentions a study of families, in which a family member had serious mental illness conducted in 1990 by the National Alliance for the Mentally Ill. The researchers reported that within the preceding year 10.6 percent of the individuals with a serious mental illness had physically harmed another person and 12.2 percent had threatened to harm another person. Most of the persons threatening harm were males. More than one third of the families reported that their ill relative was assaultive and destructive in the home. The results of these surveys are also consistent with anecdotal reports of violence against family members.

Swartz *et al.* (1998:226) argue that there is a link between substance abuse, medication noncompliance and violent behaviour. They cite a number of studies that show this link. Swanson and colleagues (in Swartz *et al.*, 1998:227) suggest that substance abuse, psychotic symptoms, and lack of contact with specialty mental health services in the community all are associated with greater risk of adult-lifetime violence among persons with severe mental illness.

In a state forensic hospital population, Smith found a significant relationship between medication noncompliance and violent acts in the community. Similarly,

Bartels and colleagues 1991(in Swarts *et al.*, 1998:227) reported a relationship between noncompliance, hostility, and violence in a group of 133 outpatients with schizophrenia. Consistent with the findings of Bartels *et al.* a new analysis from the same study (in Swarts *et al.*, 1998) shows that both violent behaviour and the combination of substance use with medication noncompliance are significant statistical predictors of police encounters for people with severe mental illness. Swarts *et al.* (1998:227) also mention a third variable, poor insight into illness. They argue that poor insight into illness may lead to both substance abuse and noncompliance and therefore increase the risk of violence, institutional recidivism and increased burden on care givers.

Hodgins (1993) argues that in recent years much evidence has suggested that major mental disorder and violence are associated. She claims that even such an eminent scholar as John Monahan, who previously argued against such a relation, has now concluded that "there is a relationship between mental disorder and violent behaviour, one that can not be fobbed as chance or explained away as third factors that cause them both" (Hodgins, 1993:ix). She goes on to argue that people have always feared the violence of the mentally disordered but the scientific community was not convinced that mental disorder increased the risk of violence. Pamela Taylor (in Hodgins, 1993) reported on a study of violent offenders referred for psychiatric evaluation. She concluded that the violent behaviour of schizophrenic men is a direct consequence of their illness and thus always occurs during acute episodes.

Hodgins (1993) claims that reporting on the relationship between violence and mental disorder can be discomfoting for it could contribute to reinforcing the stigma of mental illness and the community's fear and rejection of the mentally disordered. She says that families of mentally disordered persons, while often victims of their aggressive behaviour, fail to report acts of violence. Shame and guilt inhibit them from mentioning these behaviours to mental health

professionals and also from taking appropriate measures to protect themselves. In some instances this lack of action has had tragic consequences.

Hyde and Forsyth (1991) state that the great majority of people who have brain damage and who suffer from mental illness are not violent. They argue that when a mentally ill person commits a violent crime, sensational media coverage leads many readers to overestimate the connection between mental illness and violence and as a result all mentally ill people continue to be stigmatized.

There seems to be no consensus in terms of the relationship between violence and mental illness. For Estroff *et al.* (1994:678) the most significant finding of their study was the association between mother and adult child co-residence and violence. For these authors this association suggests that the parental activity of the mother along with her degree of proximity to her mentally ill son or daughter, involvement in that person's daily living, and vulnerability, creates the opportunity for violence. They state that fathers, even if co-resident with their mentally ill adult children are rarely reported to be attacked or threatened. Their findings therefore suggest that risk for violence by persons with psychiatric disorders encompasses elements of vulnerability, opportunity, mutual threat and dependency within their social networks.

2. 5 Mental Illness and Substance Abuse

Brink *et al.* (2003:7) state that a number of studies suggest a high prevalence of substance abuse in patients with psychotic disorders. They argue that in fact substance abuse by patients with schizophrenia seems to be the rule rather than the exception. Baker *et al.* (2002:233) argue that alcohol and other drug use among people with mental illnesses is a major public health problem. Co-morbidity of substance misuse and mental disorders is common and often associated with severe illness, failure to access treatment or inadequate treatment delivery.

Wheatley (1998:14) cited in Prins (1999:47), studied a sample of schizophrenic patients in an independent health sector medium secure unit, detained under the Mental Health Act. His results confirmed a degree of co-morbidity of substance abuse and schizophrenia in detained and forensic patients. Alcohol and cannabis featured prominently.

Laugharne *et al.* (2002:241) also report that substance misuse is a significant problem for the severely mentally ill. They argue that in the UK, over one third of patients with a psychotic illness have drug or alcohol problems, alcohol and cannabis being the most frequently used substances. According to these authors, this co-morbidity can lead to worse treatment outcomes with poor compliance and psychosocial functioning, and increased psychotic symptoms and aggression.

Brink *et al.* (2003:8) argue that in South Africa and particularly the Western Cape, drug and alcohol abuse is an ever-increasing problem. They state that in a South African Demographic and Health Survey, 27.9% of all males aged over fifteen years in the Western Cape reported alcohol dependence. In the Bridges high school survey of five schools in the Cape Metropole (January – June 2000), 43% of all students indicated that they engaged in binge drinking and 23% of the students reported having tried cannabis at least once (Brink *et al.*, 2003:8). These authors also mentioned that little is known about the prevalence of drug abuse in the general population, as most studies are conducted on specialized sample groups. According to Brink *et al.* (2003:8), studies in the USA have reported high rates of substance abuse among young patients with schizophrenia.

Owen *et al.* (1996:856) in their study "Medication noncompliance and substance abuse among patients with schizophrenia" found that persons with schizophrenia who use drugs or alcohol regularly are less compliant with their medication

regimen. Although they could not specify the actual relationship between the two they stated that individuals with co-morbid schizophrenia and substance abuse have been reported to stop taking medications because they have been told not to combine their medication with substances of abuse, or substance intoxication may cause patients to neglect taking their medication. They also thought that substance abusers may also experience increased side effects that could contribute to medication noncompliance.

Families are typically a major source of support for people with mental illness, but substance abuse places an additional burden on family relations and could reduce the amount of support they give (Clarke and Drake, 1994:145). These authors conducted a study on the expenditures of time and money by families of people with severe mental illness and substance abuse disorders, they found that families give a substantial amount of time and money to their relatives with dual disorders.

Various authors in Clarke and Drake (1994) argue that people with co-existing severe mental illness and substance use disorders present a variety of problems to treatment providers and to their families. They are often disruptive and aggressive, they frequently engage in criminal behaviour, they are at greater risk of HIV infection, they have high rates of institutionalization in jails and hospitals, they manage the practical aspects of their lives poorly and they usually make up a significant proportion of the homeless population.

When one examines these characteristics it is not surprising that mentally ill people with a substance abuse problem have strained relationships with their families. Also when relationships are difficult, families might be less inclined to help and this could contribute to the high rates of homelessness and family rejection.

Anderson *et al.* (in Clarke and Drake, 1994) argue that substance abusers are more prone to behavioural problems and because of this, families may spend a substantial amount of time addressing the consequences of criminal behaviour, physical and verbal outbursts and similar problems. They continue by stating that frequent or intense contact can be helpful in the short term, but stressful interactions may have negative long-term consequences for families and their relatives with dual disorders.

Besides the high emotional costs, caring for a mentally ill relative who is also abusing substances can present a significant practical burden to families. Economic support from families may be especially important because people with severe mental disorders and substance abuse are rarely able to support themselves fully by working. Much of the money they get from work entitlements or other sources is likely to be spent on alcohol or drugs, thereby contributing to the housing instability, poor nutrition and economic distress they so often experience (Clarke and Drake, 1994:147).

2.6 Conclusion

This chapter examined the difficulties and challenges that families face in caring for their mentally ill relatives. It traces the family's responsibility from the time of deinstitutionalisation, when the families started taking more of the caring responsibility. The chapter also discussed the burden that families face in caring for mentally ill relatives, concentrating on the objective and subjective difficulties in caring for their mentally ill relatives. The relationship between expressed emotion and the burden of care was also presented.

The literature review highlighted the importance of social networks and support for both the patient and the family members. The literature then shows how these networks are affected by the patient's substance abuse, which is often associated with aggression and violence. There is also mention of the patient's

non-compliance with their medication, followed by relapse, which often makes family members angry with the patient and often rejecting him. The family's rejection often leads to homelessness or institutionalization.

This chapter also looked at the role played by aggression, violence and antisocial behaviour in the patient's rejection by their families.

It would have been helpful to see what other writers had to say about the relationship between mentally ill persons, who were also accused of committing a crime, and their families but it seems that this is an area that has been neglected by researchers.

The next chapter (Chapter Three) will present the research design and methodology.

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CHAPTER 3

3. RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

This chapter will look at the research design and the methodology. It will also give a brief discussion of sampling and the sampling procedure, the data collection method, limitations of the study and the data analysis method.

3.2 Research Design

The study will follow qualitative research methods. Qualitative research is as described by Flick *et al.* (2004:3) "a description of life worlds from the inside out, from the point of view of the people who participate. By so doing it seeks to contribute to a better understanding of social realities and to draw attention to processes, meaning patterns and structural features." These authors further argue that in its approach to the phenomena under investigation, qualitative research is frequently more open and thereby more involved than other research strategies that work with large quantities and strictly standardized, and therefore more objective and normative concepts. The qualitative research method was selected for this study as it required a research strategy that can deliver in the first instance precise and substantial descriptions and also take account of the views of those involved, and the subjective and social constructs of their world.

The nature of the study is descriptive. A descriptive study provides an accurate and precise picture of what has been observed, it also tells us what exists or what occurs (Collins, 1999:46).

3.3 SAMPLING

3.3.1 Population

Seaberg (in De Vos, 2001) defines a population as the total set from which the individuals or units of the study are chosen. In this study therefore the population was thirty patients, in the forensic unit at Valkenberg Hospital who in May 2005 were identified as well enough to go out on long leave but their families and relatives were not willing to take them out. The researcher went through the files of patients in the forensic unit at Valkenberg hospital to find out who were the patients who have not been out on leave for a period of one year and more. This was made easy by the fact that the researcher also worked in the unit so she had an idea of who these patients were.

3.3.2 The Sample and Sampling Procedure

Arkavan and Lane (in De Vos, 2001) describe a sample as the element of the population considered for actual inclusion in the study. Seaberg describes a sample as a small portion of the total set of objects, events or persons which together comprise the subject of our study (De Vos, 2001:191).

The sample comprised relatives of ten patients who were selected from the population as described above. Initially the selection was done using random sampling methods. Kerliner (in De Vos, 2001:193) states that random sampling is that method of drawing a portion or sample of a population so that each member of the population has an equal chance of being selected. There were however problems with this sample as the researcher then could not locate two of the patients' family members. One of the patients in this sample subsequently died and two of the families refused to be interviewed.

Purposive sampling method was then used to select the rest of the sample. Collins (1999) describes purposive sampling as the procedure which involves researchers using their own knowledge and experience to select the most

suitable respondents of the study. The researcher therefore used her own knowledge of the patients to select other suitable patients whose families were also available and willing to be interviewed. Out of the ten family members who were interviewed only five were selected randomly and the other five was selected using purposive sampling method.

Purposive sampling method was also used to select the seven patients who were interviewed. The reason for using purposive sampling was because the interviews were dependent on the patient's mental state at the time of the interview. For this reason therefore the sample did not comprise of only the patients whose relatives were interviewed. Five patients were from the families that were interviewed and the other two patients' families were not in the relatives' sample.

3.4 Data Collection Method

The method of data collection used was in-depth face-to-face interviews. Even though the initial plan was to interview the relatives outside Cape Town telephonically, the researcher was able to interview all the respondents face-to-face. The relatives were selected according to who was listed as the as the primary caregiver in the hospital file and in cases where the primary caregiver (e.g. the mother) was deceased the closest living relative was interviewed (e.g. the patient's sister).

The interviews used a semi structured interview schedule with open ended and closed questions. (see Appendix I) The face-to face interviews were also helpful in that the researcher could pick up on non-verbal cues as well. The relatives interviewed were from different social backgrounds and from different areas within the Western Cape. They were from George, Worcester, Khayelitsha, Muizenberg, Table View, Langa, Gugulethu, Parow and Kraaifontein.

A naturalist setting was allowed as much as possible. Most of the interviews took place at the respondents' homes, two were done at the respondent's place of work and one respondent came to the researcher's place of work. It was also quite helpful to see the respondents in their homes as they were more relaxed and the researcher could get different views from different family members and could also get an impression of the family dynamics. The respondents were also from different language groups. They spoke Afrikaans, Xhosa and English. The researcher was fortunate in the sense that the Afrikaans speaking respondents were able to express themselves in English and sometimes mixed the two languages and the researcher was able to understand even though she had a limited grasp of the Afrikaans language. The other languages were not a problem as the researcher is fluent in both languages.

An interview schedule was used so that the focus of the research would be maintained and to make sure that all intended question areas were covered. Some of the questions were closely related and linked so it was easy for the respondents to give a response to two questions while answering the one question. The researcher quickly picked up on this and explained it to the respondents so that they would not become irritated when they felt that they were repeating themselves.

The interviews were conducted between June and October 2005. The researcher had to phone the respondents to make appointments and arrange a meeting place for the interviews. There were only two respondents who could not be contacted telephonically, and for those respondents the researcher had to just go to their homes. One of the respondents was at home and was willing to do the interview. The other respondent was not at her home, the researcher with the help of the neighbours managed to trace her to a home of a traditional healer where she was visiting for her other personal difficulties. She however agreed to

come the next day to the researcher's work place, which she did and was refunded her transport money.

The interviews were recorded through the use of a cell-phone voice recorder and the respondents gave permission for the recording of the interviews. The only problem with this was that the researcher could not record more than one interview, so she had to immediately transcribe the interview before the next interview could be recorded. This also had its advantages in that the interviews were transcribed immediately while they were still fresh on the researcher's mind as well. Only two of the interviews were not recorded because the one respondent did not seem comfortable with the recording. In the other case the researcher had done two interviews in one day and by the time she got to the second interview she had not had time to transcribe the first interview. Both respondents however allowed the researcher to write down their responses.

Seven patients were also interviewed in May 2006. A list of questions was compiled so as to guide the interviewer (see appendix II). The interviews took place at the hospital and all five patients participated willingly.

3.5 Data Analysis

Data analysis was done according to the Marshall and Rossman approach (De Vos, 1998:342). This approach states that qualitative data analysis is done in search of general statements about relationships between categories of data.

They identified five stages in data analysis:

- Organising the data
- Generating categories
- Searching for alternative explanations of the data
- Writing the report

3.5.1 Organizing the data

The data were transcribed from the audio recorder to the word processor. The researcher then spent time reading through the data so as to familiarize herself with the information. Marshall and Rossman (1995:113) state that "reading, reading and reading once more through the data forces the researcher to become familiar with those data in intimate ways. People events and quotes sift constantly through the researcher's mind." During this reading process the information was then organized into different categories according to the questions in the interview schedule.

3.5.2 Generating Themes, Categories, and Patterns

According to Marshall and Rossman (1995:114) "the process of category generating involves noting regularities in the setting or people chosen for the study. As categories of meaning emerge, the researcher searches for those that have internal convergence and external divergence." During this stage the researcher was also seeking to identify the salient, grounded categories of meaning held by the respondents in the study. The data were then studied over and over in the categories to find common themes.

3.5.3 Searching for Alternative Explanations

During this stage the researcher engages in the critical act of challenging the very pattern that seems so apparent. The researcher must search for other plausible explanations for these data and the linkages among them (Marshall and Rossman, 1995:116). The researcher therefore also looked for other explanations for the data obtained from the interviews with the relatives and the patients.

3.6 Limitations of the Study

This study seeks to explore the factors causing the rejection of state patients by their relatives. This is a sensitive issue which relatives may not be willing to discuss openly. It took some time and convincing for some of the relatives to agree to take part in the study. Relatives thought that this was a subtle way of coercing them into taking back the patients. Also it was difficult to convince the people over the phone. As a result with some respondents, even though the purpose of the interview was explained to them telephonically, when the appointment was made they still needed more explanation and assurance that this did not mean that the patient was coming home.

The other limitation was the fact that the researcher was known to the relatives as the social worker in the unit. Some relatives were not interested in taking part in the study as they saw this as a way of trying to get them involved in the patient's life. They were vehement and even rude in expressing their refusal.

Due to the limited scope of a mini thesis the sample was of necessity small and therefore restricts the generalization of findings. Another limitation was the lack of background information due to the paucity of literature relating to the subject of State Patients. It was even more difficult to find South African literature on this subject.

3.7 Conclusion

This chapter described the research design and methodology. It started with an introduction to the research design. Sampling and sampling methods were then described. Also included in this chapter is the data collection method, a brief description of how the data was analyzed and the limitations to the study.

The next chapter will present the results and a discussion. The results will be presented and then discussed linking them to literature.

CHAPTER 4

4. RESULTS AND DISCUSSION

4.1 INTRODUCTION

In this chapter the findings of the study are presented and discussed according to categories and themes as identified. Firstly the findings from the interviews with the relatives will be discussed followed by the findings of the interviews with the patients themselves.

The questions from the interview schedule used for the relatives' interviews were grouped into categories from which themes were then extracted. This process was also guided by the respondents' responses to the questions. The first part of the interview schedule which was used for the relatives contains patient's biographical information. This information is shown in Table Two below.

There were also questions about demographics and family circumstances, the patient's behaviour at home, the patient's contribution to the family whether the patient abused substances and whether the patient was aggressive and/ or violent. The last part looked at the family's feelings and attitude towards the patient and the family's support systems.

A separate interview schedule was designed for the interviews with the patients themselves and the patients were also asked about demographics and family circumstances. They were also asked about their own understanding of their illness and whether they get visitors or not. They were asked about their feelings towards their families and how their long stay in hospital without any leave has affected them.

The results regarding the main factors that contribute to the rejection of State Patients by their families will be presented according to the following categories, from which the main themes of the interviews emerged. This information is presented in Table One below. The findings according to each category will be presented and then they will be discussed and compared with relevant literature and earlier research.

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Table 1: Themes and Categories generated from the findings

Themes	Categories
1. Demographics and family circumstances	<ul style="list-style-type: none"> • Poor living conditions • Unemployment • Small dwellings in some cases shacks • Those who were employed and had own homes were not willing to accommodate the patient
2. patient's behaviour at home	<ul style="list-style-type: none"> • Did not assist with house hold chores and expected relatives to do things for them • Poor self care and lack of cooperation • Aggression • Difficult and non-cooperative when relapsing
3. Patient's contribution to the family	<ul style="list-style-type: none"> • Disability grant sometimes benefited the family but often did not • Disability grant being used for alcohol and drugs • Patients offered companionship
4. substance abuse	<ul style="list-style-type: none"> • Most patients abused substances especially dagga • Substances main reason for family's lack of interest in the patient

	<ul style="list-style-type: none"> • Relationship between the use of substances, relapse and aggression • concern for the patient and the relatives' safety
5. Aggression and violence	<ul style="list-style-type: none"> • Relatives had to watch their back at all times when the patient is at home • Fear • Relationship between the aggression and substance abuse • Uncertainty about what the patient will do or when he is going to do it.
6. Relative's attitude towards the patient	<ul style="list-style-type: none"> • Lack of understanding of the patient's illness • Unpredictability of the patient's behaviour
7. Relatives' feelings towards the patient regarding the offence	<ul style="list-style-type: none"> • Lots of ambivalence, we still love him but we want nothing to do with him.
8. Family's support systems	<ul style="list-style-type: none"> • Lack of support from relatives and friends. • Mixed feelings regarding the hospital.

4.2 Demographics and family circumstances

The patient's biographical and psychiatric information is presented in Table Two below:

Table 2: Biographic and psychiatric information

(All the patients involved in the study were males and relatives were selected according to who was listed as the primary care-giver in the hospital file, and in cases where the primary care-giver (e.g. the mother) was deceased the closest living relative was interviewed (e.g. the patient's sister).

Respondent	Relationship to patient	Age of patient	Marital status of patient	Original charge	Diagnoses	Language
1	sister	43	single	murder	schizophrenia	afrikaans
2	sister	33	single	robbery	schizophrenia	xhosa
3	aunt	36	single	murder	schizophrenia	xhosa
4	mother	36	single	murder	schizophrenia	afrikaans
5	sister	49	divorced	murder	Bipolar mood disorder	english
6	brother	43	single	murder	schizophrenia	xhosa
7	mother	32	single	rape	schizophrenia	xhosa
8	mother	35	single	assault	schizophrenia	afrikaans
9	mother	37	single	Indecent assault	schizophrenia	xhosa
10	mother	36	single	murder	schizophrenia	xhosa

The respondents came from different social backgrounds. Some had very poor social circumstances and struggled financially while others worked and could afford a minimum standard of living. Only two of the five mothers who were interviewed owned a house and even these were shacks. The others either lived with relatives or with friends who were not willing to accommodate the patient. Most of the mothers were also elderly and sickly and depended on the state Old Age Pension. One of the mothers had no income whatsoever and depended on handouts from friends or sometimes she managed to get piece jobs in different places.

The other respondents were the patient's siblings and there was also one aunt. The siblings had better social circumstances than the mothers. Only one sister was unemployed but she was able to get temporary jobs at times and had a house, which their mother left for them when she died. The other two sisters were in permanent employment and lived comfortably with their families. One of the respondents was a brother who lived in the family home by himself and ran a business from home. The last respondent, who is the patient's aunt, owns a house, is in permanent employment and lives comfortably with her children.

4.3 Patient's Behaviour at home

Six of the respondents reported that the patients' behaviour at home was not always acceptable. They did not assist with house chores and expected other people to do things for them. One of the respondents, who is the patient's sister, said *"My mother spoiled him, she used to do everything for him and now he expects this from other people. I can not do that I've got my own family and children to look after I can't always be picking up after him as well."* Another sister said, *"He was like another child I had to do everything for him. I did not want to give him anything to do because I did not want to feel indebted to him. I also did not have much trust in his work or in doing anything."*

These six respondents also reported poor self-care in the patients. The patients needed to be reminded to wash themselves and change into clean clothes. Getting the patients to co-operate with anything seemed to be a big struggle for these respondents. *One sister said "we stopped asking him to help at home because he became aggressive when we did so and he has even hit my mother because of she had asked him to wash."* Another respondent said *"we struggled to get him to take his medication, he would even lie and tell us that his treatment has been stopped or make up stories about the whereabouts of his tablets."*

The other four respondents said that the patients' behaviour was fine when the patients were not sick. They behaved well at home and were very helpful with house chores and their own self-care. Two of the respondents said that the patients used to help them a lot. Before they were diagnosed with schizophrenia the patients used to work and supported their families financially. The other two respondents said that they only struggled when the patients were experiencing a relapse. The patients became difficult and non-cooperative, and needed to be watched at all times and also refused to take their medication.

These findings are in line with Chang and Horrock (2006) s' findings. They found that the families of mentally ill patients experienced exponential increase in the intensity of stress, anger and dissatisfaction when their relatives were unstable and they needed to take full control of the day to day activities. This is also consistent with the findings of Hatfield (1987) who found that family caregivers and their families suffered increased stress in caring for the activities of daily living of their mentally ill relatives. This finding also concurred with that of Chelsa, Schultz and Andreasen, who also discovered that family caregivers frequently needed to help their mentally ill relatives to engage and interact meaningfully with people and the environment.

4.4 Patient's Contribution to the Family

Most of the respondents said that the patient had received a Disability Grant or had been employed at some stage. Only two respondents said that the patient's income contributed towards the family. Both respondents reported that the patients received a Disability Grant and the money helped the family to survive as no one else in the family was employed at the time. One of these two respondents also mentioned that her son used to work before the onset of his illness and he used to support the family. She also expressed feelings of loss in that when her son became ill she lost a person who was providing for her. The patient then received a Disability Grant but that too did not last long as it became difficult for her to manage the patient at home and the Disability Grant had to be cancelled when the patient was no longer going out on Leave of Absence.

The other eight respondents reported that although the patients had had an income at some stage, while they were out on LOA this was never used for the benefit of the family. The patients used the money for their own selfish needs and did not want their caregivers to get involved. In most cases the money was used to support the patients' drugging habits and the patients would become

aggressive if the family members wanted to know what they did with their money. One respondent said, *"When it is disability time he won't stop nagging until he sees my mother does not have money."* What came up as being most difficult for these families was that after the patients had spent all their own money on dagga and other things they would come home and demand food from them. Sometimes they would even demand more money from their caregivers so that they could get more drugs.

One respondent said *"He would go and spend all his disability grant money with his friends and his brother and he would come back and demand it from me. He once came to my house looking for his money but we were not home. The neighbours told us that they have never seen him like that, he looked like he was going to kill someone it was just by God's grace that we were not at home. With somebody like him you can never know what he is going to do."*

One of the respondents said that the patient would use all his disability grant on dagga and once the money was finished he would come and demand food from her. The patient has even broken into the respondent's house and stolen her food while she was out. Most of the respondents felt that the patients have done nothing for their families except to bring them heartache and misery. One respondent said *"I don't think he knows what meaningful family relationships are about, for him it's about what he can get out of you it's a self centeredness."*

This was one of the difficult areas for the relatives. Some of them showed some ambivalence in terms of the patient's contribution. Some of the mothers for instance felt that in a way the patients offered some form of companionship. One mother said that even when her son was out during the day knowing that he was out there in the community and was coming home in the evening gave her something to look forward to. But for these mothers as well this was only the case when the patient is well.

This is consistent with what is described by Chaffey and Fossey (2004:200) in their reference to subjective burden. They refer to the perceived stress, distress and emotional costs of caring and state that these include feelings of being overloaded, powerless and entrapped by the demands of care giving and a chronic sense of loss for previous familial relationships and aspirations for a loved one. Families experience a deep sense of loss when a relative becomes mentally ill. Also in some cases the roles that the family members used to play are now suddenly reversed by the illness. A son who was the breadwinner is now suddenly dependent on the unemployed mother both emotionally and financially.

Kuipers *et al.* (2002:72) also support these findings. They state that grief and loss are common emotions families experience with long-term mental illness such as schizophrenia. They argue that there are two types of loss: loss of the person the families used to know and loss of the hopes and aspirations they had for the person, and further state that it is the nature of the illness that negative symptoms, such as lack of motivation, apathy and social withdrawal, often persist long after the acute phases of the illness have subsided. That is why household responsibilities and employment are all too often affected.

Caring for a mentally ill relative becomes costly for the family. Findings in this study suggest that even though the patients had an income in the form of a disability grant they were not willing to use this money to contribute towards the family's expenses which made things difficult especially for the unemployed caregivers. Clark (1994) found that parents of adult children with a mental illness gave significantly more money and time to their adult children than did parents of adult children with no mental illness. He argues that this is an area that is not always seen as a problem but should actually be considered carefully in treatment planning as relatives usually spend time, which they could spend earning money, looking after their mentally ill relatives. He states that time spent

helping a relative is not always thought of as economic assistance because it is not a cash transaction.

Clarke and Drake (1994) also stress the economic burden on the families. They state that it may be important for the families to support their relative because people with severe mental disorders who also abuse substances are rarely able to support themselves fully by working as a large part of the money they get from work or other sources is likely to be spent on alcohol or drugs, thereby contributing to the housing instability, poor nutrition and economic distress they so often experience. Chang and Horrocks' study (2006) also revealed that constant, basic provision of food, shelter, medications and management was invariably required by all the mentally ill relatives regardless of the severity of their illness.

4.5 Substance Abuse

Two respondents reported that the patient did not use substances at all. One patient has never tried but the other patient according to his relative apparently smoked dagga once when he was a teenager but it made him scared so he never smoked again. The other eight respondents reported their relatives as being chronic substance abusers. They used different kinds of drugs and alcohol but the most common one to all the patients and the most problematic, according to the respondents, was dagga. The respondents said that the dagga made the patients' illness worse. One respondent said *"I could see when he was drugged that he was getting sick, he knew he should not use drugs but I do not know why he did it he used to fight with my mother over money and one day he bit my mother's finger because he wanted her ring so he can go and sell it for drugs."*

Substance abuse seemed to be a big problem for most of the respondents and for some it was the main contributing factor to the family's lack of interest in the

patient. The patients used different substances but the most used were dagga and alcohol. Most of the relatives even verbalized that living with the patient was out of question as long as he was still abusing substances. One respondent who is also a patient's mother said *"he terrorized the whole family, he was always carrying weapons, we even put away all the sharp objects in the house but he would bring them from outside. He used to spend the whole day with the Rastas and he smoked dagga everyday."* The relatives felt that it was better for them to know that the patient was sick because then they can take him to hospital and he would get treatment there but they did not know what to do with the substance abuse.

Three respondents also mentioned that their relatives were also not taking their medication and instead took other illicit drugs. These respondents felt that the noncompliance with medication and the use of drugs was the cause of the patients' relapse and this was a problem for them as relapse brought about a lot of difficulties for them, including aggression from the patient. This is consistent with the findings of Owen *et al.* (1996) that substance abuse is strongly associated with medication noncompliance. They report that persons with schizophrenia who use drugs or alcohol regularly are less compliant with their prescribed medication regimen.

Another respondent said that the patient used to smoke dagga every day and would come home after smoking and make demands to the family. He would hit them if they did not comply and this included his mother. Another respondent said that the patient's drug abuse comes from far back *"it dominated our lives when we were growing up, he would get himself into all sorts of trouble like drunken driving and we had to run to his rescue."*

Another respondent said that the dagga made the patient aggressive. He used to get involved in fights after smoking dagga and when he becomes like this it was

difficult for the family to control him. Also because he used to be a big man people were scared of him so no one would come near him when he becomes aggressive. Most of the relatives felt that the substance abuse was the most difficult aspect of the patient's behaviour and they did not know how to deal with it.

It also seems that the patients got themselves into all sorts of trouble when they were intoxicated and did not seem to care about their caregivers' feelings. One respondent said that she thinks her relative smoked every day. She used to worry about him because when he is intoxicated he would be in such a bad state that he would not even know how he got home. Also the dagga gave him a big appetite and he would come home and eat whatever is in front of him irrespective of who it belonged to and this used to get him into trouble with his siblings. He also became aggressive and violent when he had been smoking. Another problem that was common to most of the relatives was that the patients would steal their valuables and sell them for dagga.

There is one respondent who said that she did not always find the dagga smoking problematic. She said that the patient used to look sick and miserable when he had not smoked that she would give him money to buy one "stop" of dagga per day. She said this would cheer the patient up and would take him out of his misery and make him more pleasant and sociable. She said that the problem was when the patient goes out and smokes with his friends that he would smoke a lot and would then become aggressive and would be sick as well. The respondent's children and the neighbours used to be scared of him when he is like this.

These findings suggest that the abuse of substances, particularly cannabis and alcohol is endemic among the State Patients. This is consistent with the findings of various authors (Durand *et al.*, 2006, Laughane *et al.*, 2002) who also found

that cannabis and alcohol were considered to pose the greatest problem. Also similar to what was reported by the respondents is the findings by various researchers (in Clarke and Drake, 1994) who argue that people with co-existing severe mental illness and substance use disorders present a variety of problems both to treatment providers and their families. They are often disruptive and aggressive, they have high rates of institutionalization in jails and hospitals, they manage the practical aspects of their lives poorly and they usually make up a significant proportion of the homeless population.

Kuipers *et al.* (2002) assert that alcohol is a common problem among people with schizophrenia. They state that people with schizophrenia like visiting pubs, where they can be in an environment that provides some sort of social stimulation, without being under pressure to behave in a certain manner. They further more state that, visiting pubs is part of the culture of certain sections of the population in Britain and therefore patients may not feel part of their community if they were to abstain completely to alcohol. This could very well apply to these patients as well as sitting in shebeens or taverns and drinking has become part of the culture in South African Townships.

These authors actually suggest that maybe we need to educate patients about alcohol intake and safe amounts, rather than preaching abstinence. Families should also be helped to see the potential problems relating to alcohol intake and yet not lose sight of the opportunities to socialize with limited alcohol intake. (Kuipers *et al.* 2002).

These characteristics were mentioned by most of the respondents as problematic and also seemed to be the main causes for the rejection. Family members who were themselves struggling financially found it difficult to live with their substance abusing relatives as this had negative financial implications on them as well. Furthermore the respondents were unhappy that the patients often stole

their valuables to sell them to get money to support their drug habits. The substance abuse also caused an immense amount of emotional burden on the families. Consistent with this is Clarke and Drake (1994) 's argument that the extent of a patient's behavioural problems affect the family's decision to house him or her and that people with more severe psychiatric or substance abuse problems might be less likely to live with family and as a consequence, receive less assistance.

4.6 Aggression and Violence

One of the respondents described her relative as being very aggressive at all times. She said that he used to get cross and become violent even if they ask him to wash himself or help around the house. The other eight respondents described their relatives as not being aggressive generally, but would become aggressive when they are not well or after they have used substances. One respondent said that her relative was not aggressive at all.

The respondents gave different descriptions of their relatives' aggression. Some respondents said that they had to watch their backs at all times when the patient was at home because *"you can never know what he is going to do"*. Another respondent said that *"my brother is not an aggressive person but after smoking dagga he would start fights with every body, he used to be a very strong person and no one would touch him when he is like that"*.

Another respondent who is a mother said that her son is not generally aggressive but he has at times, when he is becoming ill or has smoked too much dagga, acted very strangely and has made her scared. He has also assaulted her before and chased her with a knife. This respondent said *"I am scared of him when he is ill, sometimes I run away and do not sleep at home."* Another respondent said that she used to hide away all the knives and sharp objects when the patient was at home. Various authors (Modestin and Ammann, 1985

and Wallace *et al.* 1998, in Prins, 1999) also stated that alcoholism, drug abuse and personality disorders contribute significantly to criminal behaviour of mentally ill persons.

This is consistent with the findings of Estroff *et al.* (1994). They found that more than half of the targets of violence from their respondents were the patient's relatives, especially mothers living with the patient and this made them think that perhaps the parental activity of the mother, along with her degree of proximity to her seriously mentally ill child, involvement in that person's daily living, and vulnerability, creates the opportunity for violence.

Some of the respondents felt that the aggression was related to the illness. They also said that the patient did not communicate when he was sick and this made it difficult for them to know how he was feeling and what he would then do. These respondents mentioned that the patient was very unpredictable and his aggressive outbursts always came as a surprise. One respondent, a patient's sister said *"we are always worried about when he is going to be ill, what is he going to do when he gets ill. He's put us through hell and we've been so scared and have had sleepless nights"*.

Some of the relatives attributed the violence to the substance abuse. One respondent said that the patient would become so aggressive and violent when he had been smoking that her children were scared of him.

These findings are consistent with those of Swartz *et al.* (1998:230). These authors found that greater risk for violence was associated with the combination of substance problems, medication noncompliance, and low levels of insight into illness.

4.7 Relative's Attitude Towards the Patient

The respondents were asked about their knowledge and understanding of their relative's illness. Four of the respondents did not know when the patient was first diagnosed with mental illness and they also did not know the type of illness that their relative suffered from. Five respondents knew when their relative was first diagnosed with mental illness but they did not know the type of illness that their relative suffered from. These respondents said that they were never told the name of the illness. They also did not bother to ask, all they know is that the patient suffers from a mental illness.

Only one respondent knew exactly when the relative was diagnosed and what his diagnosis is. The doctors at the hospital told the respondent about her relative's condition. She also did her own research and read about the condition. Her own words were *"To me it was incredible relief that I could give what was happening to him a name. For a while there was no understanding from us family that there were psychiatric issues, we saw somebody who is dependent and always made sure that he is dependent."*

All the respondents, even those who did not know much about the illness could identify the warning signs. All of them could tell when the patient was becoming ill. The respondents gave various reasons and problems that made it difficult for them to live with the patient at home. Three of the respondents felt that the patients were very unpredictable. They made statements like *"you never know what he is going to do, you never know what he is thinking, then he smokes dagga all the time and is always demanding money from people"*. One respondent said that they find it difficult to accept and forget the things that the patient has done and they keep asking themselves why did this have to happen to their family. She said *"you know after he killed my granny, we would do*

anything for him, we spoilt him because we were afraid of him and we tried to please him".

This is in line with Kuipers *et al.*'s views (2002). These authors argue that society has a stereotyped view of the mentally ill which becomes complicated by the unpredictability of their illness. They state that people often believe that these patients are violent, show sexually inappropriate behaviour and suffer from split personality. This often results in both families and patients experiencing rejection and this rejection is often mixed with feelings of guilt, anger, inadequacy and hopelessness. Families also adopt certain attitudes based on their fear of stigmatization.

One respondent, who is the patient's sister, said that the difficulty for them was that the patient is aggressive and that he would hit them and throw them out of the house so that he can live there alone. Another respondent who is also a patient's sister said, *"I find myself torn between my family and my brother. He once interfered with my daughter who was six years old at the time, he has recently accepted this to me and apologized for it. It makes me sick just to think of what he did to my daughter. I never told my husband about it, I don't think he will ever forgive him I do not know if I have forgiven him myself. I have done so much for him but I have never felt that he appreciated any of it"*. This is similar to what is described by Torrey (1983 in Riebschleger, 1991:4) when she said that siblings feel drawn to help the ill family member but at the same time were repulsed by their bizarre behaviour and lack of impulse control.

One respondent stated that for him the dagga smoking was his biggest difficulty. He said that he cannot control the patient when he has been smoking and he becomes aggressive and gets involved in all sorts of trouble when he has been smoking. He said that even on the night that the patient killed his mother he was ill and everyone knew he was ill but he had also been smoking dagga. Two

respondents, both mothers, stated that they did not feel safe when the patient is at home. The one respondent said *"I cannot relax, I must be alert and pray all the time"*. The other one said *"I have woken up in the middle of the night and found him standing next to my bed with a knife in his hand... Most of the time I am alone at home and he can assault me anytime"*. Another respondent who is also a mother said *"I am getting older now and I can not handle him anymore. I can not stay awake at night because I am frightened"*.

4.8 The Relative's Feelings Towards the Patient Regarding the Offence

The respondents were asked whether their feelings towards the patients have changed in any way after he committed the offence. Nine of the respondents said that their feelings had not changed and that they still loved the patient and cared about him as they did before the offence. There was a lot of ambivalence among most of the respondents as well. Even though most of the respondents said that they still cared for the patient they were adamant that living under the same roof with him was out of question.

In expressing their feelings the relatives made statements like *"It was difficult at first as we did not have a place to stay after he burnt our house down, but now we have forgiven him, he is still our brother and we still love him but we can never live with him"*.

"Our feelings towards him have not changed, we do understand that he is ill and also at the time that he committed the offence he was emotional, he had just received news of his mother's death. We do understand that he is ill and we do care about him but we can not live with him".

"We know that he was sick when he did what he did, he would never have done such a thing if he was not sick. We still love him but we are scared of him. He is still and will always be my brother but I can never live with him".

"My feelings towards him have not changed and I do not blame him for what he did because I saw him at the time he did not even recognize me. I know that he was not acting from any sanity of mind. What worries me is his ability to get back into a state that could make him do that again".

"He will answer to his god for what he did, I can not judge him. My brother is not well what he did is only known to him and his god..... I do not have a problem with him and I am not angry with him, I still feel the same way about him. Do you think that your mother could bring you into this world and then you kill her, surely there must be something wrong with a person who does that".

"I am not happy about what he did but I love him. He is still my son, I know that he was not born like that, I think that it is because of this illness that he is like that".

"I feel bad but what can I do, he is my son and there is no dumping site for people. I am also not progressing because of him, he's burnt my house in the past and I have never been able to get back what I lost then. I am only worried about what would happen to him when I die one day".

"I was very hurt about the things that he did, it was worse when he burnt down the shacks because my sister's child died there. My feelings about him have however not changed I still feel the same way about him he is still my child but I can never live with him again".

One of the respondents expressed feelings of ambivalence towards the patient. She could not express how she actually felt about the patient. The researcher could sense some feelings of anger towards the patient because he killed their mother. On the other hand she felt sorry for him because after the mother's

death there was no one else to care for him. She also expressed some feelings of guilt. The respondent made statements like *"what is hurting me is that he is telling everyone, the staff at the hospital that he's got a sister and the sister wants nothing to do with him"*.

The respondent also said *"I don't know if I will ever forgive him for what he did. You know I sometimes ask if he is so sick why doesn't he kill himself. If he is so mad why doesn't he kill himself". "He killed my mother and you know for me he planned it"*.

This is consistent with findings of various authors in Hatfield and Lefley (1987) where families came across as ambivalent in their feelings, having a sense of concern and caring mixed with resentment and anger. They also found general feelings of helplessness and entrapment.

Most of the respondents demonstrated high levels of "expressed emotion". They made a number of statements that were critical towards the patient.

4.9 Family's Support systems

Seven respondents reported that they were not getting support from anyone. They reported that the other family members have distanced themselves from the patient and his immediate family. The other people were not getting involved because they were scared of the patient or because they did not believe that he was really ill and therefore wanted nothing to do with him. Other relatives just felt that the patient was difficult to manage and they therefore distanced themselves and left the mother to struggle alone.

It also seemed that the extended family was less interested in the patient when the victim of his crime was also a member of the family. Family members found it difficult to understand the patient's mental state at the time of the offence and

therefore struggled to forgive him. One respondent said *"I've got a lot of relatives, my brothers and sisters live in Cape Town...but I am on my own no one else cares. They are still angry with my brother for killing our mother...."*

There were three respondents who felt that they were getting some support from their families, friends and neighbours. It seems that friends who also had mentally ill relatives were able to offer support. They were more understanding and always willing to listen and could also give advice at times. Most of the respondents also suggested that the patient's sibling were not likely to show interest in the patient's life. They had their own lives and their own families and were not concerned about the patient. The siblings also felt that bringing the patient to their families would bring instability to their families and they were not prepared to take that risk.

Some of the respondents felt that their only source of support was the hospital. Respondents felt that they feel much better and comfortable when the patient is in hospital because they know that he is safe there and they can also relax without worrying about where he is and what he is going to come home and do to them. Some of the respondents even said that they would prefer the patient to stay in the hospital forever if they need to. One respondent said *"I know that he is safe there I don't need to worry. My wish would be that he stays exactly where he is. At least I know he is not sleeping on the street."*

There were also some of the respondents who expressed some mixed feelings towards the hospital. One respondent for instance said that although she felt that her brother was safe in hospital she did not think that the hospital was supportive towards her. She said that the patient was once discharged from hospital and no one had advised her about this before time. She also felt that she was never called to a support group or consulted on any of the issues concerning her brother's illness. She said *"when Valkenberg sees that there is a*

family member who cares that solves the problem for them. They have no consideration for the fact that I have my own family to consider."

This is in line with Iodice and Wodarski (1987)'s statement in Riebschleger, (1991:99) that families were like unprepared dumping grounds that provide home care to clients. Spaniol, Zipple, and Fitz-Gerald (1994) also in Riebschleger (1991) pointed out that a majority of clients returned to family care resulting in stress and disruption to the family. Yet the mental health system provided little support, information or services to those overburdened caretakers.

Riebschleger (1991:99) also argues that the practice of involving siblings in crisis situations but not in treatment planning relayed conflicting messages to the siblings such as "stay involved—go away", "we see you but you don't exist", "professionals know what's best" and "there are few resources professionals can provide. She asserts that these double bind messages left siblings with little understanding regarding their roles regarding their ill brother or sister, attention to their own needs, or recognition of their personal struggle or trauma. They also increased the intensity of sibling grieving emotions such as anger, shame, fear, helplessness and guilt.

Another respondent who felt that the hospital was not supportive said "*They never came to my house when he was at home. Even when I tell them confidential information about the patient they tell him what I told them. Once I told them how I felt about the patient and that I was scared of him and the staff told the patient everything even before I left the hospital.*" The respondent also felt that she could not trust the staff at the hospital. There were three respondents who felt that there was no follow up from the hospital in the past when the patient had been sent home and feel that if this had happened they would have coped better with the patient and maybe some of the things that they did would have been avoided.

This is in line with the argument by the Group for the Advancement of Psychiatry (1986:43) that, "the major changes in mental health care brought about by deinstitutionalization have too often failed to provide proper help for patients and their families." They further argue that despite all the thought, time and money devoted overtime to improving mental healthcare, too many relatives of patients who live at home feel alone and unsupported.

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4.10. THE EFFECTS OF THE REJECTION ON THE PATIENT

Seven patients were also interviewed to find out how the rejection was affecting them or whether they were at all affected by it. The results of the patient interviews will be presented according to the following categories, from which the main themes of the interviews emerged. This information is presented in Table Three below

Table 3: Themes and Categories generated from the findings

Themes	Categories
1. living circumstances before hospitalisation	<ul style="list-style-type: none"> • Lived with parents • Independent living • Residing with other relatives
2. Understanding of the illness and the original offence	<ul style="list-style-type: none"> • Knew that they were in hospital because they are ill and that they had committed a crime. • Clear knowledge and understanding of the offence.
3. Contacts with the outside world	<ul style="list-style-type: none"> • Some got visits from relatives and others did not get any visitors • None of them had been out in the past three years
4. patient's feelings towards their families and relatives	<ul style="list-style-type: none"> • Feelings of loving and longing to be with their families • Difficulty expressing feelings
5. Effects of the hospital stay on their mental state	<ul style="list-style-type: none"> • Did not know • Answered off the point • Frustration

4.10.1 Living circumstances before hospitalization

Three of the patients said that they lived with their parents before coming to hospital but all three reported that their parents have died while they were in hospital. The other two said that they had also lived with their parents and that their parents were still alive. One patient reported that he had been living on his own. He had been married at some stage and living with his wife but he was now divorced and had no place to stay. The last one said that he was living with his brother and sometimes with his aunts.

4.10.2. Understanding of the illness and the original offence

All of the patients knew why they were at Valkenberg. They said that they had committed offences and were found unfit to stand trial because of their mental illness. All of them knew the kind of illness that they had and said that the doctors had told them. Only one patient said that he did not know his illness and that he was never told what it is. They also knew the kinds of offences that they committed.

4.10.3. Contacts with the outside world

The patients had different responses when they were asked about visitors and when they were last out on leave. One patient said that the last time he was out was in 1999 and he stayed with his mother. He said he thinks that the reason why he has not been out is because his mother did not want him. He said *"when my mother was asked to take me out for Christmas she talked about things that had happened a longtime ago, maybe it's because I have stabbed her...I really do not know. I think that now that my mother is dead my sisters want the house to themselves, they are going to leave me here and I think that they are still drawing my grant."*

Another patient said that he has not been out since his mother died three years back. He said that he does not get visitors and does not want the other relatives to visit him because *"they are trouble, they are the reason my mother is dead, I used to work and I got a grant but they always demanded money from me, they wanted to go and smoke."* He said the reason he has not been out is because he does not have anywhere to go yet, he does not have money and he does not want to interfere in his sister's family. He said that the sister is also trouble and *"anyway she is only my step sister."*

Another patient said that the last time he was out was in 1997 and he stayed with his aunt but he has not had contact with the aunt in a long time, he did not know if she was still alive, the last time he heard from her she was in an old age home. He said *"the last time I got visitors was when my mother used to come and visit in the 80's."* He also said that he has not been out because he has got no place to go to. He knows that he has got other relatives out there but he does not know who they are or how to contact them.

Another patient said that his mother and brother visit him at least once in a month. The last time the mother visited was about a week ago. He said that the last time he was out was in 2001. He stayed with his mother. He has however been able to visit his mother sometimes but would just spend the day and come back to hospital as he was unable to spend the night because the mother did not have a place to stay.

Another patient said that he does not get visitors. He said that no one has ever been to visit him, *"maybe because my family lives far, I used to go and visit my brother and my aunts but now I'm told that they do not want me but no one told me why. I have been in this place for too long I can not even remember when was the last time I was out."*

Another patient said that his parents visit once a month. The last time they visited was a week ago. He said that he has not been out for leave ever since he was admitted two years back. He did not seem to understand why he has not been out but said that his father had said that he could come home and that his father was going to come and speak to the social worker. He also said that he's got other people that he could live with but again said he wants to live with his parents.

Another patient said that his sister visits him sometimes once in a month or whenever she can find the time. The last time he got a visitor was about a month ago. He said that he has not been out since he came back to hospital about two years back after he had been out on leave for over a year. He had stayed on his own and with some friends. He said the reason why he had not been out now was because he did not have a place to go to. His sister did not have a room for him and the people that he had lived with before did not want him again.

4.10.4. Patients' feelings towards their families and relatives

One patient said *"I love my family even though they do not want me, maybe things may change now that my mother is no longer around, maybe my sisters may decide to take me."*

Another patient said *"those people are trouble and I do not want nothing to do with them, it's not because I don't have a place to stay that I have not been out, I've got a lot of places that I can go to I'm just not ready yet."*

Another patient said that he does not have family and that his only worry was that he did not have money to pay the hospital.

Another patient said that he is "ok" with his family. He understands that his mother does not have a place to stay but he would like to be discharged as he feels that he can find his own place. He is also worried that his friends are going on with their lives outside while he is stuck at Valkenberg.

The other patient said *"I miss my family. I don't understand how they could say that I do not have a place to stay because I know that I've got a place."* He also said that he wishes that his family would give him a chance to prove to them that he has changed and that he does not smoke dagga anymore.

The other patient said *"I miss my family. I would like to go out and be with them if they do not want me to stay with them I can find another place."*

The last one said *"I understand that my family does not want to live with me because of the things that I have done to them in the past. I love them and I appreciate the fact that my sister still visits me sometimes."*

Most of them struggled to describe their feelings. It was not clear whether this was because the rejection has numbed them of any feelings towards their families or this was just part of their pathology, in that they were displaying negative symptoms of schizophrenia as all but one of the interviewed patients had schizophrenia. One respondent has bipolar mood disorder.

4.10.5. Effects of the hospital stay on their mental state

Most of the patients struggled to explain how their hospital stay has affected their mental state. Some said they do not know how or there has been no effect and others just answered off the point. Only two of the patients gave appropriate answers. One of the two said being in hospital is causing him stress. He said that he was also frustrated with his mother at times as he did not think that she was trying hard enough to get out of her situation. He also said that he often

wonders sometimes if his mother was not living the way that she is living so that she can have an excuse to keep him in hospital forever.

The other one said that being in hospital has given him a chance to think about his life. He saw being in hospital as a positive thing in that he is well now, he is taking his medication and is not using substances. He said he worries a lot about where he is going to stay when he leaves the hospital and he has spoken to the social worker about getting him alternative accommodation as he realizes that his sister will not be able to accommodate him.

The others gave responses like *"I do not think that being in Valkenberg is good for me, the medication is not good."* Or *"I don't know I am fine now."*

Their lack of insight into their condition also became apparent. Although these patients do not seem to think that the rejection had much impact on their mental state, there are some suggestions from literature that the rejection can impact on people's mental health (Sayce, 2000:43). Sayce states that the feeling that the community does not like them has led to deterioration in some people's mental health.

4.11 Conclusion

This chapter presented the results of the interviews that were conducted with relatives and with the patients. The relatives were from different social backgrounds, mostly characterized by poor social circumstances. The results show that the patient's behaviour at home was not always acceptable to their relatives. There was also a lot of ambivalence in how the relatives felt towards the patient and although many admitted that they still cared for the patients they were not willing to give them another chance at staying with the family.

Family members also felt isolated and unsupported by the clinical team that is treating the patient at the hospital. There was also evidence of lack of support for the care giving relatives from the rest of the family and the communities in which they lived.

The relatives articulated that they were not willing to stay with the patients and they gave different reasons which included; fear that the patient might hurt them, anger towards the patient for what he had done in the past, loss of a loved one due to the patient's actions, and the difficulty of living with a mentally ill person who abuses substances.

Regarding the patients' responses it was difficult to see whether their responses reflected their true feelings or not. Although they often spoke about loving and caring for their families this was not evident in their body language and it was difficult for the other person to feel what they said they were feeling.

The next chapter will discuss the conclusions and recommendations.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 Conclusions

The purpose of this study was to investigate factors that caused families to reject State Patients who were entrusted into their care during periods of leave from Valkenberg Hospital. Factors that were considered included the characteristics of the families, the nature of the index offence (that resulted in the certification), the impact the family's rejection may have had on the state patient and the role of their social networks in the reintegration process.

The objectives of the study were:

- To explore and describe the factors which contribute to the rejection of State Patients, who are admitted to the forensic unit at Valkenberg Hospital, by their families
- To determine whether the type of crime that the patient committed has an influence on the family's feelings and attitude towards him.
- To determine the role played by support systems and social networks in the lives of the care givers and the patients.
- To determine how the rejection affects the patients.
- To provide recommendations about what can be done to assist the families so that they are willing to accept the patients in the future.

Conclusions drawn from this research will now be discussed according to the objectives that are listed above.

5.1.1. Factors which contribute to the rejection of State Patients, who are admitted to the forensic unit at Valkenberg Hospital by their families.

The results show that substance abuse is a major problem for most of the families and it is also the major contributor to the rejection. Families found it difficult to control the patients at home after they had been using substances. Patients also stole their family members' valuables so as to feed their drug habits and they also became violent and aggressive when they are intoxicated.

The patient made very little or no financial contribution to the family and even when they were receiving a disability grant from the state their money was spent on drugs and alcohol and they would then demand food and accommodation from the family. Often they would demand money for the substances when their own money runs out.

Another cause of the rejection was the lack of understanding for the patient's illness. Because relatives had little knowledge of the patient's illness they could not understand the psychotic actions of their relatives and could therefore not comprehend that what the patient did was due to some psychotic symptoms that he was experiencing at the time and that after being on treatment he may no longer be a threat to the family.

The findings also show violence as another contributor to the rejection. Most of the respondents had committed murders and they had murdered family members. This resulted in a lot of anger and resentment among the remaining family members.

The findings of this research show a lot of ambivalence among family members regarding their feelings towards the patients. Most of the family members, especially the mothers' responses indicated that they cared and still loved the

patient but they also stressed that living with him was not an option. It was also very clear that most of the families even though they were not visiting the patient in hospital they had not forgotten about him.

The significant amount of burden carried by the family members also became quite evident in that family members reported that the patient's behaviour at home was not always acceptable. Family members spent a lot of time and money on the patient. They supported them emotionally and financially and they did not always feel that their mentally ill relatives appreciated this.

At times when the patients were having an income, whether it was from work that they had done or whether it was a state disability grant, the caregivers felt that their mentally ill relatives were not willing to contribute towards the family's expenditure. There was a general feeling among these respondents that their relatives used their income for their own selfish needs.

5.1.2. Determining whether the type of crime that the patient committed has an influence on the family's feelings and attitude towards him.

In most of these respondents the ambivalence was related to the type of crime committed by the patient as they also expressed feelings of fear towards the patient.

There was a mixture of positive and negative attitudes towards the patients. Some of the respondents knew about the patient's illness and were well informed about the symptoms and knew the warning signs while others did not know what the illness is or when and how it started. The relatives also expressed fear as one of their difficulties in living with the patient. The unpredictable nature of the illness or the patient's behaviour made it difficult for the family members to trust him and they were also worried about potential aggressive behaviour at all

times. The negative attitudes of family members were also encouraged by the patient's substance abuse or aggression and violence.

5.1.3 The role played by support systems and social networks in the lives of the caregivers and the patients.

The results show that most of the respondents have got very poor support systems. It also came to light that some of the respondents were not supported because their relatives were scared of the patient. Others did not want to be associated with this family or the patient specifically for fears of being stigmatized. When the victim of the crime committed by the patient was a family member, other members of the extended family remained angry with him and found it difficult to forgive him. Because of this it was also not possible for them to support the family member who was supportive towards the patient.

There were however a few who felt that they could turn to other family members, friends and neighbours. Having that kind of support proved to be invaluable to those respondents.

Most of them also felt unsupported by the mental health care professionals who were looking after their relatives. One could also conclude from this that there is very poor communication between the hospital multi-disciplinary team that treats the patients and the patients' relatives or caregivers.

5.1.4. The effects of the rejection on the patients

The patients did not think that the rejection affected their mental state at all. Their responses reflected a mixture of feelings towards their families but could not relate this to their mental status. Because the researcher also could not find literature to compare with these responses it is really difficult to come to any conclusions here. Also the blandness in their responses could be as a result of the illness.

5.2 RECOMMENDATIONS

5.2.1 Recommendations from the respondents

The respondents made the following recommendations:-

- The multidisciplinary team should maintain contact with the family and inform the family at all times when patient is granted leave.
- The staff should be sensitive about confidentiality and not tell patients every thing that is discussed with the relatives.
- When the patient is at home the hospital staff should visit the family to see how they are coping with the patient at home.
- Some respondents felt that the patients should not be granted any leave and the state should take full responsibility for them.

5.2.2 Recommendations from the researcher

- The multidisciplinary team should provide the families of state patients with psycho-education as soon as a patient has been admitted into the unit. Family members should be involved in the rehabilitation programs while the patient is still in hospital
- The multi-disciplinary team should maintain close contact with the family and the family members must be prepared before the patient is allowed to go out on LOA.
- Most of the respondents expressed fear of the patient or what he might do to them when he is out in the community. Fear is a variable that can not be left un-addressed. One needs to be counseled and supported in order to deal with the fear. People with skills and knowledge like the psychiatric multidisciplinary team are the appropriate people to assist the family to deal with the fear. For example various authors have argued that persons with psychotic illness may pose greater risks to people they know than to random members of the public. Therefore developing preventive interventions to reduce harm from violent behaviour requires information

on seriousness of potential harm, identity of potential victims, and circumstances in which the violent behaviour is likely to occur.

- The members of the multi-disciplinary team should be accessible and available to family members for consultation when families feel the need to consult.
- Family therapy should be provided to the state patients' families when the patient starts to go out on LOA, so as to correct any family dysfunction and to help the family cope better with the relative who is suffering from mental illness.
- Support groups for family members should be started in the hospital while the patient is still an in-patient and in the community once the patient goes out on LOA.
- The results of this study suggest a common comorbidity of mental illness and substance abuse which often results in high incidents of violence. Effective community treatment for this population therefore requires careful attention to medication adherence and the availability of an integrated substance abuse and mental health treatment program.
- There is also a need for programs that cater for patients with comorbid personality disorders.

5.2.3 Recommendations for Policy Making

- The government should subsidise halfway houses and group homes that will accommodate those state patients who can not be cared for by their families.
- There is a need for the allocation of resources for the training of community social workers who could run rehabilitation programs for State Patients on LOA and provide ongoing support to their families.

5.2.4 Recommendations for Further Research

- The burden of caring for mentally ill relatives needs to be further researched with specific emphasis on families of State Patients.
- The relevance of social support and social networks in the life of a forensic psychiatric patient.
- The benefits of a multi-professional community based rehabilitation program need to be explored.

5.3 Conclusion

This chapter presented the conclusions and recommendations of the study. Conclusions were discussed according to the objectives that were set for the study. Recommendations from the researcher were also listed and discussed. In this chapter the researcher also makes recommendations for policy making and further research.

BIBLIOGRAPHY

Anthony, W., Cohen, M., Farkas, M., & Gagne, C. (2002). *Psychiatric Rehabilitation* (2nd ed). USA; Boston University: Centre for Psychiatric Rehabilitation.

Brink, S., Oosthuizen, P., Emsley, R., Mbanga, I., & Keyter, N. (2003). Relationship between Substance Abuse and First Episode Psychosis – a South African perspective. *South African Journal of Psychiatry*, 9 (1):7-12.

Blutzlaff, Ronald L., Jill, A.M. & Hooley M. (1998). Expressed Emotion and Psychiatric Relapse. *Archives of General Psychiatry*, 55:547-552.

Chaffey, Lisa & Fossey, Ellie (2004). Caring and Daily Life: Occupational Experiences of women living with sons diagnosed with schizophrenia. *Australian Occupational Therapy Journal*, 51:199 – 207.

Chang, K. H. & Horrocks, S. (2006). Lived Experiences of Family Caregivers of Mentally ill Relatives. *Journal of Advanced Nursing*, 53 (4):435-443.

Clark, Robin E. & Drake, Robert E. (1994). Expenditures of Time and Money by Families of People with Severe Mental Illness and Substance Use Disorders, *Community Mental Health Journal*, 30:145 – 163.

Clark, Robin E. (1994). Family Costs Associated with Severe Mental Illness and Substance Use. *Hospital and Community Psychiatry*, 45:808 – 813.

Collins, Kathleen (1999). *Participatory Research a Primer*. Republic of South Africa: Prentice hall South Africa (Pty) LTD.

Criminal Procedures Act (Act 51 of 1977). Pretoria: Government Printers

Department of Health-Western Cape (2003). *Health Care 2010*.

De Vos, A.S. (2001). *Research at Grass Roots A Primer for the Caring Professions*, Pretoria: Van Schaik Publishers.

De Vos, A.S., Strydom H., Fouche C.B. & Delport C.S.L. (2002) *Research at Grass Roots For the Social Sciences and human service professions* (2nd ed). Pretoria: Van Schaik Publishers.

Estroff, Sue E., Zimmer, Catherine, Lachicotte, William S., Benoit, Julia (1994). The Influence of Social Networks and Social Support on Violence by Persons with Serious Mental Illness. *Hospital and Community Psychiatry*, 45:669 – 679.

Flick, Uwe, von Kardoff, Ernst & Steinke Ines (2004). *A Companion to Qualitative Research*. London: Sage Publications, Thousand Oaks, New Delhi.

Group for the Advancement of Psychiatry (1986). *A Family Affair: Helping families cope with mental illness*. New York: Bruner/ Mazel Publishers.

Hatfield, Agnes B. Lefley, Harriet P. (1987). *Families of the Mentally ill Coping and Adaptation*. USA: The Guilford Press.

Hodgins, Sheilagh (1993) *Mental Disorder and Crime*. United Kingdom: Sage Publications, Inc.

Hooley, Jill M. (2004). Do psychiatric Patients do better Clinically if They Live with Certain Kinds of Families? *Current Directions in Psychological Science*, 13:202 – 205.

Hyde, Margaret O. & Forsyth, Elizabeth H. (1991). *The Violent Mind*. USA: Library of congress cataloging-in-publication data.

Joyal, C. C. Putkonen, A. & Tiihonen, J. (2004). Characteristics and circumstances of homicidal acts committed by offenders with schizophrenia. *Psychological Medicine*, 34:433 – 442.

Kaplan, Harold I. Sadock, Benjamin J. & Grebb, Jack A. (1994) *Synopsis of Psychiatry Behavioural Sciences Clinical Psychiatry* (7th ed). USA: Library of Congress Cataloging-in- Publication Data.

Kuipers, E., Leff, J. & Lam, D. (2002). *Family Work for Schizophrenia a Practical Guide* (2nd ed). Great Britain: The Royal College of Psychiatrists.

Laugharne, R. Byford, S., Barber, J. A., Burns, T., Walsh, E., Marshall, S. & Tyrer, P. (2002). The effect of Alcohol consumption on Cost of Care in Severe Psychotic Illness: A report from the UK 700 study. *Acta Psychiatrica Scandanavica*, 106:241 – 246.

Magliano, L., Marasco, C., Fiorillo, A., Malangone, C., Guaneri, M., Maj, M. & the working group of the Italian national study on families of persons with schizophrenia (2002). The Impact of Professional and Social Network Support on the Burden of families of patients with Schizophrenia. *Acta Psychiatrica Scandanavica*. 106:291- 297.

Marshall, Catherine & Rossman, Gretchen B. (1995). *Designing Qualitative Research* (2nd ed). USA: Sage Publications Inc.

Mental Health Care Act (Act 17 of 2002). Cape Town: Government Printers.

Ohaeri, Jude U. (2002). The Burden of Care-giving in families with a mental illness: a review of 2002. *Current Opinion in Psychiatry*, 16:457- 465

Patterson, Paul, Birchwood, Max, & Cochrane, Ray (2005). Expressed Emotion as an Adaptation to Loss: prospective study in first episode psychosis. *British Journal of Psychiatry*. 187:59-64

Prins Herchel (1999) *Will They Do It Again? Risk assessment and management in criminal justice and Psychiatry*. London and New York: Routledge.

Riebschleger, Joanne L. (1991). Families of cronically mentally ill people: siblings speak to social workers. *Health and Social Work*, 16:94- 104

Sayce L. (2000). *From Psychiatric Patient to Citizen: Overcoming Discrimination and Social Exclusion*. New York: Palgrave Publishers.

Serper, Mark R. Bergman, Andrea J. (2003). *Psychotic Violence: Methods, Motives, Madness*. Madison: Psychosocial Press,

Solomon, Phyllis & Draine Jeffery (1995). Subjective Burden Among Family Members of Mentally Ill Adults: Relation to Stress, Coping, and Adaptation. *American Journal of Orthopsychiatry*, 65:419 – 427

Swartz, Marvin S., Swanson Jeffrey W., Hiday Virginia A., Borum Randy, Wagner, Ryan H. and Burns Barbara J. (1998). Violence and Severe Mental Illness: The Effects of Substance Abuse and Nonadherence to Medication. *American Journal of Psychiatry*, 155:226 – 231.

Talbott, John A. (1984). *The Cronic Mental Patient, five years later*. United States of America: Grune and Straton, Inc.

Torrey, Fuller E. (1994). Violent Behavior by Individuals with Serious Mental Illness. *Hospital and Community Psychiatry*, 45:653 – 662.

Tripodi, Miriam, Potocky & Tripodi, Tony (1999). *New Directions for Social Work Practice Research*. United States of America: NASW Press.

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Appendix 1

RESEARCH QUESTIONNAIRE

IDENTIFYING DETAILS

Name of patient:
Dob: AGE:
Diagnosis:
Charge:
Date of first admission:
Current ward:
Name of parent or relative:
Home address:
.....
.....
Telephone No.:

DEMOGRAPHIC INFORMATION

How long has the family lived at the present address?

- < 1 Year
- 1 – 5 Years
- 5 – 10 Years
- > 10 Years

Have the family moved since the patient's admission to hospital?

- Yes
- No

If no does the hospital know your new address?

Type of dwelling:

- Parent or relative's own house
- Own shack
- Living with other relatives or friends
- Other (state)

.....
.....

How many people live in the house?

Employment status of the parent or relative:

- Full time
- Part time
- Shifts

Contract
Retrenched
Unemployed
Other (state)

.....

Does or did the patient receive a disability grant? Did it help towards the family's income?

.....
.....
.....

Monthly household income
< R500
R500 – R1500
R1500 – R3000
> R3000

PATIENT'S BEHAVIOUR AT HOME

Does the patient contribute to the home or the family? (e.g. household chores, shopping etc.) Explain

.....
.....
.....

Does he need supervision? (e.g. with taking his medication, self care etc.) Explain

.....
.....
.....

Does the patient abuse substances?

Yes

No

If yes: do you know what he is using?

.....
.....

how often does he use the substance?

.....
.....

Is this a problem for the family? How?

.....
.....
.....

Is the patient aggressive or violent? Explain

.....
.....

FAMILY'S ATTITUDE TOWARDS PATIENT

Patient's relationship with the relative:

- Parent
- Adoptive parent
- Foster parent
- Aunt
- Uncle
- Sibling
- Friend
- Other (state)

When was the patient first diagnosed with mental illness?

.....

What is your understanding of his illness?

.....
.....
.....

Can you tell when he is getting sick and when he is well? How?

.....
.....
.....

Are there specific reasons or problems that make it more difficult to cope with your relative's mental illness or his behaviour at home?

.....
.....
.....
.....

How is your support system? Do other relatives or friends assist you in caring for the patient? Do you feel that you get the necessary support and assistance from the hospital?

.....
.....
.....
.....

How do you feel about the crime that he committed? Has it changed the way that you feel towards him?

.....
.....
.....
.....
.....

When was the last time you visited the patient in hospital?

If not visiting why not?

When was the last time the patient went out on leave?

How long was he out?

If the patient has not been out, why not?

Is there a possibility that you may be able to live with the patient in the future or take him out for week- ends ?

.....
.....
.....
.....
.....

What would have to change to make you willing to have him live with you?

.....
.....
.....

Declaration by interviewee

Ihereby give permission for the information provided above to be used for the purposes of interviewer's research. I understand that the information is confidential and my real name will not be used when reporting on the findings.

Signed at On the/..../2005

.....
Signature

University of Cape Town

Appendix 2

Interview Schedule: Patient Interviews

1. Name:
2. What was your last residential address?
3. Who did you stay with?
4. What was your original offence?
5. Do you know why you are at Valkenberg Hospital?
6. What is your understanding of your illness? Do you know what it is?
Who told you?
7. Do you get visitors in hospital? When was the last time you got a
visitor? Who came to visit you?
8. When was the last time you were out on leave? Who did you stay
with?
9. If you have not been out why not?
10. How do you feel about the fact that no one wants to take you out?
11. How do you feel generally about your family?
12. How has your stay in hospital affected your mental state?