Families' experiences with schizophrenia

by

Stanley Molefi

Thesis presented in partial fulfilment of the requirements for the Degree of Master of Arts

(Psychology)

at

Stellenbosch University

Department of Psychology

Faculty of Arts and Social Sciences

Supervisor: Professor Leslie Swartz

December 2009

Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

December 2009

ABSTRACT

Families of people with schizophrenia often experience difficult challenges when it comes to dealing with this illness. Contemporary researchers suggest that families often take on the task of caring for their ill relatives with limited resources and support. Mental health professionals often fail to include the families in the treatment of their relatives. Although psychoeducation has been shown to be an important process that helps not only the families but relatives as well, mental health professionals commonly do not involve families in such activities. This study explored the experiences of families of people with schizophrenia and their subsequent contact with mental health professionals, as well as their understanding of schizophrenia as a mental disorder. To this end, a small sample of 10 families (four Xhosa speaking families as well as six Coloured families) was drawn in the Western Cape area on a convenience basis. In each case a family caregiver was interviewed using a semi-structured questionnaire. Data were content analyzed.

The findings of the study indicate that families find it difficult to deal with their ill relatives. Families often experience stigma-related incidents because of their relatives. They feel isolated and alone. Families often yearn to receive more information about the illness of their relatives. Also, the contact between mental health professionals and families was reported to be minimal at best. Family members reported that mental health professionals do not include them in the treatment process. Recommendations for further research and practice are made.

OPSOMMING

Die families van mense met skisofrenie kom moeilike uitdagings teë op hul pad met hierdie versteuring. Hedendaagse navorsers vind dat die families gereeld die verantwoordelikheid aanneem om na die siek familielid om te sien met beperkte hulpbronne en ondersteuning. Geestesgesondheidswerkers sluit dikwels nie die families in by die behandeling van hul familielede nie. Alhoewel psigo-opvoeding as 'n belangrike proses erken word, wat nie net die families nie, maar ook die siek familielid help, word dit nie in die praktyk toegepas deur geestesgesondheidwerkers nie. Hierdie studie verken die ervaringe van die families van mense met skisofrenie en hul daaropvolgende kontak met geestesgesondheid werkers, asook hul begrip van skisofrenie as 'n versteuring. Heirvoor is 'n klein steekproef (vier Xhosa-sprekende asook ses Kleurling families) geneem in die Wes-Kaap op 'n gerieflikheidsbasis. In elke geval is 'n semi-gestruktureerde onderhoud gevoer met 'n familie versorger. Die data is geanaliseer volgens inhoud.

Die bevindinge van die studie dui aan dat families dit moeilik vind om hul siek familielede te hanteer. Families ervaar dikwels stigma as gevolg van hul siek familielede. Hulle voel geïsoleerd en alleen. Families smag dikwels daarna om inligting te bekom oor die versteuring van hul familielede. Verder is die kontak tussen families en geestesgesondheidswerkers minimaal ten beste van tye. Families rapporteer dat geestesgesondheid werkers hulle as families nie by die behandelingsproses insluit nie. Voorstelle vir verdure navorsing en die praktyk word gemaak.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER ONE

INTRODUCTION

One of the major changes in the care of people with serious mental illness in the twentieth century was that the process of deinstitutionalization shifted the treatment of these people from state institutions to community care centres. This process had a substantial impact on the mental health system and on families of the people with mental illness as well (Thompson & Doll, 1982). Thompson and Doll assert that one of the unintended effects of doing away with state mental hospitals was the increased emotional and interactional burden which families had to deal with on a day-to-day basis. "The movement of community-based care implicitly but undeniably pull[ed] the relatives of the mentally ill into a critical care-giving role" (Thompson & Doll, p. 379).

Thompson and Doll (1982) assert that when it comes to the institutions that are involved in community care for people with mental illness, the family's role is critical. Apart from anything else, the family are the people who spend a great amount of time caring for the persons with mental illness (Thompson & Doll). In the last four decades, the dominant professional perception of the role of families of people with mental illness, particularly families of relatives with schizophrenia, has transformed from the people who cause the illness of their relatives or the people that create a hostile family environment, to the people whom are affected by the illness of their relatives (Hatfield & Lefley; Mishler & Waxler; Vaughn & Leff; all cited in Reinhard & Horwitz, 1995). It is estimated that 50 to 80 % of relatives with schizophrenia and other psychotic disorders either reside with or maintain regular contact with their families (Gibbons, Horn, Powell, & Gibbons; Lehman & Steinwaches; both cited in McDonell, Short, Berry, & Dyck, 2003).

By the 1980s it had become the norm to have spouses, parents and close relatives take on the responsibilities of caring for their ill relatives (Thompson & Doll, 1982). In addition, Thompson and Doll asserted that many families of people with schizophrenia had become "unwittingly, and sometimes unwillingly, *de facto* therapists who bear the day-to-day burden of coping with a mentally ill family member" (p. 379). The burden is considerable: families are profoundly affected negatively by the responsibilities of their caregiving function (Clausen & Yarrow; Grad, & Sainsbury; Norbeck, Chafetz, Skoldol-Wilson, & Weiss; Fisher, Benson, & Tessler; all cited in Dyck, Short & Vitaliano, 1999). The responsibilities or rather demands of caregiving include missing work, disturbance of domestic routines (Dyck et al.), supervision of a relative with mental illness, and dealing with societal stigma associated with mental disorder (McDonell et al., 2003). Behavioural problems of the relative with mental illness add on the responsibilities of the caregivers (Dyck et al.).

In addition, families often experience problems when trying to access the mental health system. Murray-Swank, Dixon and Stewart (2007) assert that families often do not receive support and information from the mental health professionals about the illness of their relatives. Families also do not know what kind of treatment their relative with mental illness is receiving and why (Murray-Swank et al., 2007). In some instances, the families are blamed by mental health professionals for causing the illness of their relatives.

Research problem

In South Africa there is considerable burden placed on the families of people with schizophrenia (Jonker, 2006). However, the study of families' experiences with serious

mental illness is not adequately investigated in the South African literature. By contrast, the American and Europe literature offers a plethora of research based on the experiences of the families with mental illness (Hoeing & Hamilton, 1966; Kuipers, Leff, & Lam, 1992). It has been established that pharmacological management alone has not had success in the treatment of people with schizophrenia (Huey, Lefley, Shern, & Wainscott, 2007). In instances where pharmacological treatment has been shown to work, success has been short lived due to high readmission rates of the patients to hospitals (Murray-Swank et al., 2007). It has also been established that taking into account the immediate environment of the patients not only provided positive results for the patients but for the family as well (Kuipers et al.). Therefore, the work that has been done about the family and their experiences with mental health has shown that recovery is not the exclusive purview of the mental health professional but a collective effort (Kuipers et al.).

In this study, the experiences of the Cape Town families of people with schizophrenia will be looked at within the context of families adapting and learning how to cope with the illness of their relatives. The study will also explore the experiences of principal carers with the mental health system. The family is usually a unit composed of a number of people who are collectively affected by the illness of their relative. Each member of the family in his/her unique way usually plays a role in caring for his/her relative. However, given the fact that the present study is small the members of the family that are going to be interviewed are those that take prime responsibility for caring for their relative.

The rationale for the present study

The purpose of this study is to examine families' experiences with schizophrenia and mental health system. A subsidiary aim is to illustrate to mental health professionals the role family members play in relation to the persons with mental illness in the community and the experiences they have with the mental health system in South Africa. Evavold (2003) asserted that though the philosophy and concept of family support and resources and services for families has started to feature in mental health system programmes, the pace at which family support is implemented is rather slow. Even though over the years families, to some extent, have taken partnership regarding the decision-making process about the treatment of their relatives with mental illness, many mental health professionals fall short of implementing this partnership (Evavold). Johnson (2006) observed that the lack of inclusion of families in care is a serious limitation because persons with schizophrenia upon discharge from the hospital return home to their families, who may not be emotionally, physically or materially prepared for this burden. Evavold says one of the key ways in which we can see how important families are in decision-making about treatment is the fact that families are commonly centrally involved in whether people with schizophrenia receive any treatment at all. The family is also involved in nursing care, economic support, arranging for health care treatment, and also ensuring compliance to medication (Evavold). The paucity of the development of family support services in mental health is related to a number of factors that include the stigma of mental illness (Kung, 2003; Weisman, Duarte, Koneru, & Wasserman, 2006), and the lack of public and professional understanding and support for family concerns (Evavold).

Given the fact that South African literature has provided very little information about the experiences of families with schizophrenia and their importance in the decision-making of the treatment of their relative, it is important to gather South African data to enable local researchers to judge if international literature on families experiences with schizophrenia is appropriate for this country's diverse population (Jonker, 2006). Adding to the international literature it is important to find data that is relevant within South African context that would help researchers to come up with appropriate models for our country (Jonker). Jonker (2006) says that this will help South African researchers and mental health professionals in providing an efficient service to families.

A personal motivation for this study

My interest in this field is personal as well as academic: My eldest brother was diagnosed with schizophrenia about nine years ago. At the time when he fell ill he was studying an engineering course at Wits Technikon (now called University of Johannesburg). His illness devastated my family especially my mother. As a family we were in denial for many years and attributed the course of his illness to many things. There was a hope that he was going to recover and resume his normal life once more.

For many years it was difficult to handle my brother. I say handle because he required to be handled. When my parents were at work the caregiving responsibilities fell on the shoulders of my siblings and me. This was quite a challenge for me and my brothers, and sisters because all of us were young at the time and did not know how to deal with his erratic behaviour. Unfortunately, my parents did not want to get my brother to stay in the hospital and thus all of us in the family had to re-orientate our lives and expectations around his illness.

I remember my friends coming over to my parents' house to visit me and seeing my brother displaying his erratic behaviour. And, I remember the embarrassment that I felt at the time and having no one to talk to about these issues. I was also confused about what was happening to him; in fact all of my siblings were confused as well. Sometimes we would blame him for his illness and expect him to get up on his feet and make something of his life.

For many years my family found the illness hard to accept, especially my mother. She would say that he is going to get better some day. There was always hope of his recovery happening at some point. One year after the other, the prospect of his recovery looked doomed as he would be in and out of the hospital.

There were times when I had to take him to the hospital because of his many relapses. It was during these times that I met many family members who had the same problem. Sitting there by the waiting rooms of the hospitals we would engage in talks about our problems with our relatives in hospital. It was during these times that I felt that my family and I are not alone. Those unscheduled discussions in the waiting area gave me a sense of belonging. Hearing other people talking about the similar problems that my family and I had was empowering because I gained a lot of knowledge about how to cope with my brother amongst other things.

It was during the talks with other family members that I realised that we as family members do not know much about the illness of our relatives. I felt at that time most of us do not have the support that we need to deal with ill relatives. I also believed that the mental health system does little to meet our needs. In my experience at that time, I believed the mental health system does not see us as partners that they can work with to

better the treatment of our ill relatives. For this reason I became interested in the question

of how families go through life living around their family member with schizophrenia, as

well as their experiences with the mental health system.

CHAPTER TWO

LITERATURE REVIEW

This literature review focuses on issues specifically relevant to family members' experiences with schizophrenia and as well as the mental health system. It comprises sections on family burden, deinstitutionalization, psychoeducation, stigma and mental illness and theory of Expressed Emotions (EE).

Defining family caregiving

Caregivers may be defined in many different ways. Caregivers vary in their relationship to the care recipient (spouse, child, professional); they may be the primary or secondary caregiver; they may live together with the care recipient or separately (Brodaty & Green, 2002). However, one thing that is common is that caregiving includes giving support and assistance to a family member who has special needs (Walker, Pratt, & Eddy, 1995). Family caregivers are sometimes described as "informal"; Lubkin and Larsen (2006) say that it is a term that is employed by professionals to describe people who take on caregiving responsibilities without receiving any source of income and who usually have personal bond to the person at the receiving end of care (for example, a family member or friend) (Lubkin & Larsen). On the other hand, "formal" caregivers, including home health care providers and other professionals, often undergo training and receive payment for their services that they tender to the care recipient (Health Plan of New York [HPNY] & National Alliance for Caregiving [NAC], 2000). Some formal caregivers are trained volunteers associated with an agency (HPNY & NAC).

However, the literature on caregiving reveals a lack of clear and precise definition, which is essential for researchers and for professionals who work with family caregivers (Barer

& Johnson; Cantor; MaloneBeach & Zarit; all cited in Walker et al., 1995). Walker et al. assert that the difficulty in defining family caregiving stems from the complex relationship between the caregiver and the care receiver with regards to their history and connection.

<u>The characteristics of family caregivers</u>

HPNY and NAC (2000) stated that more than 44.4 million people who live in America provide informal care-giving to either friends or family members. HPNY and NAC assert that spouses, extended family members, partners, friends, neighbours, and adult children (in extreme cases even small children) mostly serve as informal caregivers and therefore do not receive payment for providing care. National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP) (2004), reported that about 83% of caregivers are related to the people with whom they provide care for.

HPNY and NAC (2000) posit that studies have shown that caregivers are of all ages. Caregiving occurs across all socioeconomic strata and in all cultural groups. Caregivers come from every corner of the earth and from different walks of life (HPNY & NAC). The average age of a caregiver providing care to an adult or a person with a mental illness is 46 years. It is stated that more than half of all caregivers range between 18 and 49 years old (HPNY & NAC).

<u>Gender and family caregivers</u>

The literature suggests that majority of caregivers are women. Caregiving is often perceived as an exclusive purview of women because many of the demands of the sick people are often met by women in families (Walker & Pratt as cited in Lubkin & Larsen, 2006). Bedini and Phoenix (2004) reported that about 80 percent of people who provide

informal caregiving are women. In the event where the spouse is absent, daughters or daughters in law are mostly the people who have to undertake caregiving responsibilities. HPNY and NAC (2000) asserted that on average women spend 17 years of their lives rearing their children and another 18 years as caregivers to elderly parents, and in some cases to people with mental illness. However several studies (Awad & Voruganti, 2008) reported a trend of male caregivers that is burgeoning. In fact, Awad and Voruganti pointed out that according to some recent studies, 40% of caregivers are men.

Deinstitutionalization and mental health system

A major factor associated with family caregiving in schizophrenia is deinstitutionalization.

Defining deinstitutionalization

Deinstitutionalization can be described as a process where the mentally ill people are no longer residing in psychiatric hospitals for long periods of time but hospitalization is replaced by brief lodging in smaller and less isolated community-based centres (Bachrach, 1993).

Lamb and Bachrach (2001) assert that deinstitutionalization generally consists of three component processes:

(1)   The release of mentally ill people from psychiatric hospitals to alternative facilities in the community,

(2)   the diversion of potential new admissions to alternative facilities, and

(3)   the provision of special services for the care of mentally ill people who are not in state hospitals

Historical overview

The United States of America was the first country that saw through the implementation of the policy of deinstitutionalization on a major scale (Dillion, 2006). The treatment of people with mental illness developed rapidly in the twentieth century and took a radical transformation during World War II (Goldman et al.; Kramer; both cited in Gronfein, 1985).During World War II the enactment of the Barden-Lafollette Act of 1943 opened the door for vocational services and made it possible for the individuals with mental illness to receive federal and state rehabilitation/vocational rehabilitation services (Rubin & Roesser as cited in Accordino, Porter, & Morse, 2001). By 1946 the national policy of the United States promulgated the need for community treatment for people with mental illness by enacting National Mental Health Act into law (Accordino et al).

Accordino et al. (2001) posit that before 1948, almost half of United States had no outpatient clinics; however, twelve months later every state but five had at least one clinic. By 1954, there were about 1, 234 community outpatients clinics in the United States (Grob as cited in Accordino et al.). In 1955, the number of people that were institutionalized in state hospitals declined dramatically (Dillon, 2006). Over the next 25 years, the patients in the state institutions dropped by 75 percent, in actual figures, a fall that translate to 154,000 patients in 1980 with 559, 000 in 1955 (Dillon, 2006; Koyanagi & Bazelon, 2007).

In 1953 Smith, Kline and French labs began experimentation with chlorpromazine (Swazey as cited in Gronfein, 1985). A few years later the French firm of Rhone-Poulenc developed chlorpromazine commercially (Swazey as cited in Gronfein). By 1954 the American companies were given the endorsement and approval of the Food and Drug

Administration (FOA) to begin distributing and marketing the drug under the trade name

Thorazine (Swazey as cited in Gronfein).

The introduction of antipsychotic drugs played significant role in the

deinstitutionalization process and shaped how people with mental illness were treated at

that time, and laid the ground work for future treatment. Researchers like Brill and Patton

who were the advocates of the antipsychotic drug treatment received ovation about the

success of these drugs (Whitaker, 2004). The discharge of many mentally ill people from

the state hospitals was attributed to the antipsychotic drugs (Whitaker).

However, ever since the introduction of antipsychotic drugs in 1954 there has been much

controversy about these drugs and their role in the process of deinstitutionalisation

(Gronfein, 1983). Novella (2008) asserts that the reduction of the resident population and

high number of people with mental illness discharged from mental health hospitals had

begun prior to the introduction of antipsychotic drugs. Whitaker (2004) also posits that

the reduction of resident population in the state institutions cannot be solely attributed to

antipsychotic drugs, as there were a number of confounding factors during that time. For

example, in the early 1950s, the council of state governments in the US made the

recommendation that the federal government ought to relieve state government of the

fiscal burden by taking on half of the burden in pursuit of caring for the mentally ill, and

suggested that "outpatients clinics should be extended and other community resources

developed to care for persons in need of help, but not of hospitalization", (Whitaker, p.

445).

In the 1960s the national deinstitutionalization movement was launched through

publication of a report by Joint Commission on Mental Health, created by federal law to

report to congress (Koyanagi & Bazelon, 2007). The commission cited shocking and alarming inhumane conditions in institutions (Freedman & Moran, 1984). It also pointed out that the long-term treatment in state institutions had detrimental effects on the lives of people with mental illness (Freedman & Moran). The commission noted further that the costs of providing institutional care were often high and therefore unsustainable (Freedman & Moran). To fight these challenges, "the commission recommended major legislative and programmatic reforms aimed at preventing hospitalization, reducing lengths of hospital stays when unavoidable, and returning patients in communities with appropriate aftercare and rehabilitation" (Freedman & Moran, p. 447).

In 1963 President John F Kennedy, building on the recommendation of the Joint Commission on Mental Health, and partly because of his sister Rosemary's intellectual disability, enacted mental health legislation which acknowledged deinstitutionalization as a national policy (Stubbs, 1998). In addition, deinstitutionalization was also given impetus by what was at that time an emerging and thriving social concern for the civil rights of mentally ill people and a strong view that mental illness could be treated and in some instances even cured (Ray & Finley; Wegner; both cited in Accordino et al., 2001). The year 1965 also brought crucial developments in terms of the federal funding sources for community mental health services to help them meet the needs of large pool of mentally ill people migrating from state hospital to community health centres (Clarke, 1979).

Successes

The process of deinstitutionalization had the side-effect of revealing the inhumane conditions and appalling treatment that people with mental illness had had to endure in

mental health state institutions (Dillion, 2006). For example, Clarke (1979) discusses the case of Kenneth Donaldson, who was incarcerated against his will from 1957 until 1971. According to Clarke, prior to the incarceration Mr Donaldson had never been judged dangerous to himself or others, had never lost his ability to hold a job. Indeed, he may never have been mentally impaired. In another case, a woman was released in 1978 after spending thirty years in a Washington D. C., mental hospital (Stevens as cited in Clarke). She was poor and could speak only Spanish; she was initially admitted to a mental facility because no other institution would care for her problem – typhoid fever. Were it not for deinstitutionalization cases like these and many others might not have been uncovered.

Lamb and Bachrach (2001) assert that deinstitutionalization highlighted awareness of the humanity and needs of mentally ill persons. It has also shifted an exclusively biological ideology of psychiatry by drawing attention to the complex interface between biological, psychological, and socio-historical events that affect the lives of people with mental illness (Engel as cited in Lamb & Bachrach). Politically, deinstitutionalization accorded people with mental illness with the civil rights for equal treatment, liberty and freedom. These people can now seek recourse against the state institutions where both covert and overt discrimination may be levelled against them. In 1975 The Supreme Court's issued a landmark decision in O'Connor v Donaldson. The court ruled that people with mental illness, having committed no crime and presenting no imminent danger to themselves or others, cannot be involuntarily committed to an institution (Hogan, 2002).

Problems with deinstitutionalization

Accordino et al. (2001) assert that shifting the locus of care from state institutions to community health centres was not as effective as anticipated by the advocates of deinstitutionalization. One area in which there has been less success than at once hoped is in the rates of institutionalization and readmission to mental hospitals. Stiles, Culhane, and Hadley (1996) conducted a comparative study about the status of state mental hospitals in the United States between 1949 and 1988, and discovered that admission rates in 1988 nearly double those of 1949. Early optimism about deinstitutionalization saving costs has also proved unfounded. The process of moving people with mental illness from state institutions to community care failed to reduce the costs of caring for these patients (Clarke, 1979; Freedman & Moran, 1984; Lamb & Bachrach, 2001;). Good community care is probably at least as costly as in-patient care (Bachrach, 1993). However, Clarke (1979) says that this issue of cost has not been settled, for example he cited a study done by Sharfstein and Nafziger both whom analyzed the costs and benefit of community versus institutional care for a single patient using cost comparison over a 3-year period. Their findings revealed that the cost of community care was 2.05 times less than the cost of state hospital care. In addition, subsequent research also suggests that community mental health services are more cost-effective than state institutions (Knapp et al.; Marks et al.; both cited in Wiley-Exley, 2007). A review of 42 economic assessments of developed countries showed that community centres provide care at a lower or equal cost in comparison to state hospitals (Roberts, Cumming, & Nelson as cited in Wiley-Exley).

Freedman and Moran (1984) pointed out that deinstitutionalization took place with a lack of thorough planning and little extensive research on assessing and evaluating the process and its overall impact. Another problem with deinstitutionalization was that the population of people with mental illness was poorly defined and also misunderstood (Bachrach; Grob; Olfson, Leon, & Weissman; all cited in Accordino et al., 2001). Subsequent research on this issue has been stronger methodologically, and cost is clearly not the only consideration when community care is evaluated (Saxena, Thornicroft, & Whiteford, 2007).

Deinstitutionalization in South Africa

The implementation of deinstitutionalization process came much later in South Africa in comparison to North America and Europe. In fact, in South Africa much of this process took place around the 1990s. For example in the late 1990s the Western Cape saw a process were 696 people with chronic psychiatric illnesses who had been residing in long term care being discharged to community centres (South African Health Review as cited in Strachan, 2000). In other parts of the country, for example, in Gauteng, the deinstitutionalization process was motivated by legal imperatives. For instance, the newly appointed judges at that time were sceptical about the mandatory incarceration of people in contracted mental health care facilities, and thus about 300 cases of detention were discharged (South African Health Review as cited in Strachan).

Strachan (2000) asserted that in Cape Town in the 1990s there were a number of chains of rehabilitation groups for persons with mental illness. Many of the patients who were discharged from the state hospital to being cared for by their families at home ended up being supported solely by the community centres (Strachan). For example, in one of the

rehabilitation centres in Maitland, Cape Town, 98% of the patients had no connection with their family members, but the author anticipated that with more intensive follow-up the more patients would come to have contact with their families (Strachan).

Deinstitutionalization, family studies and schizophrenia

Deinstitutionalization is a policy that came about in the context of attempts to abolish the inhumane treatment that mentally ill individuals used to endure in state institutions. The policy was made possible by strong political leadership, lobbied by human rights organizations, and caring family members. Deinstitutionalization was not just a matter of getting people out of institutions, however; it was also about changes in how care of people associated with mental disorder is conceptualized.

There were changes that took place theoretically in how professionals understood the role of families in certain mental disorders. For example, in the case of schizophrenia there were many family theories (e.g. double bind theory, symbolic studies, communication deviance studies) that gained credence during the earlier period of wide scale deinstitutionalization. Though there were a few family studies that took place prior to deinstitutionalization, most such studies took serious momentum at the height of the deinstitutionalization process. A plethora of these family studies became prominent between the 1960s and the 1980s. These family studies were in concert with the rhetoric or rather the goals that were enshrined in the policies of deinstitutionalization.

Family studies broadened the focus from people with schizophrenia to considering their families as well. Deinstitutionalization brought with it new challenges for families. Whereas in the past many family members had suffered at being excluded from the lives of their institutionalized relatives, now families had to face the challenge associated with

having their relatives living at home. In addition, in the early days of family theories, the

families had to contend with the challenges of being blamed by mental health

professionals for causing the illness of their relatives, as the review below will show.

A brief historical overview of family studies and schizophrenia

Eroticized parent-child relationships

Early on it was believed that parents' failures to preserve appropriate age and sex

boundaries between family members played a prominent role in the aetiology of

schizophrenia (Liem, 1980). These failures were said to manifest themselves in many

ways.

In one version of this theory, a parent was seen as going to the child rather than spouse to

have his/her emotional needs satisfied (Liem, 1980). In other situations, the parent would

expect the child to assume parenting role (Liem). The distortion of appropriate roles in

both situations were said to be the product of parent pathology (Liem). Liem cited a study

done by Walsh; she investigated both "child as mate" and "child as parent" themes in

individual and conjoint Thematic Apperception Test (TAT) stories of normal,

"schizophrenic", and "nonschizophrenic" psychiatric control families with young adult

offspring. She also looked into family interactions during the conduct of conjoint TAT

sessions for proof of agreement or disagreement when one person displays these themes

(Walsh, as cited in Liem, 1980). While there were no significant differences among three

groups of families in the rate of "child as parent" themes, Walsh concluded mothers,

fathers, and children in the schizophrenic families showed significantly more "child as

mate" themes compared to other family members in both their individual and conjoint

stories (Walsh as cited in Liem).

Double bind theory

Double bind theory was first developed by George Bateson and colleagues after studying

the interaction and communication of families of people with schizophrenia.

Double bind theory asserts that schizophrenic symptoms are manifestations of negative

social interactions in which the individual is perpetually subjected to conflicting

injunctions, while being denied the opportunity to adequately engage such injunctions or

perhaps to simply evade them (Bateson, Haley, Jackson, & Weakland as cited in

Koopmans, 2001). If, for example,

> a mother tells her son that she loves him but at the same time is turning her head
>
> away in disgust, the child [catches] two conflicting messages about their
>
> relationship: [the apparent] message of affection on the verbal level and one of
>
> [acrimony] on the nonverbal level. (Koopmans, 2001, p. 292)

It is argued that the child's ability to respond to the mother is injured by such

contradictions, because one message invalidates the other (Koopmans, 2001).

Furthermore, because the child is solely reliant on the mother; the child is too young and

has not even developed sufficient sense of self or the interpersonal skills to engage her

about the apparent contradictory messages (Bateson et al. as cited in Koopmans).

Double bind theory postulates that the symptoms of schizophrenia reflect the

accommodation of individuals to exposure to such interactions over a certain period of

time (Koopmans, 2001). Once the child has been socialised into conceiving their universe

in terms of contradictory environmental input, they become incapacitated to engage

effectively to any input from the environment (Koopmans).

Their inability to respond effectively to such information is in the long run no

longer contingent on the extent to which stimuli from the environment are in fact

contradictory in specific interactive sequences. Instead, the individual will

generally experience any input from the environment as conflicting information.

(Koopmans, 2001, p. 292)

Double bind theory further postulates that unfortunately the long term effects of this

inability will typically reflect schizophrenic symptoms such as flattened affect, delusions,

and hallucinations, and incoherent thinking and speaking (Bateson et al. as cited in

Koopmans, 2001).

Visser (2003) asserts that double bind theory is characterised by four communicative

elements:

1. At least two persons who enter into repeated communication and whose

   relationship is intense and vital, (e.g. parent and child).

2. A primary negative injunction with threat of punishment, (e.g. the parent tells

   his/her child, "Do not do x or I will punish you").

3. A secondary injunction (often implicit) which conflicts with the primary one,

   (e.g. "if you do not do y you will be punished, and y requires that x be done").

4. A tertiary injunction that impedes the child from critically engaging the

   conflict of the primary and secondary injunctions, for instance, "that's life", or

   "because I said so"

Disordered family communication

Liem (1980) asserted that the starting point of theories of disordered family

communication is the theoretical and empirical work of Bateson et al., and Wynne and

Singer. The concept of communication deviance refers, inter alia, problems in creating and maintaining a shared focus of attention, both preconditions for meaningful communication (Liem). Liem posits that Wynne and Singer distinguished two common types of deviant communication styles. One was an amorphous style in which communication is vague, indefinite, and loose. The other was identified as fragmented (e.g. communications are easily interrupted, are inadequately integrated, and typically are short of closure) (Wynne & Singer as cited in Liem). Liem says that Wynne and Singer asserted that these are long-term characteristics of families of young adults with schizophrenia and which in fact herald the onset of schizophrenia and also contribute to its development. Liem argued that even though the authors' theoretical perspective was identified as transactional, often focusing on the mutual nature of parents and child effects, their empirical research was focussed almost exclusively on the impact of parental communication deviance on the child.

Symbiotic relationships in families of people with schizophrenia

This clinical and theoretical work attributes a hypothesized incapacity on the part of people with schizophrenia to tell the difference between the self and world to an early symbiotic bond between mother and child (Bowen; Lidz, Fleck, & Cornelison; Searles; all cited in Liem, 1980). Other main postulates of a symbiotic relationship theory encompass dependency issues, intrusiveness and separation difficulties (Liem). These studies claimed to show that mothers and children in what they termed schizophrenogenic families were prone to describe their own past and current relationships in ways that suggest greater symbiotic attachment than mothers and children in "normal" families with young adult with other mental disorders (Liem, 1980). Young

adults with schizophrenia were reported to be more prone than were other adults to characterize mother figures in projective stories as more symbiotically attached to child figures (Liem).

Power relationships in families of people with schizophrenia

A later development in thinking about families and schizophrenia focused on power issues and on the distribution of power in families (Lidz et al.; Reichman; both cited in Liem, 1980).

For example, observations of the interactions of mothers, fathers, and sons in what were termed normal, schizophrenic, and non-schizophrenic psychiatric control families showed that fathers of people with schizophrenia were more dominant as opposed to mothers and sons than were fathers in both types of control groups (Liem, 1980). In families of people with schizophrenia, it was argued that fathers assume complete control and sons stay withdrawn and dormant (Wild et al, 1975; cited in Liem).

Although it may be tempting to say that these early family studies are obsolete and therefore not relevant today, it is also important to note though that they still continue to inform and influence how mental health professionals perceive the role of the families in the aetiology of the ill relatives' mental disorders. As the section on psychoeducation, later to be discussed, will show, many mental health professionals are still reluctant to work with family members despite the evidence that shows that such partnership would be beneficial to the treatment of the ill relatives.

Expressed emotion

The genesis of the concept of expressed emotion

George Brown developed the construct of expressed emotion in the 1960s (Leff, 1998).

In the 1960s, Brown and his colleagues observed that patients with schizophrenia that

were discharged from the hospital and went on to live with their siblings or in lodges as

opposed to living with their families of origin did better (Brown et al. as cited in Hooley,

2007). Therefore Brown and his colleagues made a link between the family relationships

and relapse of patients with schizophrenia (Hooley). Hooley asserts that Brown, together

with Michael Rutter, began working on the problems of how to measure the range of

feelings and emotions in the families of people with schizophrenia. The end – result of

such work was the development of the construct of expressed emotion (Leff).

Although the EE construct was first develop to explain communication in families of

people with schizophrenia, EE has been applied in a plethora of psychiatric disorders

(Leff, 1998). As the current study focuses on schizophrenia, only the literature on EE and

schizophrenia will be reviewed.

Measurements of expressed emotion

Hooley and Parker (2006) assert that the gold–standard assessment of EE is a semi-

structured interview better known as Camberwell Family Interview (CFI). The CFI is

conducted with the primary caregivers of the patient with schizophrenia in the absence of

the patient. Caregivers are not interviewed together but separately (Hooley & Parker).

The interview sessions are recorded for later coding (Hooley & Parker).

The CFI is used to make ratings of five scales: criticism, hostility, emotional over–

involvement, warmth and positive remarks (Hooley & Parker, 2006). Hooley and Parker

assert that three of the five scales, namely, criticism, hostility and emotional over-involvement are the most important ratings in EE. The classification of caregivers as high or low in EE is made based on the ratings of these scales (Hooley & Parker). Hooley and Parker say that if for instance, the caregiver makes an above – threshold number of critical remarks (six or more in case of schizophrenia), or makes any comment that is regarded as hostile or displays evidence of marked over-involvement (a rating of 3 or more on a 0 – 5 scale), he or she is given a classified as high in EE.

Difficulties in the measurements of EE

Hooley (2007) asserts that "[A]n inherent assumption in the traditional approach to EE classification is that there is something qualitatively different about the families who score above or below the specified critical threshold" (p. 352).

Hooley (2007) further states that although there are several studies that have offered empirical support for this assumption dichotomizing EE rather than using critical remarks frequency as a continuous variable, the use of a dichotomous variable does create problems. Firstly, it implies that what come to be termed "low EE families" do not have as many problems as "high EE families" and thus need not any help (Hooley). Therefore, low EE families are often not offered family – based treatments or given support (Linszen et al. as cited in Hooley). Secondly, assuming a dichotomous classification of EE impedes the range of the variable in statistical analysis (Hooley).There are always difficulties when a complex and multidimensional concept is reduced to a simple dichotomous variable.

Hooley and Parker (2006) cited other problems that limit the practical utility of EE. For example, the first problems that Hooley and Parker noted is that EE can only be

examined by raters who have received between 40 and 80 hours of formal training. It is furthermore, an expensive exercise to train clinicians how to do ratings of EE (Hooley & Parker). Thirdly, each CFI takes 1 – 2 hours to administer and another 2 – 3 hours to code (Hooley & Parker). All these factors may place constraints on the optimal use of EE measures in resource-poor contexts.

Expressed emotion, relapse and schizophrenia

Many studies have shown that EE is associated with relapse rate in schizophrenia (Dixon, Adams, & Luckstead, 2000; Kuipers et al., 1992). Core elements of EE that are associated with increased relapse rate are high rates of criticism and hostility (Hooley, 2007), and these have been shown to be amenable to intervention. The question arises though of whether people who display high levels of EE share any common characteristics, and this is discussed below.

Expressed emotion and relatives of people with schizophrenia

Hooley (2007) states that high and low–EE relatives differ from each other in ways that have implications for how they try to manage psychopathology with their ill relatives. Hooley cited his earlier study that revealed that high–EE relatives often have a more internal locus of control for their own behaviour than do low–EE relatives. Hooley observed that high–EE relatives often assume active role in dealing with their own life problems and challenges. By contrast, the low–EE relatives are said to be more fatalistic (Hooley). In addition, on self–report measures of personality, high–EE relatives often score in ways that suggest they are more conscientious and as well as less tolerant and more rigid in their approach to life than are low-EE (King et al. as cited in Hooley).

Hooley (2007) asserted that several studies (Barrowclough & Parle; Scazufca & Kuipers; Tarrier) have suggested that low-EE relatives have a low stress levels as opposed to high–EE relatives.

EE and culture

There have been many attempts to use the EE concept cross-culturally, including in countries such as India, China, Israel, Japan, Iran, Nigeria and Australia (Leff, 1998). The evidence as to the robustness of the concept cross-culturally has not been consistent. Jenkins and Karno (as cited in Hooley, 2007) note that cultures shape the expressions of the kinds of behaviours that permit criticism. Levels of EE are lower in India than they are in the United Kingdom and USA (Leff et al., 1987). On the other hand Hashemi and Cochrane (as cited in Hooley) reported that 80% of the relatives of British Pakistani patients were rated as being high EE compared to the 45% of white and 30% of British Sikh families. A major difference was how the relatives in these different ethnic groups scored on the EE component of emotional overinvolvement (Hooley). Whereas the modal score for the white and Sikh families lies was 1 (OEI is rated on a 0 – 5 scale), the modal score for the Pakistani families was 4. Hooley says that the findings bring to light the role culture plays in the expression of critical or emotionally over-involved attitudes.

Family burden and schizophrenia

As has been explained elsewhere in this thesis, the advent of extensive policies of deinstitutionalization saw the shifting of the locus of care of mentally ill persons from psychiatric hospitals to families (Jenkins & Schumacher, 1999; Magliano, 2008). Although this shift was intended to aid the patients in the community, the family often had to take responsibility for caring for their loved ones without knowledge or

preparation for the caring role (Loukissa, 1995).The concept of family burden was introduced around the 1960s after a great deal of attention was given to the understanding of the burden that families experienced for caring for their mentally ill relatives (Abelenda & Helfrich, 2003; Glanville & Dixon, 2005).

Defining family burden

In the literature on family burden there is a lack of a precise definition of this concept (Awad & Voruganti, 2008; Ohaeri, 2002; Tessler & Gamache, 1994). In fact, there have been many criticisms levelled against the family burden concept largely on the grounds that it obscures possible multidimensionality (Poulshock & Deimling as cited in Tessler & Gamache), and focuses only on the negative aspects of looking after relative with mental illness. Similarly, Awad and Voruganti asserted that although the negative consequences of caring for an ill relative have received much attention, there are instances (though less frequent) where the experience of caring for persons with schizophrenia can be a self–satisfying act. In similar vein, Ohaeri (2002) observed that the term 'burden' does not fully encapsulate the totality of the experience of providing care for an ill relative. Awad and Voruganti posited that in order to highlight positive aspects of caregiving experience, it was proposed that the concept of 'burden of care' be replaced with a rather unbiased term (e.g. 'experience of caregiving'). However, the burden of care concept continues to be mostly used, often mirroring the depths of negative effects of burden of care (Awad & Voruganti).

The family burden definition that is mostly used in the literature is that of Hoeing and Hamilton (1966). Hoeing and Hamilton distinguished between two sets of burden, objective and subjective. The objective burden refers to the concrete factors that are seen

to bring family life into disruption such as loss of income (Glanville & Dixon, 2005),

disruption of daily routine (Magaña, Garcia, Ramirez, Hernández & Cortez, 2007), social

life and work interfered with (Thompson & Doll, 1982), the well-being of the other

family members, and in particular abnormal behaviour likely to cause distress (Samele &

Manning, 2000). The subjective burden refers to experience or psychological or

emotional impact of looking after a mentally ill relative (e.g., feeling worried or strained)

(Samele & Manning).

The satisfaction of caregiving in families

Uwakwe (2006) says that although caregiving can lead to psychological, mental, physical

and material burden, and stress, the caregiving experience may still be satisfactory to

some families. The first study that investigated the satisfaction of caregiving was done by

Bulger, Wandersman, and Goldman (as cited in Abelenda & Helfrich, 2003). Bulger et al.

reported that majority of the participants in their study pointed out that looking after

"their children made caregivers feel happier and closer to the children, enhanced

caregiver's self – esteem, and provided insights about their personal strengths and values"

(Abelenda & Helfrich, p. 28). In other studies that investigated the benefits of caregiving,

Rhoades and McFarland (1999) cited work done by Tennestedt and Rebelsky in which

qualitative data were gathered from 48 family caregivers in Massachusetts. The

participants that cared for their elderly people stated that the benefits included

satisfaction, reciprocity, companionship, and personal growth. Ekwall, Kristensson,

Hallberg and Rahm (as cited in Rhoades & McFarland) in their study found that male

caregivers were more satisfied than their female counterparts. Male caregivers reported

that caregiving had broadened their horizons and helped them grow as people.

<u>Negative factors associated with caregiver burden</u>

Negative factors that are associated with caregiver burden include: self–blame and guilt experienced by parents, the financial strain of treatment, and the parents' responsibility to provide extensive supervision for the patients (Loukissa, 1995). Reinhard and Horwitz (1995) say that one of the "factors that may influence the meaning of the caregiving and burden experience is the relationship of the family caregiver to the person with a serious mental illness" (p. 742). For example, several studies (Dixon et al., 2000; Tessler & Gamache, 1994) have pointed out that the relationship between the caregiver and ill relative is sometimes marked by erratic behaviour (e.g. verbal and physical aggression) of the ill person, thereby making the experience of caregiving difficult to bear. Glanville and Dixon (2005) mentioned that symptom type (positive or negative) may contribute to family burden. For example, positive symptom behaviours such as hallucinations and delusions together with a high degree of social dysfunction and recurrent relapses are often linked with greater family burden than negative symptoms of apathy and social withdrawal (Glanville & Dixon).

Awad and Voruganti (2008) cited a recent community survey that included 697 caregivers and 439 ill relatives with schizophrenia that identified the following ten negative impacts of schizophrenia on caregivers:

- A decrease in family social outings and activities

- Constant disagreements, disputes or fights among family members

- Depression in other family members (e.g. siblings of the ill relative)

- Embarrassment of other family members (caused by erratic behaviours)

- Economic difficulties

- Delay or cancellation of vacation plans

- Decreasing self – esteem or confidence in other family members

- Decline in the work or school performance of other family members

- Increase in alcohol use

Furthermore, Awad and Wallace (as cited in Awad & Voruganti, 2008) asserted that important issues that caregivers also reported to significantly contribute to their perception of burden are:

- Lack of motivation and poor self-care on the part of the person with mental illness

- Lack of access to crisis psychiatric care and hospitalization when needed

- Disrupted family dynamics and collective coping styles

Background to the caregiver burden concept

Awad and Voruganti (2008) asserted that in 1955 Clausen and Yarrow published what was probably one of the earliest US studies that specifically looked into the impact the mental illness of the relative had on the family. In 1961 Mandelbrote and Folkard (as cited in Awad & Voruganti) did a study that provided data that suggested that 55% of families of people with schizophrenia were distressed and felt limited as a result of living with their relative at home. Awad and Voruganti (2008) observed that in that study (Mandelbrote & Folkard) an unexpected finding was that only 2% of the families revealed that stress as a result of looking after their relatives was the main problem. It appears that during that era a high degree of tolerance seemed to have been a recurring theme in many studies, contrary to the high levels of burden that the families and particularly primary caregivers were exposed to (Awad & Voruganti).

In 1963, Grad and Sainsbury (as cited in Loukissa, 1995) did a ground breaking study

that would be a foundation for future research on caregiver burden. In their study they

asked the caregivers about four areas:

a) Worrisome conduct (e.g. uncooperativeness, physical complaints, and

   expression of delusional thought content).

b) Disturbance and disruptions in seven aspects of family life, which included:

   physical health, siblings in the home, social and leisure activities, domestic

   routine, income, employment, and social relations with neighbours and

   members of the community.

c) Symptoms of the relative mental illness; and

d) The assessment of family members', especially caregivers' overall feelings of

   burden.

The findings of the study revealed that most distressing behaviours were physical

complaints from the ill relatives, behaviours that were deemed harmful to the ill relatives

or others (34%), unrealistic demands (34%), strange behaviours and odd ideas (27%), and

non – compliance and, disobedience (26%) (Loukissa, 1995).

Awad and Voruganti (2008) noted that three years later, Hoeing and Hamilton (1966) did

a classic study on the experience of burden, neatly differentiating the concept of objective

and subjective burden, as has been discussed earlier. Hoeing and Hamilton's

conceptualization of burden informed contemporary researchers and still continues do so

at the present time (Awad & Voruganti). However, Loukissa (1995) posited that another

area that was studied during the 1960s and 1970s was the effect of brief hospitalizations

on the relatives. Once more, Loukissa cited Crad and Sainsbury, who were probably the

first authors to describe the emotional and economic stress on the family that was as a result of the policy towards shorter hospitalizations and the community care of mentally ill patients. Crad and Sainbury reported that one of the way of reducing increased responsibility and distress, usually refereed to as family burden, is by having the ill relatives readmitted to the hospital (Lousikssa).

Ethnicity, culture and family burden

The findings of several studies that have investigated whether there is a difference in how different ethnic groups (e.g. White and African-American people) cope with the illness of the relatives were not consistent (Pruchno, Patrick, & Burant, 1997). Some studies (Hinrichsen & Ramez; Lawton, Rajagopal, Brody, & Kleban; Macera; Mintzer & Macera; Mui; Young & Kahana; all cited in Pruchno, et al., 1997) asserted that lower levels of caregiving burden are often reported by African–Americans families as opposed to their White counterparts. Some of the reasons why African–Americans families are accepting of their ill relatives could be because they have met many adversities in their lifetimes (Neighbors, Jackson, Bowman, & Curin; Rodgers-Rose; Spurlock; Taylor & Chatters; all cited in Pruchno, et al., 1997). Also, African–Americans families are likely to lean on their extended families for support (Hill; Markides & Mindel; Staples; all cited in Pruchno et al., 1997). On the other hand, the authors suggest that White families maintains an individualistic lifestyle that could make them feel alone and isolated in their difficult journey with their ill relatives.

Other studies (Rosenfarb, Bellack, & Aziz as cited in Awad & Voruganti, 2008) pointed out that the differences between White and African–American families could be because of their respective cultural backgrounds that shapes both perceived burden and relatives'

attitudes towards ill relatives. Nonetheless, the differences between White and African–

American families may not necessarily be as a result of cultural differences but socio–

economic differences. Having said that, several studies (Tessler, Fisher, & Gamache as

cited in Awad & Voruganti) suggested that culture does indeed play an important role in

how families perceive burden. Tessler et al. found that Hispanic families were more

accepting of mental illness of their relatives and hopeful of the future.

<u>Assessment of family burden</u>

Tessler and Gamache (1994) posit that the concept of burden of care is very general and

refers to a broad range of challenges experienced by family members (psychological,

economic, mental, and social). Awad and Voruganti (2008) assert that it is difficult to

conjure a measurement for a concept as diverse as burden. Therefore, it is quite a

challenge to for one assessment scale to provide enough information about such a

multifaceted concept (Awad & Voruganti). However, a number of family burden

assessment scales were developed from the 1960s to the present time. For example,

Loukissa (1995) says that Spitzer et al. developed the Family Evaluation Form, a standard

interview for relatives of people with mental illness to describe the relative's conduct in

the week before being evaluated and its impact on the family. It consisted of 455 items

contracted into 45 summary scales to examine both objective and subjective burden

(Loukissa). In 1980, Platt and colleagues became one of the first research teams to

develop a discreet multi–dimensionality to the concept of family burden, with the Social

Behavior Assessment Schedule (SBAS; Platt et al.; both cited in Jenkins & Schumacher,

(1999), which comprised three dimensions:

    (a) Disturbed conduct

(b) Social performance

(c) Unpleasant effects on others

<u>Direct and indirect effects of caregiving</u>

Caring for ill relatives does not affect the caregivers only emotionally, but materially as well. It is against this backdrop that several studies (Genduso & Haley, 1997; Lee et al., 2008; Tessler & Gamache, 1994) investigated the material impact of mental illness, particularly the effects of the illness, schizophrenia has on caregivers. The effect of material cost of schizophrenia on caregivers has been subdivided into direct and indirect costs

Direct costs

Direct costs are medical and non–medical (Genduso & Haley, 1997). Genduso and Haley posit that direct medical costs includes "[P]revention, detention treatment, and rehabilitation services and [comprise] such services as hospitalizations, nursing home days, outpatient psychiatric visits, outpatient other physician visits, prescription drugs, and capital investments in medical facilities" (p. 874).

Indirect costs

Lee et al. (2008) asserted that the indirect costs associated with schizophrenia are often underestimated. In similar vein, Lee et al. observed that indirect costs linked to schizophrenia are often more than economic. For example, Tessler and Gamache (1994) asserted that indirect cost often include amount of time spent by caregivers fretting over their ill relatives. Relatives of the ill relatives worry about many issues, (e.g., matters that concern the safety and well–being of their relatives (Tessler & Gamache). Genduso and Haley (1997) state that as the onset of schizophrenia often strikes early, the relatives who

get affected by this enduring illness at the young age may not be able to work for themselves for the rest of their lives.

As a result, caregivers may have to cut down on their working hours to look after their ill relatives (Genduso and Haley, 1997). Lee et al. (2008) cited a study in the UK by Guest and Cookson that looked into the absence of caregivers from work and the impact this had on productivity. The findings of the study revealed that indirect costs due to lost productivity accounted for 49% of the National Health Service expenditure on schizophrenia in the UK (Guest & Cookson as cited in Lee et al., 2008). Awad and Voruganti (2008) also cited a study that gave estimates of the number of caregivers giving up their work to look after their relatives with schizophrenia ranged from 1.2% for first episode patients to 2.5% for exceedingly demanding long – term patients.

MetLife Mature Market Institute and the National Alliance for Caregiving (2006), organizations that were developed to give support to caregivers, cited a study by Neal and Hammer (2006) that examined the occasional absenteeism reported by a high number of caregiving employees. Neal and Hammer found that costs associated with absenteeism as a result of caregiving responsibilities were quite high.

Stigma and mental health

This section will highlight the impact that stigma has on both the persons with mental illness and their families.

Thornicroft (2006) says that

> In modern times stigma has come to mean any attribute, trait or disorder that
> marks an individual as being unacceptably different from the 'normal' people

with whom he or he routinely interacts, and that elicits some form of community

sanction. (p. 170)

According to Thornicroft (2006) there are three different stigma components that can be

identified: stereotypes, prejudice and discrimination. Stereotypes can be described as a

process of generalizing from an overt physical characteristic and non-observable

characteristics (e.g., HIV/AIDS infected person) to a set of assumed traits, for instance,

being irresponsible, reckless (Dovido, Major, & Crocker, 2003). Prejudice can be

described as "the unwarranted negative attitudes people hold towards [e.g., mentally ill

people] based on their own beliefs and preoccupations and preconceptions" (p. xiii).

Discrimination may be a consequence of prejudice, which is basically a cognitive and

affective response, which often results in unfair treatment (Angermeyer, Buyantugs,

Kenzine & Matschinger, 2004).

In summary, stereotype deals with beliefs we may hold about people, and prejudice deals

with attitudes based on these beliefs, and discrimination is a set of behaviour which may

follow from stereotypes and prejudice.

People with mental illnesses are exposed to and affected by these three forms of stigma in

their daily lives; for example the opportunities accorded to people with serious mental

illnesses like schizophrenia are significantly constrained by public stigma (Corrigan et al.,

2002). Thornicroft (2006) posits that people with mental illness are made liable to

systematic disadvantages in most areas of their lives. Members of the public are also

highly unlikely to allow mentally ill people to lease their properties (Sartorius & Schulze,

2005) and less likely to befriend and interact with them (Corrigan et al., 2002).

Scheffer (2003) asserts that

On a systemic level, stigma as a social phenomenon has a strong influence on the

policies that govern the nature of, access to and funding for treatment and support,

eligibility for social assistance or the right to refuse treatment. At the level of the

community, stigma may affect how organizations including social service

agencies, employers, health care providers, or schools respond to individuals with

a mental illness and to their families. At the individual level, stigma [affects help

seeking behaviors of mentally ill individuals], creates profound changes in

identity and changes the way in which they are perceived by others. (p. 3)

Stigma has also been linked with the medical diagnosis. In other words, members of the

community are likely to stigmatise a person mainly because of his/her medical diagnosis.

For example, (Angermeyer et al., 2004; Reid et al., 2005) pointed out the diagnosis of

schizophrenia is often associated with dangerousness and neediness. Reid et al. (2005)

also found that the diagnostic labelling make people to exaggerate the illness of persons'

with mental illness, lowers evaluations of the person's social skills and also produces

unfounded beliefs that recovery is not possible in every mental illness. Reid et al. (2005)

say that when the disease model of labelling is applied to the brain, the perception that

people generally hold is that the person with mental illness has a serious lack of

judgements and also incapable of reason.

Jorm (2000) mentioned that people often have a serious lack of insight about mental

disorders. In Australia the public's accurate knowledge of depression was estimated at

only 39% and of schizophrenia at 27% (Jorm, 200). Wahl (1995) observed that people

often have their own ideas about the etiologies of mental disorders (e.g. schizophrenia).

Jorm, Korten, Jacomb, Christensen, Rodgers and Pollitt (1997) found out that 55% of members of the public believed that schizophrenia was caused by a "weak character".

The challenges associated with stigma also affect the family because it is very unlikely that any of these obstacles can affect the person with mentally illness without affecting the family as well, particularly the primary caregiver (Jones & Hayward, 2004). As providing care for a mentally ill relative may be a burdensome experience to many family members, stigma may make the experience even more difficult. Similarly, Kung (2003) expressed that "the stigma attached to mental illness and the practical strains involved in caring for a patient are significant sources of stress for the family" (Kung, 2003, p. 547).

Stigma also affects the families of people with mental illness purely because of their association with the persons with mental illness. Scheffer (2003) asserts that it is common for families to report instances of "stigma by association resulting in discriminatory and prejudicial behaviours towards them" (p. 4).

Jones and Hayward (2004) observed that stigma can affect families in ways that would make it difficult for them to support their ill relatives without fear of feeling uncomfortable or embarrassed at the reactions of others. Kuipers et al. (1992) pointed out that the negative reactions from extended family members and friends, may lead the family to feel rejected. "The sense of rejection is often mixed with feelings of guilt, anger, inadequacy and hopelessness" (Kuipers et al. p. 69).

Hendrickson, Schmal, and Ekleberry (2004) reiterated that when the family is feeling rejected by friends and extended family members or isolated and feeling inadequate, and

experiences hopelessness as a result of being stigmatised, the family distress may lead to powerlessness. Unfortunately, as a result of the distress, the family may take out their frustration on their ill relative. For example, the family may blame the relative for his/her illness, or show hostility and become too critical towards their ill relative. Several studies (Dixon et al., 2000; Jorm et al., 1997) have shown that the outcomes of families who are hostile or critical towards their relatives are often negative. By using the concept of expressed emotion EE several studies have shown that hostility and too much criticism towards ill relatives often leads to premature relapse (Dixon et al.).

Paradoxically, the concept of EE, which has been developed to help us understand caregiver burden, may be used by professionals to further stigmatise families (Adams, Wilson & Bagnall, 2000; Berlund, Vahlne & Edman, 2003; Dixon & Lehman, 1995), labelling them as unable to care for their relatives.

Given the public and professional misperceptions about mental illness, it is likely that families of people with mental illness; in this case schizophrenia, may be apprehensive about acknowledging the diagnosis of their relatives. In fact, families may not even seek professional treatment for fear of having their ill relatives labelled as "schizophrenic". However, labelling or learning of a diagnosis of one's ill relatives play an important in the lives of families. For example, without a diagnosis the family may not know how to deal with the strange behaviour of their schizophrenic relative. The family may not know the kind of treatment that they have to seek to help their relative. They might not even know what kind of information to look for or who to turn to for help. Labelling also gives the family the ability to work around how they are going to cope with the illness of their family member.

Labelling also has important professional uses. For example, Nevid, Rathus and Greene (2003) posited that on a professional level "[w]ithout labeling and organizing patterns of abnormal behavior, researchers could not communicate their findings to one another, and progress toward understanding these disorders would come to a halt" (p. 63).

Nevid et al. (2003) say that important decisions are reached based on classification and labelling (e.g., certain psychological disorders respond better to one therapy than another or to one drug than another).

<u>The consequences of stigma</u>

The impact on help-seeking behaviours

Families of people with schizophrenia, or any other mental illness for that matter, are often responsible for seeking treatment for the illness of their relatives. Several studies have reported that because of the stigma attached to mental illness, the families often shy away from seeking treatment. Scheffer (2003) posits that the stigma that is often associated with mental illness and the lack of knowledge about the symptoms of mental illness have been indicated as the main impediments for seeking help for mental health problems.

Families feeling trapped and isolated

Stigma alienates both families and their ill relatives from the society. As a result families may withdraw from its social networks thereby making it difficult for them to cope with the illness of their relatives on their own. Therefore, families may feel trapped in their situations and isolated, leading to a vicious cycle (Hendrickson, Schmal & Ekleberry, 2004).

Occupation and stigma

The prospects of people with schizophrenia being employed are generally low partly because of the stigma associated with this mental illness. For example, members of the public are less likely to hire people who are labelled mentally ill (Dovido et al., 2003). Thornicroft (2006) also says that a US study asked employers about the prospects of offering employment, and found that ex-convicts were more likely to find employment in comparison to people with mental illnesses. Scheffer (2003) mentioned a survey done about employment and mental illness. The survey "Consumer Experience with Stigma" focussed on the experience of individuals with severe mental illness and provides information about the pervasive discrimination in the workplace that often impedes them from reaping their full professional and personal potential (Scheffer, 2003). Seven out of ten said that they have received negative reception when their illness was revealed. In fact, people treated them as incompetent regardless of the skills set that they possessed (Scheffer, 2003). Three out of ten said that the issue of telling people about their mental illness other than close contacts is often avoided. Three quarters also stated when in the process of filling in job application they have learned not to disclose their psychiatric histories. This can have an indirect effect on family function, with families having to bear the financial burden of stigmatization of people with mental illness.

Causes of stigma towards mental illness

Cultural attitudes, stigma and mental illness

Bakshi, Rooney and O'Neil (1999) assert that all communities have culturally embedded attitudes and beliefs that associate mental illness with negative connotations. Therefore, these communities may be prejudiced against people with mental illness and their

families. Bakshi et al. also noted that prejudice against people with mental illness and their families generally may lead to avoidance, ridicule, rejection, fear and also perceiving individuals with mental illness as weak, although attitudes vary across different communities. For example, in communities such as China and India people with mental illness are often said to bring shame to their families. As a result of these prejudices even family members often distance themselves from their ill relatives. Although societies in the West have become somewhat more open, showing marked degrees of greater tolerance towards mentally ill people, negative attitudes were still evident (Thornicroft, 2006). In fact, Reid et al. (2005) say that negative attitudes about schizophrenia in particular are fairly consistent over time and across different places. The problem is so pervasive that a pessimistic approach has spread even among some mental health staff (Reid et al.). Mavundla (2000) found that general hospital nurses had negative feelings about caring for mentally ill people in South Africa. Stigma against mentally ill individuals is so widespread in the world that in 2001 the World Health Organization (WHO) identified stigmatization as one of the major impediments to mental health programme development and thus went on a campaign to alert public institutions worldwide about the importance of the problem.

Reid et al. (2005) noted that the anti-stigma programmes such as the WHO initiative have had the message that the public's perception must be shaped in such a way that they see the problems in question as disorders, illnesses or diseases. The public, therefore, may come to hold views that mental illnesses are caused primarily by biological factors like chemical imbalance, brain diseases and genetic heredity (Reid et al.). The aim of the approach was that if the causes of mental disorders were ascribed to factors beyond the

individual's control, people's reactions to those with mental illness would, it was argued, change and be less negative (Reid et al.).

In summary, stigma profoundly affects the lives of people with mental illness and their families.

Psychoeducation and schizophrenia

<u>Introduction</u>

The mental illness of a family member can be very debilitating to the family as whole. The impact this might have on family members individually may evoke different reactions. Given that a mental illness such as schizophrenia often strikes in late adolescence or early adulthood, parents mourn the loss of the child who might have had bright future ahead of him or her (Huey, Lefley, Shern, & Wainscott, 2007). Siblings may grieve the loss of a playmate or older brother or sister (Huey et al., 2007). However, beyond the shackles of pain, grief and loss, the family is the place on which the ill relative can depend on. Hence, Murray-Swank et al. (2007) posit that family members play an integral role in the lives of most persons who have serious mental illness. For example, Dixon et al. (2000) say that families are the primary resource in their relatives' lives, (as stated elsewhere in this report) often responsible for providing emotional support and material support, case management and advocacy.

The reality is that families assume these responsibilities while impeded by poor insight and lack of understanding of the disorder and scarcity of actual resources, minimum support, and in most cases these families do not even receive training on how to cope with the illness (Solomon, Draine, Mannion & Meisel, 1996). The reality of the presence of the disorder, in addition to the consequences of managing the debilitating illness such

as schizophrenia, may result in the family experiencing enormous stress and

overwhelming burden. Therefore, the needs of the families to acquire information,

education and most importantly problem solving skills are essential. (Solomon et al.).

The mental health system often provides services that are orientated only toward the

patient and families do not feature in these services. Solomon et al. (1996) found families

to be dissatisfied with their level of involvement in their relatives' treatment and often

feeling left out of the process. Similarly, Murray-Swank et al. (2007) say that there have

been consistent reports that assert that family members of people who have serious

mental illness cite that their needs for information and supports are rarely met in order for

them to help their relatives with psychiatric illnesses. Murray-Swank et al. further

postulate that family members often feel frustrated about not knowing where to find help

in coping with mental illness of a loved one: "A lack of knowledge, combined with

societal stigma regarding psychiatric disorders, often leaves family members feeling

profoundly isolated in dealing with the many challenges they face relating to their loved

ones" (Murray–Swank et al., p. 172).

Also, Murray-Swank et al. (2007) asserted that families are frequently confused and

perturbed by the mental health system. Murray-Swank et al. stress that families are

uncertain about whom to contact in what seems to be a confusing mental health system,

and unclear about programmes, and services for which their relative is likely to receive,

and incapable of adequately evaluating whether their relatives actually benefits from

treatment. Families need to know basic information about the illness, and especially

about likely course and prognosis, and they also need to be informed about how the

mental health system will work with their relative and themselves if they are able to

contribute best to the treatment process. Psychosocial treatment interventions for families of people with mental illness, particularly schizophrenia, have been developed by mental health practitioners to meet these needs and also provide a service with which the families are able to utilise to better their coping mechanisms (Dixon et al., 2000).

<u>Defining psychoeducation</u>

Bäuml, Froböse, Kraemer, Rentrop and Pitschel-Walz (2006) noted that the term psychoeducation was first employed by Anderson et al. and described as a behavioural therapeutic concept that constituted four elements;

(1)   Briefing the patients about the illness,

(2)   problem solving training,

(3)   communication training, and

(4)   self-assertiveness training whereby persons with mental illness were also included.

However, the precise meaning of the term has eluded historical and contemporary researchers alike, and there is a lack of consensus about the definition of psychoeducation. Since its inception three decades ago the framing of psychoeducation depends largely on the researcher using it, particularly in the field of schizophrenia. It is against this backdrop that the working group 'Psychoeducation of Patients with Schizophrenia' in Germany sought to "create a well-defined, manualized, and curriculum-orientated therapeutic method that was adapted to fit the needs of neurocognitively impaired patients with schizophrenia" (Bäuml et al., 2006, p. 3). The Psychoeducation of Patients with Schizophrenia group framed the following definition:

The term psychoeducation comprises systemic, didactic-psychotherapeutic

interventions and their relatives about the illness and its treatment, facilitating

both an understanding and personally responsible handling of the illness and

supporting those afflicted in coping with the disorder. The roots of

psychoeducation are to be found in behavioural therapy, although current

conceptions also include elements of client-centred therapy in various degrees.

Within the framework of psychotherapy, psychoeducation refers to the

components of treatment where active communication, exchange of information

among those afflicted, and treatment of general aspects of the illness is prominent.

(Bäuml et al., 2006, p. 3)

Characteristics of psychoeducation

Psychoeducation programmes usually do not have set features, but models differ

significantly in format, for instance there are differences like: "multiple-family, single-

family, or mixed sessions – the duration of treatment, consumer participation, location –

for example clinic based, home, family practice or other community settings – and the

degree of emphasis on didactic cognitive-behavioral, and systemic techniques" (Dixon et

al., 2001, p. 904).

Dixon et al. (2000) assert that although the specific elements and construction of the

various programmes are not the same, the programmes that usually have good outcomes

have certain features in common:

1. They view schizophrenia as an illness;

2. They are implemented by mental health professionals,

3. These programmes are provided as a package that are inclusive of medication as part of the overall treatment,

4. They regard family members as partners and therapeutic agents, although family outcomes are important,

5. They focus on patient outcomes, although family outcomes are important, and

6. They do not include traditional family therapies which assume that family interaction and communication style play a primary etiological role on the development of schizophrenia.

Benefits of psychoeducation

Several studies (Dixon et al., 2000; Rummel-Kluge, Pitschell-Walz, Bäuml & Kissling, 2006) have shown that psychoeducation in families of patients with schizophrenia has important uses for these families. For example, it is has been reported that psychoeducation decreases the relapse rates of these patients, plays a significant role in the course of the patient's illness, and assists not only the families but the patients as well to deal with the mental illness (Dixon et al.; Rummel-Kluge et al.). Psychoeducation also improves treatment adherence (which is one of the most crucial factors with which the outcome of a disease is measured) (Atri & Sharma, 2007). It has been reported that psychoeducation improves the confidence of relatives in coping with the illness and promote psychological health of the patient (Morris et al. as cited in Hussein, El–Shafei & Okasha, 2006). Psychoeducation also helps high - EE families to express their feelings in ways that would not affect their ill relatives negatively (Bressi, Manenti, Frongia, Porcellana & Invernizzi, 2008). Pickett-Schenk, Lippincott, Bennett, and Steigman, (2008) developed a psychoeducation programme which they called The Journey of Hope

course. They found that the Journey of Hope course improved family members'

emotional well–being and how they conceive their relationship with their ill relatives

(Pickett-Schenk et al., 2008). Psychoeducation also enhances the problem–solving

capacities of families (Bustillo, Lauriello, Horan, & Keith; Dixon, McFarlane, Lerley,

Luckstead, et al.; Penn & Mueser; Thornicroft & Susser; all cited in Reid et al., 2005). It

has also been reported that it not only makes the experience of caregiving satisfactory,

but enhances perceptions of mental health professionals and participation in family

treatments (Ascher-Svanum, Lafuse, Barrickman et al. as cited in Reid et al., 2005).

Psychoeducation also addresses the issue of social isolation and stigma (Reid et al.,

2005). For example, McFarlane (as cited in Reid et al., 2005) pointed out that this is

achieved by directly enlarging the size and complexity of the social network, and

exposing the family to other families that are in the same situation by providing a forum

for mutual aid and by offering family members an opportunity to make better the

experiences of other adults with similar problems. O'Connor (as cited in Reid et al.,

2005) says that family support groups affect the caregiver experience in four ways. They:

(a) Assist the primary caregiver to build a self – identity as a caregiver,

(b) Encourage and help with a sense of personal competence,

(c) Promote caregivers to make use of formal support groups, and

(d) Provide a site and create space within which to experience the caregiving role.

O'Connor (as cited in Reid et al., 2005) asserted that when caregivers share their

experiences in this manner a sense of empowerment is attained. Also, the caregivers'

horizons are broadened in such a way that they begin to conceive of their experiences as

not a personal issue but a more collective experience (O'Connor as cited in Reid et al.).

Barriers to implementing psychoeducation with families

The families of ill relatives may not be able to take part in the psychoeducation programmes organized by mental health professionals for a number of reasons. For example, implementation of family psychoeducation may be hindered by realities in the lives of family members (Dixon et al, 2000; McFarlane et al., 2003), such as transport issues in cases where family members live far away from the hospital. Similarly, Reid et al. (2005) found that participants complained about driving or catching public transport in the evenings. It has previously been reported (Biegel & Song; Gasque-Carter, & Curlee; Solomon; all cited in Reid et al.) that the barriers "of transportation and time commitments and competing demands for time, and energy are common limitations for parents wishing to access psychoeducation programmes" (Solomon as cited in McFarlane et al., 2003, p. 236).

The families may also not take part in psychoeducation programmes because they do not know much about such programmes and therefore do not believe that they would work. Also, families may be sceptical about psychoeducation as they may hold perception that such programmes carry with them "training" that would require them to take on yet more caregiving responsibilities, and therefore might stay away from such programmes (World Schizophrenia Fellowship, 1998).

Stigma is another factor that has identified as a barrier to family members becoming involved in psychoeducation programmes (McFarlane et al., 2003). The family may be afraid of being rejected by the society if the illness of their relatives is known (McFarlane et al.).

Families' non-belief in treatment

Hendrickson et al. (2004) assert that some families may not be willing to open up to strangers about the illness of their relatives. For example, this may be due to the ethnic culture of the family or fear that the family has regarding the service that the government offers (Hendrickson et al.). Kuipers et al. (1992) asserted that the set of norms of the society that the family comes from also determines if the family will become part in services such as psychoeducation. In China, for instance, mental illness is chastised in the society as something bad. Therefore, the families of people with mental illness often hide the illness of their relatives because there are afraid of losing face (Kuipers et al.). In other Asian countries, mental illness is sometimes conceived of as punishment of the gods (Weisman, Duarte, Koneru, & Wasserman, 2006). Kyziridis (2005) asserted that the families of mentally ill relatives often abandon their relatives or fail to seek proper treatment because of the fear of being ridiculed by the society.

Denial of the disorder and misperceptions

Mental illness is a debilitating illness that often alters the lives of the patients and family members forever. It is often difficult for family members to accept that their relative has a mental illness. Hendrickson et al. (2004) posit that the family may be uninformed about mental illness. Therefore the family might not know how to handle the fact that their relative is mentally ill if such a diagnosis is acknowledged (Hendrickson et al.).

Hopelessness and being drained out

Hendrickson et al. (2004) also observed that families may refuse treatment as a result of being emotionally and psychologically exhausted from the whole process; and because of diminished hopes of recovery and loss of faith in the mental health system. The family may have reached a point where they are worried about the effect that giving their relatives with mental illness too much attention may have on other siblings, who may feel left out and neglected (Hendrickson et al.).

Negative contact with mental health professionals

The family may have a negative history, real or perceived, of contact with the mental health professionals in their previous engagements. Therefore, the family may have negative feelings about entering in a treatment programme that may fail again. Also, some mental health professionals may still use old theories that blame the family for the illness of their relatives.

Guilt and shame

Hendrickson et al. (2004) assert the family may feel embarrassed by the strange behaviour of their ill relatives. Therefore, guilt may come from the family believing that the erratic behaviour of their relatives is caused by something that the family did or failed to do (Hendrickson et al.). Furthermore, Hendrickson et al. asserted when the family firmly believes this to be true, they may evade treatment mainly as a result of blaming themselves and feeling guilty. It often happens that families are not aware that many mental disorders have biological origins. Therefore, the family often attributes the illness of their relative to some psychological reason or as result of bad child rearing (Hendrickson et al.).

<u>Barriers to mental health practitioners' implementing psychoeducation</u>

Psychoeducation programmes are still not implemented by many psychiatrists, despite their overwhelming success rate (Aguglia, Pascolo-Fabrici, Bertossi & Bassi, 2007). In some countries such as Italy, for example, many psychiatrists in the state institutions, still view psychoeducational approaches with suspicion and oppose them categorically (Aguglia et al.). Dixon and Lehman, Greenberg et al., and Solomon (all cited in MacFarlane et al., 2005) pointed out that the lack of family psychoeducation availability may mirror mental health providers' underappreciation of and poor insight about its usefulness and importance. Atri and Sharma (2007) cite a study done in Germany by Hamann, Mischo, Langer, Leucht, and Kissling which assessed the current status of relapse prevention in schizophrenia and the study revealed some shocking findings. Hamann et al. found that psychiatrists did not offer psychoeducation as part of treatment plans. In fact, Hamann et al. says that when it is offered only about one third of patients and their families is told about it, even though it has been shown to increase medication compliance among other things (as cited in Atri & Sharma, 2007).

Hogarty (as cited in Atri & Sharma, 2007) discussed the possible reasons why few families of the severely mentally ill have ever been offered family psychoeducation within North America, despite its success. There are many possibilities: "multiple policy and organizational impediments, which may include staff burdens, scepticism about psychoeducational programs, philosophical differences and lack of leadership, may be responsible" (Atri & Sharma, 2007, p. 35).

Since clinicians and administrators often exclude families from treatment, the former may not understand the impact of mental illness on the latter (World Schizophrenia

Fellowship, 1998). Unfortunately, they may also not know about the effectiveness of family psychoeducation (World Schizophrenia Fellowship). As clinicians and administrators often perceive the treatment of psychiatric disorders through the lens of medication alone, psychosocial interventions may appear superfluous (McFarlane et al., 2003).

Mental health professionals also cite the cost and length of structured family psychoeducation programmes as another barrier (Dixon, Lyles et al. as cited in McFarlane et al., 2003). However, in a study done by Rummel-Kluge et al. (2005) measuring a short term psychoeducational intervention with routine treatment, they found that patients in the intervention group were hospitalized in the following year for only 17 days compared with 30 days in the control group. Based on this study and data from the federal health monitoring system on hospitalisation days of patients with schizophrenia in Germany in the year 1999, they did a model calculation and found that if it were possible to triple the number of patients receiving psychoeducation in schizophrenia from currently about 20% to 60%, it would be possible to save 13 hospital days each for about 48 000 patients, adding up to over 600 000 hospital days. Thus, at the rate of 250 Euros per hospital day, over 150 million Euros in direct costs could be saved in Germany alone by making sure that psychoeducational programmes becomes a standard treatment.

Language and discrimination as barriers to the treatment of schizophrenia

There are barriers to treatment of schizophrenia which are exacerbated in South Africa, and these barriers affect both patients and families.

The apartheid system promulgated the system of mental health care along racial and language lines (Emsley, 2001). As far back as 1889 there were clashes between English–

speaking nurses and administrations that pushed for proficiency in the Dutch language; indigenous languages were totally excluded (Marks, 1998). The advent of democracy saw the Black government moving towards redressing power imbalances which existed socially, economically and politically (Drennan, 1999; Emsley, 2001; Swartz, Drennan & Crawford, 1997). The Department of Health made it its mission to provide accessible, equitable, adequate and appropriate mental health service (Emsley) to every citizen living in South Africa regardless of race, culture and linguistic differences.

However, Swartz and Drennan (2000) noted that "changes in the access which non–native speakers of English and Afrikaans have to mental health care in South Africa have been slow and hesitant" (p. 186). In addition, there are scarcities in resources. Emsley (2001) stated that in South Africa there is about one registered psychiatrist per 100 000 inhabitants. Furthermore, psychiatrists are distributed unevenly throughout the country, majority of which are concentrated in Cape Town and Johannesburg (Emsley). The North West province has no full time state psychiatrist, and Northern Cape and Mpumalanga have one each (Emsley). In addition, Swartz and Drennan asserted that of few psychiatrists that we have in South Africa most are white and speak only English and/or Afrikaans.

South Africa's challenges have world world-wide parallels. Drennan (1999) notes that in Britain the issue of immigrants and access to equitable to mental health bear a striking similarity to those confronting Black people in South Africa. He stated that the mental health professionals are overwhelmingly white and do not speak the languages of Blacks and other immigrant patients or even share similar experiential backgrounds (Drennan). In America Bloom, Masland, Keeler, Wallace and Snowden (2005) states that the

Language Access Coalition and other organizations have documented instances in which patients did not benefit from public services because linguistically proficient staff and services were not available.

Sentell, Shumway and Snowden (2007) said that the issue of language barriers may be particularly problematic in mental health care because so much of mental health diagnosis and treatment relies on direct communication rather than objective tests or medication. For example, Hausman (2001) says that patients may be misdiagnosed and given inappropriate treatment choices. Quality of care for those who are not proficient in the dominant language is affected through interaction with health professionals who, because of language barriers, may be unable to meet ethical standards in providing health care (Bowen, 2001). For instance, the use of untrained interpreters may be problematic if for example, the person tasked with interpreting is a young member of the family. This may lead to embarrassment as privacy may be violated (Association of Community Organizations for Reform Now, 2004).

Patients may also lose vital information through health promotion/prevention programmes (Bowen, 2000). Flores (2006) says that patients who face language barriers are highly unlikely to have a consistent source of medical care in comparison to other patients who do not share the problem. They may also be in receipt of preventive services at reduced rates, and susceptible to default on their medication.

In summary, the family members of people with schizophrenia face many challenges, including issues regarding the illness itself, as well as attempt to access mental health system. The following chapter introduces the methodology for this study.

CHAPTER THREE

METHODOLOGY

Background to the study

This small study made use of the infrastructure of a broader prospective study of clinical,

biological and functional aspects of outcome in first-episode psychosis. The study was

situated at Stikland hospital with Professor Robin Emsley as principal investigator and

Dr. Bonga Chiliza as project manager.

<u>Research approach</u>

The research questions of the present study determined the design, format and use of a

qualitative research study (Evavold, 2003). Qualitative methods are useful for areas of

research that are poorly understood and ill defined (Motlana, Sokudela, Moroka, Roos, &

Snyman, 2004). In this study, the attempt was, (1) to understand the experiences of Cape

Town families living with a family member with schizophrenia, (2) the reported nature of

their interface with the health system, and (3) their understanding of schizophrenia as a

disorder. Semi-structured interviews were conducted to gather personal recollections

from families about their experiences with both schizophrenia and mental health system.

The aim was to get the families to take the present researcher into their world so that one

could begin to understand their experiences with schizophrenia and mental health system

(Evavold).

Procedure

The present researcher formulated a list of semi-structured questions that were used to facilitate the interview processes (see Appendix A). The list consisted of 14 questions formulated to explore the experiences of family members with schizophrenia as well as their contact with mental health system. The questions were partly based on personal experience and knowledge of living with a family member with schizophrenia. The questions were also based on the literature research on families' experiences with schizophrenia and the problems they have with the mental health system.

Areas of interest in this study included the knowledge of the diagnosis of the ill relatives by the family members; the participants' feelings about providing care to their ill relatives, both the negative and positive things about being a caregiver; the coping mechanisms that the participants employ in order to deal with the illness of their relatives. The participants were also asked how many times they have spoken to the doctor treating their ill relatives since the first admission to the hospital; and how the participants felt about the possibility of a support group for families of people with schizophrenia. Interviews lasted between one hour and one hour thirty minutes. All interviews were digitally recorded with permission of participants.

Participants

The target group

The study targeted family members from the Western Cape of people with schizophrenia currently receiving treatment in Stikland Hospital, Western Cape. A convenience sample of relatives (six were coloured and four Xhosa-speaking) was recruited.

<u>Participant recruitment</u>

The participants were recruited in Stikland hospital in the research unit for people with schizophrenia. The patients with schizophrenia have regular appointments scheduled by a research nurse (Sister I Mabanga) to have them come in to the hospital for treatment. The family members often accompany their ill relatives on the day of their appointments. Sister Mbanga telephoned the family members beforehand and told them about the present researcher and the study. She also asked them if they would like to take part in the study. Once that was done Sister Mbanga explained to the family members that on the day that they would be coming through to the hospital with their relatives the present researcher would interview them while their relatives are were being examined by the doctor. She also informed them that refreshments would be offered because the interview sessions could take a long time.

<u>Criteria of inclusion and exclusion</u>

The family members had to meet three criteria. First, these family members had to be the primary caregivers of people with schizophrenia. All the patients met the DSM IV criteria for schizophrenia. Secondly, the ill relatives of the family members had to have been receiving treatment for some time in the hospital. Thirdly, the family members would have had previous contact with mental health professionals. Details of respondents are provided in Table 1.

Table 1

Study Participants

Pseudonym	Relationship of participant to patient	Age	Race	Home language
Mrs Jacobs	Mother	50+	Coloured	English
Mrs Khanyisa	Mother	50+	Coloured	Afrikaans
Mrs Jackson	Foster mother	50+	Coloured	Afrikaans
Mrs Valerie	Mother	50+	Coloured	Afrikaans
Mrs Kennedy	Mother	40+	Coloured	Afrikaans
Mrs Davids	Mother	40+	Coloured	Afrikaans
Mrs Thembisa	Sister	20+	Black African	Xhosa
Mrs Siyabonga	Mother	40+	Black African	Xhosa
Mrs Mbalo	Mother	40+	Black African	Xhosa
Mr & Mrs Jones	Father & Mother	40+	Black African	Xhosa

Note: All names are pseudonyms

Data analysis strategy

The researcher examined the family members' experiences with schizophrenia and their subsequent contact with mental health system. In preparing for data analysis the researcher read Grounded Theory literature and the work of Holloway (as cited in Evavold, 2003) which used similar strategise to analyze the data. The process of data analysis requires the researcher to break down the data and to search for codes and categories which are then turned into themes (Evavold). Evavold (2003) asserted that Holloway has suggested using several steps when analysing data:

> Ordering and organizing the collected material, re-reading the data, breaking the material into manageable sections, identifying and highlighting meaningful phrases, building, comparing and contrasting categories, looking for consistent patterns of meanings, searching for patterns, themes and typologies, and interpreting and searching for meaning. (p. 44)

To start with the course of categorising and organising the data that the present researcher had collected, he transcribed six of the ten interviews. In the case of the four Xhosa interviews a professional language specialist (a senior academic in a university department of African languages) did transcriptions and translations. The six interviews that the researcher did were in English with some Afrikaans. The process of the researcher doing the transcriptions himself is consistent with suggestions by Payne (2007), advocates of grounded theory, who assert that it is important for the novice researcher to undertake "a few transcriptions because this [will allow him/her] to develop an intimate familiarity with the data and to identify some potential analytic lines of inquiry" (p. 76).

Since, the present researcher had used semi open–ended questions in the interview sessions the researcher utilized these as a basis to elicit multiple themes. In the analysis process the researcher bore in mind that there might be an overlap between themes. Therefore the researcher employed constant comparison to counter the overlap of themes, a process recommend by Payne (2007). Parker (2005) asserted that when analysing themes researchers must pay close attention to differences reported, and inconsistencies in response and the implications thereof and the researcher explored these as well. Qualitative data analysis needs to take account of context, and there is some danger in a content analysis that the context of data may be lost (Silverman & Marvasti, 2008). For this reason two brief case studies are presented at the end of the results section to give a more holistic sense of the families' reported experiences.

Since the present researcher had three main aims, firstly to examine the subjective realities of the participants through living with relatives that are affected by schizophrenia (Payne, 2007), and secondly, their understanding of schizophrenia as a disorder. Thirdly, to explore the participants' accounts of experiences with mental health system the present researcher was careful not to treat these accounts as factual reflections of their contact with mental health professionals (Parker, 2005). Firstly, participants' accounts are narrated through recall which can distort the actual previous events. This was particularly true in this study as some of the participants had a problem recalling certain events that took place between them and the mental health professionals. Secondly, the context within which the interview took place between the researcher and participants had to be taken into account. As Riley, Schouten and Cahill (2003) note, the interface of power

dynamics between the researcher and participants may influence how the participants articulate their stories.

<u>Measures of achieving trustworthiness</u>

There is a major debate about using the concepts of validity and reliability in qualitative research; these are generally used in quantitative research. Although some qualitative researchers retain the terms "reliability" and "validity" for qualitative research and some do not use these terms (Rolfe, 2006), it is generally agreed that qualitative studies should be subjected to critique and evaluation (Long & Johnson 2000). However, having said this, it is also important to note Spencer, Ritchie and Dillon (2003) observed that Lincoln and Guba suggested that qualitative research should be assessed using its own terms. To this end, Spencer, Ritchie, Lewis & Dillon (2003) assert that Lincoln and Guba came up with the development of parallel criteria to assess the trustworthiness in qualitative research.

Therefore, the traditional quantitative concept of internal validity, which Lincoln and Guba translate as truth value, is substituted by another concept called credibility (Spencer, Ritchie, Lewis & Dillon, 2003). Also, external validity, or the extent of generalizing the research findings to the population, is replaced by transferability. Reliability, or the stability of findings, "is replaced by the notion of dependability, which is achieved through an auditing process called an 'audit trail', in which the researcher documents methods and decisions, and assesses the effects of research strategies (rather than concerned about replication)" (Spencer, Ritchie, Lewis & Dillon, 2003; p, 40).

One of the ways of assessing credibility in research findings is to evaluate how well categories and themes cover data (Graneheim & Lundman, 2004). Graneheim &

Lundman (2004) say it is important that, "no relevant data have been inadvertently or systematically excluded or irrelevant data included" (p, 110). In the present study, the researcher was guided by the open-ended questions formulated for the interview process. Therefore, credibility was achieved by extracting themes according to the open-ended questions and putting them into categories, and by checking to see whether extraneous data emerged which did not fit the pre-arranged questions.

Another aspect that deals with trustworthiness is dependability. Graneheim and Lundman (2004) say that Lincoln and Guba described dependability as a concept that 'seeks means for taking into account both factors of instability and factors of phenomenal or design induced changes' (Graneheim & Lundman, 2004; p, 110). Graneheim and Lundman (2004) say that that is, the extent of which data change over time and other changes, and interpretation that the researcher makes when analyzing the data. Graneheim and Lundman (2004) posit that in instances where data are extensive and the collection cover long periods of time, the danger of inconsistency during data collection is a cause for concern. Graneheim and Lundman (2004) further assert that even though it is crucial to question the same area for all the participants, "interviewing and observing is an evolving process during which interviewers and observers acquire new insights into the phenomenon of study that can subsequently influence follow – up questions or narrow the focus for observation" (p, 110). In the present study the data were not extensive and the collection process did not extend over long period. Therefore, the issue of inconsistency, even though a concern, did not present any problems. However, during the interview process the researcher acquired a greater depth of understanding about the phenomenon

of the study. As the research process evolved, the researcher learnt to ask specific

questions which he had not formulated as clearly at the start of the process.

Language issues

Language was an issue in the data collection process. My first interview was with a

Xhosa speaking participant. I am a Sotho speaking person and started speaking Xhosa

about five and half years ago. When I started the first interview I was slightly anxious

because I knew that the type of Xhosa that is spoken in Cape Town, particularly by young

people, is different at times from the Xhosa that is spoken by old people of rural

background. My Xhosa speaking friends used to tell me to be careful when speaking to

older men and women. As the Xhosa speaking participants were older women and one an

older man, I was afraid that they might not understand me. Therefore, I would have to

code switch from Xhosa to English when explaining things. I was concerned that this

might make the participants uncomfortable and compromise their ability to express

themselves fully. However, much to my surprise, my Xhosa has improved over the years

and I was able to hold the interviews with a reasonable degree of confidence. I also did

not pick up any uneasiness from the participants; in fact, they expressed themselves with

an apparent openness that I did not expect.

The Coloured participants were fluent both in Afrikaans and English. With this group I

was comfortable enough to conduct the interviews in English. Though all of them can

speak English about half of them code-switched between English and Afrikaans. This

presented some problems as I would have to ask the participants to repeat what they had

said in Afrikaans in English. Some of the participants appeared not to like this, but all complied.

Reflexivity on the interview processes

I entered the interview process with some preconceived ideas about families' experiences with mental illness and the mental health system. Therefore, I began with the interviews feeling enormous empathy for what I anticipated the participants' situation might be. This made things difficult for me to carry on with some of the interviews because I would be overwhelmed with my own emotions. One of the issues I had to bear in mind was that though I had had a particular experience in Johannesburg, these families might have had different experiences. My bias was towards the belief that families of people with schizophrenia have negative experiences with the mental health system everywhere; I had to make sure that I was open to hearing different experiences, and especially to hearing positive things about their experiences with the health system.

Confidentiality and informed consent

Before I began with the interview process I explained fully what my study was all about to the participants and asked them to take part in my study. I also informed the participants that should they decline to be part of the study, this would not affect them or treatment of their ill relatives in any way. I made it clear that their participation in the study was completely voluntary. I also made them aware that taking part in this study would not benefit them directly and that there would not be monetary incentives. I told the participants that the only people that would have access to the medical files of their ill relatives were myself and the usual hospital staff members. I also informed the

participants that their names would not appear in the final product of the study. All the participants signed the consent forms (see Appendix B).

Ethical considerations

Ethical approval for this study was obtained through the Committee for Human subjects Research (CHR), Stellenbosch University, a National Institutes of Health (NIH)– accredited Institutional Review Board (see Appendix C). During the interview process ethical issues went beyond formal approval. For example, I had to bear in mind that when interviewing the participants my questions might unleash painful memories that the participants did not anticipate. As it happened, there were instances where some of the participants were in tears or silent for brief moments because there were overwhelmed by emotions. Each time I asked the participants if they would like to stop the interview. I also informed the participants that they were at liberty not to respond to the questions that made them uncomfortable. For example, in one case, a participant after mentioning that she has consulted a traditional healer on behalf of her ill relative asked me not to go deeply into that issue and I respected this. Participants were informed that if they felt they needed further support they would be offered the opportunity for counselling, but did not take this up.

CHAPTER FOUR

RESULTS

Participants' understanding of the term 'schizophrenia' according to the explanation of the doctor

The understanding of the term "schizophrenia" eluded some of the participants, as they reported that they simply do not know what it means. The following extract from the conversation between Mrs Siyabonga and S.M illustrates the point:

> S.M: *Mother do you know you what schizophrenia is?*
>
> Mrs Siyabonga: *Hmm, hmm….. I don't know….*

Mrs Mbalo also expressed similar sentiments. In fact, she wanted to know from the researcher (S.M) whom she called 'doctor' what schizophrenia is. She also appeared not to know that the doctor that is treating her son knows what is wrong with him:

> S.M: *Mmh … can I ask you something? I think I forgot to ask you earlier on.*
>
> *Um …. Do you know what schizophrenia is?*
>
> Mrs Mbalo: *What doctor?*
>
> S.M: *Schizophrenia?*
>
> Mrs Mbalo: No, what's that? I want to know…..
>
> Mrs Mbalo: does doctor know what's wrong with my son?

Mrs Jackson also reported that she does not know what schizophrenia is, but admitted that the doctor might have previously explained to her what the term means. However at the time of the interview with S.M she could not recall what schizophrenia is:

> S.M: *Um… um what do you know about schizophrenia?*

Mrs Jackson: that's a sickness she's got…

S.M: Um

Mrs Jackson: I never used to know that sickness. I can't even say that word in my mou …(chuckling)

S.M: … is doctor XXXX treating your …?

Mrs Jackson: for that sickness, yes.

S.M: Um …. um did he explain to you what schizophrenia is? [Noise in the corridor]

Mrs Jackson: ah .. yes .. but you know, sometimes I remember things. I had an accident last ah …two years back. From the accident I remember things then afterwards is blank again then I remember again I don't remember again …..

Mrs Valerie reported that she cannot remember what schizophrenia is. However, she did say that the doctor might have given her an explanation of the term previously. She also reported that she does not believe that her son has mental illness. In her eyes he appears to be 'normal' mainly because he behaves accordingly:

Mrs Valerie: No, I don't want to lie; I can't remember what they said ….

S.M: Do you think he has schizophrenia?

Mrs Valerie: Who? He?

S.M;   Yes

Mrs Valerie: Hey, I never took psychiatry, but when I look at he is normal.

S.M: Hmm.

Mrs Valerie: Hmm, he's normal, because he does all he needs to do. He is employed. He…. Even when talking to him, he's fine.

Some of the participants reported that their understanding of schizophrenia was gathered through the media.

> *S.M: I request you to tell me as to what is schizophrenia?*
>
> *Mrs Khanyisa: Yes … how .. I have heard about it and even read in the newspapers*
>
> *S.M: Where did you hear about it?*
>
> *Mrs Khanyisa: I heard about it, I read it from newspapers*
>
> *S.M: Hmm, so what did the newspaper say it is?*
>
> *Mrs Khanyisa: …… they described it as a person who smokes, a person who smokes tik…… drugs…. The mind shrinks slowly…*

Some participants reported that schizophrenia is a "nervous breakdown", a well known lay term for mental disorder (Swartz, 1998). Mrs Daniels reported that despite the doctor's explanation of what schizophrenia is, she still believes it to be a nervous breakdown:

> *S.M: Hmm… So if she explained to you what schizophrenia is, and you still don't kno… understand what it is, did you ever, you know, ask her again, you know?*
>
> *Mrs Daniels: It's nervous breakdown.*

Witchcraft and/or evil spirit

Witchcraft

Some of the participants reported that the illness of their relative is caused by supernatural forces. The participants identified witchcraft as a source of their relatives' illness:

> *S.M: So when she was telling you about, you know, all of that, how did you, you*
>
> *know, how did you feel?*
>
> *Mrs. Daniels   .... the only thing that came to to mi ... my mind, at first, oh lord,*
>
> *witchcraft? definitely*

Mr and Mrs Jones also reported that their son has been bewitched. They stated that their son smokes tik (methamphetamine) with his friends but is the only one that has fallen sick. Mr and Mrs Jones stated that tik was used as a means with which their son was bewitched. In other words, the people who bewitched their son planted things on tik and as a result their son fell ill:

> *Mrs Jones: my son smokes tik with the other kids but he is the only one that is*
>
> *ill......*
>
> *Mr Jones: he sees things that we don't see, what it that? In Xhosa we say this is*
>
> *witchcraft.*

Another important finding that came up from Mr and Mrs Jones was that they felt that because the doctors do not believe in witchcraft, they would shy away from revealing their beliefs about the aetiology of the illness of their son to the doctors. Both mentioned to S.M during the interview that they have been consulting the traditional healer while their son is also receiving treatment in Stikland hospital.

Similarly Mrs Siyabonga reported that her brother may be bewitched. She asserted that her brother smokes dagga and the people that may be bewitching him could have used this substance to get to him:

> *S.M: Hmm, she doesn't think that you are .... that he is bewitched or something*
>
> *like that?*

Mrs Siyabonga: That may be the case, but those who bewitched him may enter

…. they would get a chance because he used these things. Because they would not

get a chance if he wasn't smoking and drinking, you see?

Some of the participants reported that even though they do not necessarily believe that

their relatives are bewitched, the thought had crossed their minds because of previous

personal experiences:

Mrs Jackson: and she never went to work again, sometimes … then I think what

she said, people are making her to be like this, I don't want to believe in that!

S.M: Mmm

Mrs Jackson: But they say that there are certain things that people do.

S.M: Such as.

Mrs Jackson: Such as make that you can never work, your child can never work

for you. Jealousy... I don't actually believe in that.

S.M: Mmm

Mrs Jackson: But it happens! My daughter….

S.M: You talking about witchcraft?

Mrs Jackson: Yes, my daughter, my daughter the youngest one, my own

daughter, she was working for Coca –Cola, she's got holes underneath her feet,

no doctor can never cure her, she is out of work now, she was disabled from 2002

Evil spirit

Some of the participants reported that they believe that the illness of their relatives is the

result of evil spirit. Mrs Jacobs reported that evil spirit had something to do with the

illness of her son. However, she did not say anything about evil spirit causing her daughter's illness as well:

> *S.M: Why do you believe that?*
>
> *Mrs Jacobs: Well (laugh) evil can come to you through the TV. and through, I mean whatever evil is around us all the time and we have to be careful, be weary...*
>
> *Mrs Jacobs: (Laugh) I feel that ... my son also said to me when he close the window "mommy the evil spirit entered me" and I ... I will tell you that night it was very frightening for me as because as well because me and my husband stopped smoking for five years and we picked it up again because he said "mommy say our father with me" and I am telling you and you would.... I would pray with him and say our father and we would get to the end and he would go on like a baboon... ha...ha...ha couldn't say amen....*

Verbal aggression by family members towards persons with schizophrenia

Some of the participants reported that they shout at their ill relatives. This reaction is often as a result of the participants' repeated failed attempts to get their relatives to re-orientate their problematic behaviours to the conduct that is desirable For example, in this study, Mrs Valerie mentioned that at times it would be as if she is "talking to a stone", as she put it because her son would simply not engage her and she ends up shouting at him:

> *Mrs Valerie: I talk hard at him, doctor, because he doesn't listen to what I say. He would be staring at the wall.*

Some of the participants reported that they often experience strong feelings of hate towards their ill relatives. This is because of their repeated failed efforts of trying to get their relatives to change their behaviours:

> *Mrs Kennedy: There was a time I yell at him, I think maybe because I hated him … I couldn't …. I couldn't stand what he was doing so I think maybe…. after I …. that I was …. when I scolded him, when I scream at him he just look at me and said "that's the reason why I don't want to stay here"……I ask "what … why don't you wanna stay here when I am talking to you. I am talking to you ….. because you are making me very cross every time you doing the same".*

Mrs Mbalo also reported that the behaviour of her son prompts her to react by shouting at him:

> *Mrs Mbalo: Many times, because he's so slowly, man.*
>
> *S.M: Mmh.*
>
> *Mrs Mbalo: If I say "WASH THE DISHES", he takes his own time. He's so slowly, and   when I say "Goodness, you are half – dead. You are slow!" then he laughs. He laughs me out*

Verbal aggression by persons with schizophrenia towards family members

Some of the participants reported that they are not only the people who are doing the shouting at the house but also something that their ill relatives do as well. Family members reported that their relatives with schizophrenia sometimes shout at them upon provocation:

> *Mrs Jacobs: and, uh that was the end of that but I mean there were times again and then she is tired from this workplace and then she would say to me "DON'T*

YOU UNDERSTAND ME", you know, shouting at me ..... (sigh) I would just look

at her. I .... I would just look at her ..... and I would just say to her "You must

calm down. You see how aggressive you are with me.....".

Some of the participants reported that their relatives shout at them often after repeated

failed efforts from the relative to receive what he/she desires from the family members.

This is the case with Mrs Margaret's daughter often places unreasonable demands on her,

which Mrs Margaret sometimes would reluctantly honour just to appease her daughter or

escape being irritated with her. However, sometimes Mrs Margaret would stand her

ground and deny her daughter her wishes. This is evident in the extract below:

Mrs Margaret: you see, and she smokes a lot .... cigarette ...s he is smoking a

lot of cigarettes and I don't want to give and she's swearing ..... this morning

she's swearing at us all in the house .... she is swearing at .....

Acts and threats of violence

Some of the participants reported incidents of violence. Participants reported that their ill

relatives attacked some of the family members without being provoked:

S.M: How did you deal with that?

Mrs Siyabonga: Okay, since he ..... he attacked him but my brother did not take

that seriously because he saw that he was sick.

Mrs Kennedy also reported a similar experience at her home. It was the first time that her

son acted violently and Mrs Kennedy was so shocked that she threatened to call the

police to have him locked up:

S.M: Hmm

> *Mrs Kennedy: he was fighting with his girlfriend…. my… my went out to stop*
>
> *him and he picked up the spade and hit my daughter with it ……*

Some of the participants reported that their relatives often threatened them with violence after being provoked:

> *Mrs Margaret: and …. Next he told me "if you ever touch me again …. you*
>
> *will see what I do with you". He told me and I stand up and I get him and I told*
>
> *him "I am your mother don't talk to me like that….*

There is also another participant whose ill relative expressed threats of violence against her. Mrs. Jackson's daughter is 21 year old who sometimes behaves violently. Mrs. Jackson reported that her daughter attacks other children in the street. She is also violent at home and fights with her siblings. Mrs Jackson stated that her daughter would pick a fight with one of her siblings unprovoked. However, Mrs Jackson also stated that she has also threatened to hit her daughter. The threats of violence often come up when she has tried everything to control the erratic behaviour of her daughter. Equally so, her daughter threatened her after Mrs Jackson denied giving her cigarette:

> *Mrs Jackson: and she wants cigarette every ten minutes she wants a cigarette if I*
>
> *don't …. She even said on Saturday I am going to kill you ….*
>
> *S.M: Um*
>
> *Mrs Jackson: I AM GOING TO KILL YOU .. YOU! I was still in bed on Saturday*
>
> *morning ….*
>
> *S.M: Um*
>
> *Mrs Jackson: I was …. we were …. they were preparing for the funeral and I*
>
> *was still sleeping and she came to me she asked …. she wanted the clothes that*

she must wear so I showed her …. and she takes the bag with my clothes and I

said "no don't take that one"….

S.M: Um

Mrs Jackson: ….. she said "Its my clothes these" and I said "that's not your

clothes", she said "you I am going to kill you".

S.M: Um

Mrs Jackson: and I said … I ask "Did you really mean you going to kill me" she

said "Yes" without even deny it…

Stigma

Some of the participants reported that they often find it difficult to tell people about the

illness of their relatives. The reasons for the participants not to tell people about the

illness of their relatives varied from one family member to another. Some of the

participants did not disclose the mental illness of their relatives because of the perceived

negative reactions from friends and family members. There were also some participants

who have had a stigma related experience firsthand:

S.M: Um

Mrs Jacobs: I won't tell everyone that is schizophrenia

S.M: Um…. so, what do you think would happen, you know, if you were to….?

Mrs Jacobs: (laugh) well, its just the stigma attached to your mental state….

Mrs Jacobs: Oh, people stigmatize you, they do, they do because they see this is

madness, mad, you are mad….

Mrs. Jacobs also experienced stigma at her home. This was an interesting point to note

because home is often a place where one seeks comfort. Home is often a place where one

can lean on and draw strength from in times of need. However, for Mrs. Jacobs home is a place where acts of stigma often affected her. Mrs. Jacobs reported that a few years back she had what she termed a "nervous breakdown" and was receiving treatment for it, and to this day she it still on medication. Whenever there is quarrel between her and her husband the issue of her mental condition always comes up. Her husband tells her that she is mad. Mrs. Jacobs said that if her husband could have it his way he would see to it that she is institutionalized.

Some of the participants reported that they have not as yet experienced stigma by association from the members of the community. However, they reported that their ill relatives were the ones who were the recipients of stigma. Dixon et al (2000) asserts that the issue of stigma often affects both the family members and the ill relatives. Mrs Valerie stated that she has not fallen victim to the sword of stigma as yet because she is a well-respected member of the community because of her position in the church. However, she reported an incident where she had to bear witness to her son being stigmatized. This is what she told S.M about the incident of stigma against her son:

> Mrs Valerie: *My son was walking down the street and people called but he didn't hear them. He was busy talking to himself. So the people Jason don't you hear they are calling you, you mad thing.*

Another important finding that came up was that the act of stigma is a pervasive phenomenon. It does not happen only in one's neighbourhood perpetuated by members of the community but is an act that takes place in every sphere of the family member's lives. For example, Mrs Daniels fell prey to stigma in her place of employment. She had to tell her employers about the illness of her daughter because very often she would have to take

time off from work and accompany her daughter to the hospital. Somehow her colleagues also heard about the illness of her daughter:

> *S.M:* *What stigma?*
>
> *Mrs Daniels:* *People… people can some be so ….. "You are crazy".*
>
> *S.M:* *Um, how do you…?*
>
> *Mrs Daniels:* *Yeah, they can be so vicious, they will tell you straight, you are crazy, crazy people mad people.*
>
> *S.M:* *How do you know that? How do you know that people….?*
>
> *Mrs Daniels:* *I Hear. I was told that already.*
>
> *S.M:* *Where?*
>
> *Mrs. Daniels:* *At work.*

Information and support groups

Almost all of the participants reported that they do not attend support groups. However, they indicated that if such a package was available in the hospital they would take part in it. The participants reported that the support group is an important forum that could provide a number of benefits. For example, one of the anticipated benefits of a support group was the information that participants would receive:

> *Mrs Siyabonga:* *No I didn't even know that there is one, if there is one I'll attend it.*
>
> *S.M:* *Why*
>
> *Mrs Siyabonga:* *For example, the things they... people who have.... people who use drugs in their houses ... who get them...*
>
> *S.M:* *Hmm*

> *Mrs Siyabonga: So that they may stop the drugs*
>
> *S.M: Hmm*
>
> *Mrs Siyabonga: So that I may be able to advice my brother, do this, don't do that, so that you can be okay.*

Some of the participants reported that the information they would receive from the support group would help them contain the erratic behaviours of their loved ones. The issue of containment was particularly important to Mrs Jackson because her foster daughter behaves very violently. Mrs Jackson reiterated that it is difficult to contain the aggression displayed by her foster daughter. In fact, she feels that she is fighting a losing a battle because her efforts seems to be getting nowhere:

> *Mrs Jackson: ... because I want to learn more about this sickness of hers and how to control it.*
>
> *Mrs Jackson: If I can know what to do when she starts going on like that then I will do anything to prevent it from happening, because one or other time she is going to hurt somebody seriously then what I am going to say, where was I? Because all the fingers is going to point at me 'Where were you when this child did this?...*

Mrs. Jacobs is the only participant that reported to have had the opportunity to be part of a support group and this had taken place in Stikland hospital. Two of her children have been diagnosed with schizophrenia. Her daughter is currently undergoing treatment. Previously her son underwent treatment at a different ward in the hospital. It was during that time when her son was still receiving treatment in another ward that Mrs Jacobs took

part in a support group. She still sees the need for a support group because she would

have a place or rather group of people that would listen to her:

> *Mrs Jacobs: It was terrible because I felt the whole world is falling apart*
>
> *around you. You got nobody to talk to....*
>
> *S.M: Um... the support group that you were talking about do you think they*
>
> *would help you?*
>
> *Mrs Jacobs: Mmh.. like I said that they call themselves support group, ok they*
>
> *give you nice evening to help you relax and to give you.. perhaps to lift you up*
>
> *but I mean this is once a moment... I mean perhaps the moment you need to say oh*
>
> *god I am going through this now. You know, someone that can listen to you on the*
>
> *other side of line or … or on the phone and say "Well, ya, you know, I went*
>
> *through that too", and you know, do that or this helped me to cope with it and*
>
> *things like that.*

Important to note in this interview is Mrs Jacobs's reiteration of being listened to by

someone who went through what she is going through. Other participants also stated that

they have a need to talk to someone who had been in the same shoes as them.

Another finding that came up is that of the well – being of the participants. Mrs Mbalo

explained that the support group would be important because she would have the

opportunity to express her feelings and thoughts. She reported that disclosing one's

problems to others, one often comes out feeling better:

> *Mrs Mbalo: We can't talk with everyone but it's inside you*
>
> *S.M: Mmh*

> *Mrs Mbalo   Now, maybe there come a... there a come.. came a time when you*
>
> *think no man, talk man, talk out. And then.. you're feeling better when you've*
>
> *talking out...*
>
> *S.M: Mmh*
>
> *Mrs Mbalo: And then I'm feeling better when I'm talking it out, because*
>
> *sometimes when I sit and I think all these things, it makes me ...confused.*

Case studies

In order to contextualise the findings in more comprehensive narratives, two brief case studies are now presented.

Case study 1: *Mrs Jacobs*

Mrs. Jacobs is the mother of two children, a boy and girl, both of whom have been diagnosed with schizophrenia. Mrs Jacobs's children are now in their early twenties. Her son, the elder of the two, was in a university of technology prior to his diagnosis of schizophrenia. He was not able to complete his studies. Her daughter is now working but was also diagnosed with schizophrenia just after she finished her diploma in. Mrs Jacobs's husband was a psychologist but has since retired. She believes that her husband also has schizophrenia because of his reported erratic behaviour that features in their daily lives; she declined to elaborate on this. Mrs. Jacobs reports that she has also had a mental illness, which she describes as a 'nervous breakdown'. She is still taking medication.

Of her two children, her son was the first to fall ill. Later her daughter fell ill as well. The son received treatment at Stikland hospital where her daughter is currently receiving treatment. Mrs Jacobs describes her life as difficult. Her husband is, according to her,

emotionally abusive. She reports that he often blames her for bringing schizophrenia at their home. Her son, she says, does not help with domestic chores. He does not, she says, even clean up his own mess. She says that she is the person who makes sure that he takes a bath, wears clean clothes and also cleans up his room. Mrs Jacobs finds this very exhausting and she often reaches a point of frustration. During the interview she appeared to be very frustrated:

> *Mrs Jacobs: you know, I do everything for him. And I tell him, "I just have to wipe my bum and I would done everything for you".*

Mrs Jacobs also stated that she would like to go on holiday. She said that she would like to get away from taking care of her family for a while. However, she said that she could not do so because at Stikland hospital there is no respite service which could relieve her of her duties for a little while.

The story of Mrs Jacobs reveals the complex interactions in her family, with the load experienced by her as almost unbearable. Though Mrs Jacobs may have been told about the negative symptoms of schizophrenia, her experience of her son is of a young man who is frustratingly passive and who does not do his chores.

Case study 2: *Mrs Jackson*

Mrs. Jackson is married and has three children. Her second oldest son is diagnosed with schizophrenia and receives treatment at Stikland hospital. A few years ago, Mrs Jackson lost her oldest son. He was shot and killed by gangsters. Since then Mrs Jackson has been diagnosed with depression. She reports that she often tells her family that she does not want to live anymore, she wants to die. She has attempted suicide on several occasions.

She describes her life as difficult. She says that her son with schizophrenia constantly shouts at her and other family members.

She describes her life as one of overload. She says she does everything in the house, cleans the house, and prepares food for all meals. She also looks after her son and make sure he follows his treatment. She says that her husband does nothing in the house and does nothing to help her with her son. This, she reports, is partly the reason why she was wants to die. She also stated that she often feels very lonely especially when it comes to looking after her son.

Mrs Jackson said that what she finds particularly distressing is her son's erratic behaviour. She says that she does everything for her son but he does not appreciate what she does for him. She reported that she often worries about what is going to happen to her son once she has past away. She said that she knows that his siblings would not take care of him because he is difficult to live with.

Mrs Jackson's story highlights the sense of despair and loneliness family members may feel in the context of serious mental illness. Caring in this case as in many others is very gendered with the mother bearing the brunt of caring, according to her own report. The despair for her is associated with what may well be a clinical depression and she reports suicidal thoughts.

Concluding comment

What is striking about both these case studies and about the other data collected is that most participants seem to have a poor understanding about the illness of their relatives. A better understanding could help them cope better with the burden. There may be a number of factors that could explain the poor level of knowledge of illness, including the

low level of education of participants. It may very well be the case however that a less than ideal relationship between the mental health professionals and participants may be a further contributor. A number of participants reported being distressed by the erratic behaviours of their ill relatives. Yet, by participants' accounts it appears that these disturbing behaviours are seldom reported to the doctors treating the relatives. Once again, this may be suggestive of a poor relationship between the people who are the cornerstone in the lives of person's with schizophrenia (the family members) and the other people who are dispensing clinical care (mental health professionals). These issues, and others, are further discussed in the following chapter

CHAPTER FIVE

DISCUSSION

Methodological issues affecting interpretation of the data

A key limitation of this study was that it focussed on a very small number of participants. The findings of this study are therefore not representative of the population of coloured and Xhosa speaking families. Another limitation is the issue of language that arose during the interview sessions. As has been explained before, the coloured family members who were both fluent in Afrikaans and English, in their narration gravitated towards Afrikaans. Therefore, they may not have been able to articulate their stories fully in English. Also, in the interview schedule there was not a question that specifically asked the participants how they coped with the illness of persons with schizophrenia. The issue of coping was mentioned by all participants but had the question been asked more systematically, more depth might have been gained on this issue.

A major limitation of the data obtained is that the information is based solely on self-report. This is not a problem in itself, but no responses, without further verification, can be seen as representing the truth of what has happened. All accounts are affected by participants' memory and also by how they chose (consciously or otherwise) to present themselves to the present researcher. It is not possible from data of this sort to make any firm recommendations for changed practice; what the data do give however is an indication of family members' reported experiences.

Participants' knowledge about the illness

The literature on psychoeducation suggests that family members are often not included in the treatment of their ill relatives (Murray-Swank et al., 2007). Furthermore, family

members often report lack of support from mental health professionals (Murray-Swank et al.). As a result family members cite a lack of understanding of how to use the mental health system (Murray-Swank et al.). Family members often report that because of the absences of a service such as psychoeducation they do not receive information about the illness of their relatives. These trends in the literature are reflected in the findings of this study, as almost all of the participants reported that they do not know the illness of their family members.

The fact of not knowing the illness of their relatives reportedly affects the participants in many ways. For example, some participants reported that they believe their relatives behave erratically on purpose. Therefore, some of the participants react harshly to their relatives because of this belief that they hold about their relatives. This may be even more difficult in the case of negative symptoms of schizophrenia, which are often neither dramatic nor bizarre but can appear to family members to be evidence of laziness or obstinacy

Some of the participants reported that they would like to know more about the illness of their relatives. It would be difficult for family members to know what kind of information to search for and where to find such information. In my interview sessions with the participants I asked them for their reasons for not seeking such information from the doctors that are treating their relatives. A number of participants reported that they do not know why they have not done so. Other participants reported that it simply did not occur to them to ask the doctors for information on the illness of their relatives. Given the power imbalance between relatives and doctors this may not be surprising.

It must be noted that it is the duty of the doctor to explain to the families the illness of their relatives. It must also be equally noted that the issue of disclosing the illness of the relatives to family members is particularly challenging to doctors. In general, the doctor must seek consent from the ill relatives in order to inform the family members about his or her illness. Anderson and Mukherjee (2008) reported that the prospect of trying to gain consent from the relatives with serious mental disorder constitutes a stumbling block to the doctors' explaining to the family members the professional understanding of the illness. In instances where the patient has a severe mental illness and has been admitted involuntarily the doctor does not have to seek the consent of such a patient before informing the family about the mental illness, but issues of confidentiality remain a concern.

The question of whether the respondents in this study had in fact been told about the illness must remain open, for a range of reasons, including possible unreliability of recall. From the available data we cannot know whether explanations have or have not been given. What does seem clear though is that if the information has been given it has not been retained, which opens the question not just of whether to inform relatives but how best to inform them about potentially distressing but important information.

There are a number of possible reasons for problems in communication between doctors and relatives. Some of the mental health professionals may communicate with the family members using medical jargon, and may underestimate the problems such use of terminology might create. Secondly, from the collected data it appears that some of the participants may be illiterate. Therefore, they may not be familiar with the terminology that the mental health professionals may be using. It is important for the mental health

professionals to make sure that the family members understand what has been explained.
In fact, mental health professionals should use lay terms when providing an explanation
about an important issue such as the diagnosis of one's relative. Since family members
often have to accompany a person with schizophrenia to the hospital when the latter has
to be seen by the doctor, one innovation could be to arrange for the screening of a video
recording on television in the waiting area where an explanation of the diagnosis is given
with the use of examples.

Cultural beliefs about the illness

Several studies that have investigated the relationship between witchcraft beliefs and
schizophrenia asserted that belief in witchcraft is very common everywhere in the black
diaspora, especially in the case of schizophrenia (Adebimpe, 1997). These findings are
also reflected in this study, as some of the participants attributed the illness of their
relatives to witchcraft. As alluded to earlier, belief in witchcraft could be seen against the
backdrop of the participants' cultural background. What is important to note though is
that as the participants were Xhosa and Coloured families it is not known to what extent
the White families might have attributed the illness of their relatives to witchcraft.
Some of the participants attributed the illness of their relatives to spirit possession. This is
consistent with the findings of Kurihara, Kato, Reverger, and Tirta (2006) that revealed
that 51% of family members attributed schizophrenia to disturbance by spirits. Mrs
Jacobs is one such participant, and she stated that the illness of her son is caused by spirit
possession. What it is particularly interesting about Mrs Jacobs is that she reported that
she had a 'nervous breakdown' some time ago. She is still taking medication for her
condition. Furthermore, she mentioned that her husband is a retired psychologist, and

therefore one would also expect that he would have explained to her what causes schizophrenia. Despite this, Mrs Jacobs continues to hold powerful subjective beliefs about the cause of her son's illness. These beliefs may be explained partly as cultural and partly as consequent on Mrs Jacobs's own mental state.

The participants also stated that they consulted traditional healers because of beliefs in witchcraft and spirit possession. Helman (2005) stated that in South Africa it is a common practice for black people to consult the traditional healers either for the benefit of their relatives or their own. And, this often happens while the black families or their relatives are receiving treatment from a western doctor.

Helman (2005) further explained that the problem with receiving two contrasting treatments at the same time is that this may compromise effectiveness of one of the treatments. This assertion may be true for these participants - some also revealed that their ill relative is receiving treatment from the traditional healer without the knowledge of the doctor. This means that the doctor is not aware that the family members have or are consulting the traditional healer on behalf of their relative. This finding underscores the importance of developing a trusting relationship between doctor and relatives insofar as this is possible. Commonly, it is the family members who decide the kind of treatment that their relative is to receive. In fact, family members may decide if their relatives should receive treatment at all. The importance of involving family members in the treatment of their ill relatives and in such a manner to maximise trust in the health system cannot be stated strongly enough.

Issues faced by families: Frustrations with and verbal aggression towards persons with schizophrenia.

The participants reported that they often displayed verbal aggression against their relatives. This appears to arise partly from the family members' frustration with their relatives' behaviours'. The participants reported that they often reach a point where they feel burnt out because they find it difficult to cope with the illness of their relatives. As a result family members resort to verbal aggression partly to vent their frustration or to assert their authority.

The theory of expressed emotion (EE) is relevant to this finding. EE theory postulates that family members often display hostility or become too critical of their relatives. Verbal aggression, hostility and being too critical can be seen in the same light. These emotional reactions from family members often affect the relatives negatively. Although in this study the effects of verbal aggression from family members towards their relatives were not directly explored, the family members did report that the impact is detrimental. In similar vein other investigators (Bhugra & McKenzie, 2003; Leff, 1998) asserted that family members who show hostility and too much criticism may contribute to the person with schizophrenia relapsing prematurely.

Verbal aggression from persons with schizophrenia

One of the symptoms that the participants found particularly challenging was verbal aggression from their ill relatives. The participants reported feeling distressed and powerless and taking much strain as a result of this disturbing behaviour from persons with schizophrenia. One participant stated that her blood pressure was often high because of the verbal abuse that emanates from her relatives. This may be a subjective

assessment, but is not inconsistent with the literature; in fact Haley (as cited in Burns, 2000) found that physical manifestations of caregiver burden included elevated blood pressure and impaired immune function, abnormal lipid levels, and poor self-care. In addition, Duraet and Teri (both cited in Burns, 2000) state that caregiver burden is associated with depression which affects between 25% and 70% of caregivers. Although the researcher did not ask the participants directly whether they had received advice from mental health professionals about how to deal with the disturbing behaviours from their relatives, participants reported that they are coping with this problem by trial and error. Unprompted, one spoke about feeling depressed as a result of the behaviour of the relative with schizophrenia.

In this study the participants reported that at times the persons with schizophrenia displayed verbal aggression as a result of being provoked. Provocation must be seen within the context of caregiver burden. For example, the participants reported that their repeated attempts to control the behaviour of their relatives with schizophrenia may lead to the relatives becoming irritated. Though there can never be justification for family members to verbally abuse their ill relatives (or other family members), the behaviour must be understood in the context of mutual frustrations in the family.

It is difficult to tease out the many causes of aggression shown by people with mental illness towards family members. Some studies (Hiday, 1995) have supported the findings of this study that individuals with mental illness, especially people with schizophrenia, often become verbally aggressive because of being provoked by their family members. In contrast, other studies have reported different findings. For example, Vaddadi (1997) asserted that verbal and physical abuse by mentally ill relatives can be attributed to a

number of factors: "underlying personality disorder, relapse of psychotic illness, use of illicit drugs and alcohol, and learned behaviour could all contribute to an aggressive outburst" (Vaddadi, p.150).

It must also be noted that all relatives of the participants in this study had reported that their relatives with mental illness had problems with substance abuse. Methamphetamine (Tik) and other drugs are often associated with heightened aggression,

Taking a more empathic view of aggression, Hiday (1995) stated that persons with schizophrenia use verbal aggression as a form of a defence mechanism. He asserts that "the vulnerability of persons with major disorders may make them attractive objects for bullying which provokes them to [show aggression]" (p. 125). Hiday further postulated that a history of people with mental illness being bullied may make them prone to aggressive reactions, especially towards long – time perpetrators. One can expect that ill relatives "will react in the same manner and for the same reasons as non – mentally disordered persons in situations of unfairness, which by definition bullying and victimization meet" (Hiday, p. 125).

Participants said that they seldom reported issues of aggression on the part of their relatives with schizophrenia to the doctors treating them. The reasons for this are not clear, but a context of great distance between the doctors and the families could be a possible contributing factor. One of the participants did report the verbal aggression of her foster daughter to the doctor, but only when she felt extremely distressed and had reached a point where she could no longer continue coping with this problem.

Physical aggression by persons with schizophrenia towards their family members

Overt expressions of physical violence of persons with schizophrenia towards their family members were also reported. This issue of physical violence by persons with schizophrenia made the participants on occasion fear the former and in some instances they feared for their own lives. This reportedly had a negative effect on the role of caregiving (e.g. some of the participants reiterated that they are fearful of making sure that their relative adheres to medication). The issue of looking after a person with mental illness is a difficult challenge on its own, much less having to deal with violence that seems to be a prominent feature in the lives of these family members. Nordström, Kullgren and Dahlgren (2006) aptly stated that violent conduct of persons with schizophrenia in combination with a mental disorder complicates the parent-child relationship. Nordström et al. quoted a study done in Australia that revealed that 90% of caregivers of individuals admitted to being subjected to either verbal or physical abuse by mental ill persons in receipt of care. Furthermore, twenty percent had been subjected to physical injury (Vaddadi, Soosai, Gilleard, & Adlard as cited in Nordström et al.). There are, then, many possible causes for aggression by people with mental illness towards their family members, all of which may apply to the relatives of participants in this study. These include a history of victimization and a feeling or experience of being provoked in the present, comorbid substance abuse, which increases risk of violence both in individuals with serious mental illness and without (Steadman et al as cited in Foley et al., 2005), difficulty living and social conditions (Swanson, Swartz, & Estroff as cited in Stuart, 2003) and the nature and quality of their closest social interaction, especially with family members. The most common victims of violent crime with serious mental illness

are family members or members of their close social networks (Estroff, Swanson, Lachicotte, Swartz, & Bolduc; Steadman et al.; Nordström & Kullgren; all cited in Foley, 2005). Stuart (2003) quoted a MacArthur Violence Risk Assessment Study by Monahan, Steadman, Silver et al., that revealed family members or friends (87%) are more prone to be attacked by the persons with schizophrenia and violence often took place in the home. In another study, Estroff et al. (as cited in Stuart) looked into violence and the social network of mentally ill relatives and ascertained that violent acts often erupted in the family when relationships were fraught with mutual threat, hostility, and financial dependence and when there was a diagnosis of schizophrenia with simultaneous substance abuse. Given high levels of crime in South Africa in general, violence is an issue for all families, and this would need to be taken into account in any locally tailored programme.

Stigma and mental illness

The findings on stigma experienced by family members and persons with schizophrenia are consistent with several studies (Huey et al., 2007) that mentioned the negative effects of this phenomenon on the family members and their relatives as well. The participants found it difficult to disclose the illness of their relatives to friends and families because of the unpleasant reactions from these parties. Dixon et al. (2000) stated that when family members withdraw from disclosing to people who matter to them, this affects their help seeking behaviours. Stigma also affected the family members simply because of their relations to people with schizophrenia, an experience often referred to as associative stigma. The participants also reported that they feel isolated and alone as a result of being

stigmatized. Several studies (see Dixon et al. for a review) have reported that it is common for family members to feel isolated and alone as a result being stigmatised.

Participants' ideas about a support group

The findings that the family members reported that they would welcome support echoes the findings of many studies. In the study done by Pickett-Schenk et al. (2008), family members also stated that support groups have many important uses. In the present study the participants asserted that through a support group they may be able to receive appropriate information about the illness of their relatives. The saliency of receiving information was important to some families because of the need to know the diagnosis of their relatives. Other participants reported that by receiving information they would be in a position to control the erratic behaviours of their relatives. The issues of containment were particularly important to some of the participants as their ill relatives' erratic behaviours were sometimes marked by physical aggression towards family members, as discussed earlier.

The participants stated that they often feel the need to talk about their ill relatives with other people. However, as explained above, the issues of stigma often prohibit family members from doing so. Family members may end up feeling isolated and alone in the midst of a very long and difficult journey with their ill relatives. The family members reported that a support group would help them express their feelings to others. As some of the participants asserted that they would much rather talk about their problems with people who have been in the same situation, a support group would exactly meet this requirement and need. Pickett-Schenk et al. (2008) found that their support group worked because the facilitators of the programme were themselves family members of people

with schizophrenia. Thus, their participants reported that they identified and related to the topics of the support group because the facilitators knew exactly what they were talking about.

Another important finding related to the family members' subjective well–being. The participants reported that by expressing their problems with their relatives they would feel better. In one of the interviews, Mrs Valerie told the present researcher that she was feeling better because she was talking about her experience with her ill son. She reported that she felt like something had been lifted off of her shoulders.

Furthermore, some of the participants reported that a support group would enable them to help other family members. This is an important finding to note because although some of the participants reported that they struggle to cope with the illness of their relatives, however they are willing to share whatever pieces of information they think may be helpful with others. Being able to help others may in itself build self-esteem and well-being

Mental health professionals may learn much from offering programmes such as support groups. Family members possess a wealth of information about the illness of their relatives and may even enable mental health professionals to improve their treatment.

Conclusion

This study had the modest aim of beginning to collect information on the perceptions and talk of family members of people with schizophrenia. The sample is small and may not be representative, but what emerged was a fairly consistent picture of lack of understanding of the disorder, considerable family strain, and little evidence of a close working partnership between the family members and mental health professionals. With

deinstitutionalization, the families of people with schizophrenia are or need to be the bedrock in the lives of these people. The stance taken by all family members interviewed suggests that it may indeed be helpful to follow more closely the evidence from international literature and to involve families more centrally in treatment.

The current study, though small, has the advantage of being embedded in a larger research programme on first episode psychosis, and the findings will be communicated to the research team to assist in preparation for evaluated intervention studies of different models of family support, appropriate to the local context. If what many participants in this study say is shown to be accurate, we have some way to go to foster the best possible relationships between family members and the mental health system, and to support these families, and people with schizophrenia, in the best manner possible.

REFERENCES

Abelenda, J., & Helfrich, C. A. (2003); Family resilience and mental illness: The role of occupational therapy. *Occupational Therapy in Mental Health, 19*, 25-39.

Accordino, M. P., Porter, D. F., & Morse, T. (2001). Deinstitutionalization of persons with severe mental illness: Context and consequences. *Journal of Rehabilitation, 6*(2), 16-21.

Adams, C., Wilson, P., & Bagnall, A. M. (2000). Psychosocial interventions for schizophrenia. *Quality in Health Care, 9*, 251-256.

Adebimpe, V. R. (1997). Mental illness among African Americans. In I. Al-Issa & M. Tousignant (Eds.), *Ethnicity, immigration, and psychopathology* (pp. 95-106). New York: Premuim Presss.

Aguglia, E., Pascolo-Fabrici, E., Bertossi, F., & Bassi, M. (2007). Psychoeducational intervention and prevention of relapse among schizophrenic disorders in the Italian community psychiatric network. *Clinical Practice and Epidemiology in Mental Health, 3*(7). Retrieved June 22, 2008, from http://www.cpementalhealth.com/content/3/1/7

Anderson, K. K., & Mukherjee, S. D. (2007). The need for additional safeguards in the informed consent process in schizophrenia research. *Journal of Medical Ethics, 33*, 647-650.

Angermeyer, M. C., Buyantugs, L., Kenzine, D. V., & Matschinger, H. (2004). Effects of labelling on public attitudes towards people with schizophrenia: Are there cultural differences? *Acta Psyciatrica Scandinavica, 109*, 420-425.

Association of Community Organizations for Reform Now. (2004). *Speaking the language of care: Language barriers to hospital access in America's cities.* Washington, D.C.: Author.

Atri, A., & Sharma, M. (2007). Psychoeducation: Implications for the profession of health education. *California Journal of Health Promotion, 5*, 32-39.

Awad, A. G., & Voruganti, L. N. P. (2008). The burden of schizophrenia on caregivers. *Pharmacoeconomics, 26*, 149-162.

Bachrach, L. L. (1993). American experience in social psychiatry. In D. Bhugra & J. Leff (Eds.), *Principles of social psychiatry* (pp. 534-548). Oxford: Blackwell.

Bakshi, L., Rooney, R., & O'Neil, K. (1999). *Reducing stigma about mental illness in transcultural settings: A guide.* Melbourne: Australian Transcultural Mental Health Network.

Bäuml, J., Froböse, T., Kraemer, S., Rentrop, M., & Pitschel-Walz, G. (2006). Psychoeducation: A basic psychotherapeutic intervention for patients with schizophrenia and their families. *Schizophrenia Bulletin, 32*(Suppl. 1), 1-9.

Bedini, A. L., & Phoenix, T. (2004). Perceptions of leisure by family caregivers: A profile. *Therapeutic Recreation Journal, 38*, 366-381.

Bhugra, D., & McKenzie, K. (2003). Expressed emotion across cultures. *Advances in Psychiatric Treatment, 9,* 342-348.

Bloom, J. R., Masland, M., Keeler, C., Wallace, N., & Snowden, L. R. (2005). Overcoming language barriers to public mental health services in Califonia. *California Program on Access to Care Findings, 4*, 1-2.

Bowen, S. (2000). *Language barriers in access to health care.* Ontario: Health Canada.

Berlund, N., Vahlne, J. O., & Edman, A. (2003). Family intervention in schizophrenia: Impact on family burden and attitude. *Social Psychiatry and Psychiatric Epidemiology, 38*, 116-121.

Bressi, C., Manenti, S., Frongia, P., Porcellana, M., & Invernizzi, G. (2008). Systemic family therapy in schizophrenia: A randomized clinical trial of effectiveness. *Psychotherapy and Psychosomatics, 77*, 43-49.

Brodaty, H., & Green, A. (2002). Defining the role of the caregiver in Alzheimer's disease treatment. *Drugs and Aging, 19*, 891-898.

Burns, A. (2000). Behavioral and psychological symptoms of dementia (BPSD): A clinical and research update. *International Psychogeriatrics, 12*, 347-350.

Clarke, J. (1979). In defense of deinstitutionalization. *Health and Society, 57*, 461-479.

Corrigan, P. W., Rowan, D., Green, A., Lundin, R., River, P., Uphoff-Wasowski, K. et al. (2002). Challenging two mental illness stigmas: Personal responsibility and dangerousness. *Schizophrenia Bulletin, 28*, 293-309.

Dillon, E. (2006). *New programs in the old asylum: The deinstitutionalization of long-term psychiatric hospital patients in Argentina.* Unpublished doctoral dissertation, Louisiana State University, Louisiana.

Dixon, L., Adams, C., & Luckstead, A. (2000). Update on family psychoeducation for schizophrenia. *Schizophrenia Bulletin, 26*, 5-20.

Dixon, L., & Lehman, A. (1995) Family interventions for schizophrenia. *Schizophrenia Bulletin, 21*, 567-578.

Dixon, L., McFarlane, W. R., Lefley, H., Lucksted, A., Cohen, M., Falloon, I., Mueser, K., Miklowitz, D., Solomon, P., & Sondheimer, D. (2001). Evidence-based

practices for services to families of people with psychiatric disabilities. *Psychiatric Services, 52*, 903-910.

Dovido, J. F., Major, B., & Crocker, J. (2003). Stigma: Introduction and overview. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma*. New York: Guilford Press.

Drennan, G. (1999). Psychiatry, post-apartheid integration and the neglected roles of language in South Africa institutional contexts. *Transcultural Psychiatry, 36*, 5-22.

Dyck, D. G., Short, R., & Vitaliano, P. P. (1999). Predictors of burden and infectious illness in schizophrenia caregivers. *Psychosomatic Medicine, 61*, 411-419.

Emsley, R. (2001). Focus on psychiatry in South Africa. *British Journal of Psychiatry, 178*, 382-386.

Estroff, S. E., Swanson, J. W., Lachicotte, W. S., Swartz, M., & Bolduc, M. (1998). Risk reconsidered: Targets of violence in the social networks of people with serious psychiatric disorders. *Social Psychiatric Epidemiology, 33*, 95-101.

Evavold, S. A. (2003). *Family members of the mentally ill and their experiences with mental health professionals.* Unpublished doctoral dissertation, University of Virginia, Virginia.

Flores, G. (2006). Language barriers to health care in the United States. *The New England Journal of Medicine 335*(3), 229-231.

Foley, S. R., Kelly, B. D., Clarke, M., McTigue, O., Gervin, M., & Kamali, M. et al. (2005). Incidence and clinical correlates of aggression and violence at

presentation in patients with first episode psychosis. *Schizophrenia Research, 72*, 161-168.

Freedman, R. I., & Moran, A. (1984). Wanderers in a promised land: The chronically mentally ill and deinstitutionalization. *Medical Care, 22*, 1-68.

Genduso, L. A., & Haley, J. C. (1997). Cost of illness studies for schizophrenia components, benefits, results, and implications. *The American Journal of Managed Care, 3*, 873-877.

Glanville, D. N., & Dixon, L. (2005). Caregiver burden, family treatment approaches and service use in families of patients with schizophrenia. *Israel Journal of Psychiatry and Related Sciences, 42*, 15-22.

Graneheim, H. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Journal of Nurse Education Today*, *24*, 105-112.

Gronfein, W. (1985). Psychotropic drugs and the origins of deinstitutionalization. *Social Problems, 32*, 437-454.

Hausman, K. (2001). Cultural factors affect success of African Americans' MH care. *American Psychiatric Association, 36*(10), 1-3.

Health Plan of New York & National Alliance of Caregiving. (2005). Care for the family caregiver: A place to start. Washington D.C.: White House Conference on Aging.

Helman. C. G. (2008). Culture, health and illness: An introduction for health professionals. London, England: Butterworths.

Hendrickson, E. L., Schmal, M. S., & Ekleberry, S. C. (2004). Family Interventions. In E. L. Hendrickson, M. S. Schmal & S. C. Ekleberry (Eds.), *Treating co-occuring disorders* (pp. 143-167). Binghampton, NY: Haworth Press.

Hiday, A. (1995). The social context of mental illness and violence. *Journal of Health and Social Behavior, 36*, 122-137.

Hoeing, J., & Hamilton, M. W. (1966). The schizophrenic patient in the community and their families and his effect on the household. *International Journal of Social Psychiatry, 12*, 165-76.

Hogan, M. F. (2002). The president's new freedom commission on mental health: Transforming mental health care *Capital University Law, 32*, 907-923.

Hooley, J. M. (2007). Expressed emotion and relapse of psychopathology. *The Annual Review of Clinical Psychology, 3*, 349-72.

Hooley, J. M., & Parker, H. A. (2006). Measuring expressed emotion: An evaluation of the shortcuts. *Journal of Family Psychology 20*, 386-396.

Huey, L. Y., Lefley, H. P., Shern, D. L., & Wainscott, C. A. (2007). Families and schizophrenia: The view from advocacy. *Psychiatric Clinics of North America, 30*, 519-566.

Hussein, H., El-Shafei, A., & Okasha, T. (2006). Working with families of patients with schizophrenia: A rewarding alternative to classical community care in developing countries. *Egyptian Journal of Psychiatry, 25*, 11-17.

Jenkins, J. H., & Schumacher, J. G. (1999). Family burden of schizophrenia and depressive illness: Specifying the effects of ethnicity, gender and social ecology. *British Journal of Psychiatry, 174*, 31-38.

Johnson, K. (2006). *Perceptions of community psychology among Honours/BPsych students in the Western Cape*. Unpublished master's thesis, University of Stellenbosch, Stellenbosch, Western Cape, South Africa.

Jonker, L. (2006). *Resilience factors in families living with a member with a mental disorder.* Unpublished masters thesis, University of Stellenbosch, Stellenbosch, Western Cape, South Africa.

Jones, S., & Hayward, P. (2004). *The role of the family: Coping with schizophrenia – a guide for patients, families and caregivers.* England: Oneworld Publications.

Jorm, A. F. (2000). Mental health literacy: Public knowledge and beliefs about mental disorders. *British Journal of Psychiatry*, *177,* 396-401.

Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Pollitt, P. (1997). Public beliefs about causes and risk factors for depression and schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 32*, 143-148.

Koopmans, M. (2001). From double bind to n-bind: Towards a new theory of schizophrenia and family interaction. *Nonlinear Dynamics, Psychology, and Life Sciences, 5*, 289-323.

Koyanagi, C., & Bazelon, D. L. (2007). *Learning from history: Deinstitutionalization of people with mental illness as precursor to long-term care reform.* Washington, D.C.: Kaiser Family Foundation.

Kuipers, E., Leff, J., & Lam, D. (1992). *Family work for schizophrenia: A practical guide.* London: Bell & Bain Ltd.

Kung, W. W. (2003). The illness, stigma, culture, or immigration? Burdens on Chinese American caregivers of patients with schizophrenia. *Families in Society, 84*, 547-557.

Kurihara, T., Kato, M., Reverger, R., & Tirta, I. G. R. (2006). Beliefs about causes of schizophrenia among family members: A community-based survey in Bali. *Psychiatric Services, 57*, 1795-1799.

Kyziridis, T. C. (2005). Notes on the history of schizophrenia. *German Journal of Psychiatry, 8,* 1433-1055.

Lamb, H. R., & Bachrach, L. L. (1993). Lessons learned from deinstitutionalization in the US. *British Journal of Psychiatry, 162*, 587-592.

Lamb, H. R., & Bachrach, L. L. (2001). Some perspectives on deinstitutionalization. *Psychiatric Services, 52*, 1039-1045.

Lee, H. I., Chen, P. S., Yang, Y. K., Liao, Y. C., Lee, Y. D., Yeh, T. L. Y., Yeh, L. L., Cheng, S. H., & Chu, C. L. (2008). The functionality and economic costs of outpatients with schizophrenia in Taiwan. *Psychiatry Research, 156*, 306-315.

Leff, L. (1998). Needs of the families of people with schizophrenia. *Advances in Psychiatric Treatment, 4*, 277-284.

Leff, J., Wig, N. N., Ghosh, A., Bedi, H., Menon, D. K., Kuipers, L., Korten A., Ernberg, G., Day, R., & Sartorius, N. (1987). Expressed emotion and schizophrenia in north India, III: Influence of relatives' expressed emotion on the course of schizophrenia in Chandigarh. *British Journal of Psychiatry, 151*, 166-173.

Liem, J. H. (1980). Family studies of schizophrenia: An update and commentary. *Schizophrenia Bulletin, 6*, 429-455.

Long, T., & Johnson, M. (2000). Rigour, reliability and validity in qualitative research. *Journal of Clinical Effectiveness in Nursing, 4*, 30-37.

Loukissa, D. A. (1995). Family burden in chronic mental illness: A review of research studies. *Journal of Advanced Nursing, 21*, 248-255.

Lubkin, I., & Larsen, P. (2006). *Chronic Illness: Impact and Interventions (6th ed.).* Sudbury: Jones & Bartlett Publishers.

Magaña, S. M., Garcia, J. I. R., Hernández, M. G., & Cortez, R. (2007). Psychological distress among Latino caregivers of adults with schizophrenia: The roles of burden and stigma. *Psychiatric Services, 58*, 378-384.

Magliano, L. (2008). *Families of people with severe mental disorders: Difficulties and resources.* Denmark: World Health Organization.

Marks, D. (1998). *Disability: Controversies and current debates.* London: Routledge.

Mavundla, T. R. (2000). Professional nurses' perception of nursing mentally ill people in a general hospital setting. *Journal of Advanced Nursing, 32*, 1569-1578.

McDonell, G., Short, R. A., Berry, C. M., & Dyck, D. G. (2003). Burden in schizophrenia caregivers: Impact of family psychoeducation and awareness of patient suicidality. *Family Process, 42*(, 91-103.

McFarlane, W. R., Dixon, L., Lukens, E., & Lucksted, A. (2003). Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy, 2*, 223-245.

Metlife Mature Market Institute & National Alliance for Caregiving (2006). The Metlife caregiving cost study: Productivity losses to U.S. Business. Cape Town: Metlife Inc.

Motlana, L. M., Sokudela, B., Moroka, T., Roos, J. L., & Snyman, M. (2004). In touch with reality. *South African Psychiatry Review, 7*, 26-29.

Murray-Swank, A. M., Dixon, L. B., & Stewart, B. (2007). Practical interview strategies for building an alliance of patients who have severe mental illness. *Psychiatric Clinics of North America, 30*, 167-180.

National Alliance for Caregiving & American Association of Retired Persons. (2004). *Caregiving in the U.S.* Sacremento, C.A.: Author.

Neal, M. N., & Hammer, L.B. (2006). *Working couples caring for children and aging parents: Effects on work-family fit, well-being, and work*. Mahwah, NJ: Lawrence Erlbaum.

Nevid, J. S., Rathus, A. S., & Greene, B. (2000). Classification and assessment of abnormal behaviour. In J. S. Nevid, A. S. Rathus & B. Greene (Eds.), *Abnornal psychology in a changing world* (5th ed.) (pp. 62-95). New Jersey: Pearson Education Inc.

Nordström, A., & Gunnar, K. (2003). Do violent offenders with schizophrenia who attack family members differ from those with other victims? *International Journal of Forensic Mental Health, 2*, 195-200.

Nordström, A., Kullgren, G., & Dahlgren, L. (2006). Schizophrenia and violent crime: The experience of parents. *International Journal of Law and Psychiatry, 29*, 57-67.

Novella, E. J. (2008). Theoretical accounts on deinstitutionalization and the reform of mental health services: A critical review. *Medical Health Care and Philosophy, 11*, 303-314.

Ohaeri, J. U. (2002). The burden of caregiving in families with a mental illness: A review of 2002. *Current Opinion in Psychiatry 16*, 457-465.

Parker, I. (2005). *Qualitative psychology*: *Introduction to radical research*. New York: Open University Press.

Payne, S. (2007). Grounded theory. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 65-86). London: Sage.

Pickett-Schenk, S. A., Lippincott, R. C., Bennett, C., & Steigman, P. J. (2008). Improving knowledge about mental illness through family-led education: The journey of hope. Psychiatric Services, 59, 49-56.

Pruchno, R., Patrick, J. H., & Burant, C. J. (1997). African American and white mothers of adults with chronic disabilities: Caregiving burden and satisfaction. *Family Relations, 46*, 335-346.

Reid, J., Lloyd, C., & De Groot, L. (2005). The psychoeducation needs of parents who have an adult son or daughter with a mental illness. *Australian e-Journal for the Advancement of Mental Health, 4*(2). Retrieved October 22, 2008, from http://www.auseinet.com/journal/vol4iss2/reid.pdf

Reinhard, S. C., & Horwitz, A. V. (1995). Caregiver burden: Differentiating the content and consequences of family caregiving. *Journal of Marriage and the Family, 57*, 741-750.

Rhoades, D. R., & McFarland, K. F. (1999). Caregiving meaning: A study of caregiviers of individuals with mental illness. *National Association of Social Workers, 24*, 291-298.

Riley, S., Schouten, W., & Cahill, S. (2003, May 2). Exploring the dynamics of subjectivity and power between researcher and researched. *Forum: Qualitative Social Research, 4*, Atricle 02. Retrieved October 15, 2008, from http://www.qualitative-research.net/index.php/fqs/article/view/713/1545

Rolfe, G. (2006). Validity, trustworthiness and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing, 53*, 304-310.

Rummel-Kluge, C., Pitschel-Walz, G., Bäuml, J., & Kissling, W. (2006). Psychoeducation in Schizophrenia: Results of a survey of all psychiatric institutions in Germany, Austria, and Switzerland. *Schizophrenia Bulletin, 32*, 765-775.

Samele, C., & Manning, N. (2000). Level of caregiver burden among relatives of the mentally ill in South Verona. *European Psychiatry, 15*, 196-204.

Sartorius N., & Schulze, H. (2005). *Reducing the stigma of mental illness*. Cambridge: Cambridge University Press.

Saxena, S., Thornicroft, G., Knapp, M., & Whiteford, H. (2007). Resources for mental health: Scarcity, inequity, and inefficiency. *Lancet, 370*, 878-889.

Scheffer, R. (2003). *Addressing stigma: Increasing public understanding of mental illness*. Toronto: Centre for Addiction and Mental Health.

Sentell, T., Shumway, M., & Snowden, L. (2007). Access to mental health treatment by English language proficiency and race/ethnicity. *Journal of General Internal Medicine, 22*, 289-293.

Silverman, D., & Marvasti, A. (2008). *Doing qualitative research: A comprehensive guide*. Los Angeles: Sage.

Spencer, L., Ritchie, J., Jane, L., & Dillon, L., National Centre for Social Research (2003). Quality Evaluation: A Framework for assessing research evidence. *Government Chief Social Researcher's Office*. Retrieved May 30, 2009, from http://www.gsr.gov.uk/downloads/evaluating_policy/a_quality_framework.pdf

Solomon P., Draine, J., Mannion, E., & Meisel, M. (1996). Impact of brief family psychoeducation on self-efficacy. *Schizophrenia Bulletin, 22*, 41-50.

Steinert, T., Weibe, C., & Gebhardt, R. P. (1999). Aggressive behavior against self and others among first-admission patients with schizophrenia. *Psychiatric Services, 50*, 85-90.

Stiles, P. D., Culhane, D. P., & Hadley, T. R. (1996). Before and after deinstitutionalization: Comparing state hospitalization utilization, staffing and costs in 1949 and 1988. *Administration and Policy in Mental Health, 23*, 513-526.

Strachan, K. (2000, March). Deinstitutionalisation – a Cape Town case study. *Mental Health in South Africa Update, 50*. Retrieved May 29, 2008, from http://www.hst.org.za/uploads/files/upd50.pdf

Stuart, H. (2003). Violence and mental illness: An overview. *World Psychiatry*, 121-124.

Stubbs, P. (1998). Broken promises: The story of deinstitutionalization. *Perspectives*, *3*(4). Retrieved August 11, 2008, from http://www.mentalhelp.net/poc/view_doc.php?type=doc&id=368

Swank, A. M., Dixon, L. B., & Stewart, B. (2007). Practical interview strategies for building an alliance of patients who have severe mental illness. *Psychiatric Clinics of North America, 30*, 167-180.

Swartz, L. (1998). Specific areas of interest. In L. Swartz (Ed.), *Culture and mental health: A southern African view.* (pp. 97-215), Cape Town: Oxford University Press Southern Africa.

Swartz, L., & Drennan, G. (2000). Beyond words: Notes on the 'irrelevance' of language to mental health services in South Africa. *Transcultural Psychiatry, 37*, 185-201.

Swartz, L., Drennan, C., & Crawford, A. (1997). Changing language policy in mental health services: A matter of interpretation? In D. Foster, M. Freeman & Y. Pillay (Eds.), *Mental health policy in South Africa* (pp. 166-180). Cape Town: Masa Multimedia.

Tessler, R., & Gamache, G. (1994). Continuity of care, residence, and family burden in Ohio. *The Milbank Quarterly, 72*, 149-169.

Thompson, E. H., & Doll, W. (1982). The burden of families coping with the mentally ill: An invisible crisis. *Family Relations, 31*, 379-388.

Thornicroft, G. (2006). From stigma to ignorance, prejudice and discrimination. In G. Thornicroft (Ed.), *Shunned: Discrimination against people with mental illness* (pp. 170-203). New York: Oxford University Press.

Uwakwe, R. (2006). Satisfaction with dementia care – giving in Nigeria: A pilot investigation. *International Journal of Geriatric Psychiatry, 21*, 296-297.

Vaddadi, K. S. (1997). Burden of care in the home: Issues for community management. *Advances in Psychiatric Treatment, 3*, 146-153.

Visser, M. (2003). Gregory Bateson on deutero-learning and double bind: A brief conceptual history. *Journal of History of the Behavioral Sciences, 39*, 269-278.

Vaughn, C. E., & Leff, J. (1976). The measurement of expressed emotion in the families of psychiatry patients. *British Journal of Social and Clinical Psychology, 15*, 157-165.

Wahl, O, F. (1995). *Media madness*. New Jersey: Rutgers University Press.

Walker, A., Pratt, C., & Eddy, L. (1995). Informal Caregiving to aging family members: A critical review. *Family Relations, 44*, 402-411.

Weisman, A., Duarte, E., Koneru, V., & Wasserman, S. (2006). The development of a culturally informed, family-focused treatment of schizophrenia. *Family Process, 45*, 171-186.

Wiley-Exley, E. (2007). Evaluations of community mental health care in low- and middle-income countries: A 10-year review of the literature. *Social Science & Medicine, 64*, 1231-1241.

Whitaker, R. (2004). The case against antipsychotic drugs: A 50-year record of doing more harm than good. *Medical Hypotheses, 62*, 5-13.

World Schizophrenia Fellowship. (2008). *Families as partners in care.* Toronto: Author.

APPENDICES

Appendix A: List of semi-structured questions

1. Please tell me about your relative and what has happened to him/her.

2. What do you think your ill family member is suffering from?

   - What do you think the illness does to your family member?

3. Please tell me what schizophrenia is?

4. What do you think caused this illness?

5. Tell me about the prescribed medication your family member is taking? How often does he/she take them? Do you think medication that your family member is taking have effect? Does it make get better or does it make the situation worse?

6. Did the onset of the illness of your family member affect the relationship, harming your family member in any way, and if so, how?

7. Has there been any point where your family member physical attacked any of you in the family and if so, how did your family deal with the situation?

8. How does your family cope with the illness of your family member?

   - Good and bad things.

9. Has the onset of the illness of your family member had any impact on the financial resources of your family?

10. Please tell me about the psychiatrists who are treating your ill family member?

    - Are they Black or White? Do you understand the things that they tell you about the illness of your family member? What sorts of questions do they ask you and your ill family member?

11. Has there been a time during the course of the hospital visits when a mental health professional explained what schizophrenia is?

12. Who do you turn to for help (e.g., traditional healer, priest or members of the extended family) and who do you think should be involved in the decision-making?

13. Have you ever consulted a psychologist?

14. What do you think might be helpful to you and your ill family member?

    - What do you think the future holds?

Appendix B: Informed consent form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: African families' experiences of schizophrenia
REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Professor Leslie Swartz/ Mr Stanley Molefi

ADDRESS: Department of Psychology, Stellenbosch University

CONTACT NUMBER: 021 808 3461/073 198 6263

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask Mr Molefi, who will be interviewing you if you agree to be interviewed, any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Committee for Human Research at Stellenbosch University **and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.**
What is this research study all about?
We are interested in the experiences that families of people who have been treated for mental illnesses undergo. The Department of Psychiatry at Stellenbosch University are doing studies on large numbers of people. I am going to be speaking to about ten families so we can get a good sense of the issues that families like your face.

Why have you been invited to participate?
I was given your name by the Department of Psychiatry at Stellenbosch University because your family member is in treatment there. This is the only reason you and other people have been chosen from a list of names. We think it is important to listen to the views of family members of those who are in treatment.

What will your responsibilities be?
If you agree, I will be interviewing you and I will also be recording what we say on this tape recorder so I can have a record of your views. All I am asking for you to do is to answer my questions as honestly as you can and also to feel free to make other comments and to ask me any questions.

Will you benefit from taking part in this research?
You will not get any direct benefits from this research. We hope that what you and other family members tell us will help us improve services for people like your relative who has been ill.

Are there in risks involved in your taking part in this research?
There should be no risks involved in taking part in this research. There is a chance though that you may feel upset or worried by our discussion. If this is the case please let me know and I can arrange for you to be seen for counseling by someone at the university.

If there are any questions you do not wish to answer or if you want to stop the interview at any time, please tell me and this will be fine.

If you do not agree to take part, what alternatives do you have?
If you do not wish to take part or you decide to stop the interview, this will not affect your treatment in any way. It is your right to refuse to participate in all or part of the study.

Who will have access to your relative's medical records? What happens about privacy?
Members of the research team may wish to look at your relative's medical records to see how what you are telling us links with what the doctors have written on the files. Nobody else will be allowed to see your relative's records. All information you give us know will be treated as confidential and we will not link your name or your family's name to anything you tell us. When we have finished our interviews, I will writing a thesis using the information and we will also be publishing the findings in an academic journal. We will not publish your name in the thesis or in the articles and nobody will be able to link what you say to yourself.

Will you be paid to take part in this study and are there any costs involved?
No, you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit if you are interviewed away from your home. There will be no costs involved for you, if you do take part.

Is there any thing else that you should know or do?
- ➢ **You can contact Professor Leslie Swartz. at tel 0218083461 if you have any further queries or encounter any problems.**
- ➢ **You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.**
- ➢ **You will receive a copy of this information and consent form for your own records.**

Declaration by participant

By signing below, I ………………………………...…………. agree to take part in a research study entitled *(insert title of study)*.

I declare that:
- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I give permission for my responses to be tape-recorded and for the information to be transcribed and used later.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....….........…………….. on (*date*) …………....……2008.

....
Signature of participant   Signature of witness

Declaration by investigator
I Stanley Molefi declare that:

- I explained the information in this document to …………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ....….........…………….. on (*date*) …………....……… 2008.

....
Signature of investigator   Signature of witness

Appendix C: Institutional Review Board letter of approval

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot · your knowledge partner

16 May 2008

Prof L Swartz
Dept of Psychology

Dear Prof Swartz and Mr Molefi

RESEARCH PROJECT: "AFRICAN FAMILIES' EXPERIENCE OF SCHIZOPHRENIA (Sub-study to: A prospective study of clinical Biological and Functional Aspects of outcome of first episode psychosis)"

PROJECT NUMBER : N06/08/148

It is my pleasure to inform you that the abovementioned project has been provisionally approved on 16 May 2008 **for a period of one year from this date**. You may start with the project, but this approval will however be submitted at the next meeting of the Committee for Human Research for ratification, after which we will contact you again.

Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary to make their final decision.

Please note that a progress report (obtainable on the website of our Division) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

I wish to remind you that patients participating in a research project at Tygerberg Hospital will not receive their treatment free, as the PGWC does not support research financially.

The nursing staff of Tygerberg Hospital can also not provide extensive nursing aid for research projects, due to the heavy workload that is already being placed upon them. In such instances a researcher might be expected to make use of private nurses instead.

Please quote the abovementioned project number in all future correspondence.

Yours faithfully

MERTRUDE DAVIDS
RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)
Tel: +27 21 938 9657 / E-mail: mertrude@sun.ac.za

C:\DOCUMENTS AND SETTINGS\MERTRUDE\MY DOCUMENTS\2008\N0808148_SWARTZMOLEFI\N0808148_SWARTZMOLEFI_PROVISIONAL APPROVAL.DOC

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en ·steun · Research Development and Support Division
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel: +27 21 938 9677 · Faks/Fax: +27 21 931 3352
E-pos/E-mail: rdsdinfo@sun.ac.za