

EXPERIENCES OF CAREGIVERS OF INDIVIDUALS SUFFERING FROM SCHIZOPHRENIA IN RURAL AREAS OF THE MPUMALANGA PROVINCE OF SOUTH AFRICA

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ABSTRACT

The article reports on a research study done at a rural area in Mpumalanga Province. A qualitative, exploratory, descriptive and contextual design was followed to investigate the experiences of caregivers of individuals with schizophrenia. In-depth individual interviews were conducted with a purposefully selected sample of twelve caregivers. The Tesch (1990) constant comparative method to analyse content of qualitative data was used for the analysis. Five main categories emerged from the data analysis: emotions; physical burden; lifestyle changes; inadequate support and relationship burden. Themes were extracted from the categories. The results of the study showed that caring for individuals with schizophrenia can put considerable burdens and restrictions on the caregivers. The emotional distress that occurred as a consequence of caring for schizophrenics was compounded by other psychosocial burdens such as, poverty, patients' poor self-care, non-compliance with medication, psychotic episodes, and lack of support by family and community members. Recommendations were made regarding the improvement of health care services to the caregivers and family members with schizophrenia.

Keywords: community-based psychiatric care, emotional demands made on caregivers, individuals with schizophrenia, rural Mpumalanga, support burden of caregivers

INTRODUCTION

Schizophrenia is a serious, persistent, stressful mental disorder to the sufferer and the family. The disease is chronic and results in psychotic behaviour; characterised by concrete thinking and difficulties in information processing, interpersonal relationships and problem solving abilities. A central feature of schizophrenia is a disturbance of the integrity or privacy of the self, with associated loss of autonomy or sense of being in control and independent. The illness tends to run a chronic course, characterised by a variable pattern of relapses and remissions (Baumann, 2007:457; Stuart, 2005:251).

Dealing with chronic illness may result in feelings of burden or strain for caregivers that can diminish their quality of life (Sales, 2003:34).

There has been an apparent shift in the care of psychiatric patients from institutional to community care in recent years. In South Africa, the new Mental Health Care Act (No. 17 of 2002) makes provision for de-institutionalisation and as a result the role of the family caregivers has gained importance. However, studies have shown that only a quarter of schizophrenic patients make a good recovery despite the availability of effective treatment (Stuart, 2005:250). Other studies have demonstrated that family caregivers of persons with schizophrenia suffer from significant stresses (Saunders, 2003:176). The caregivers have to cope with psychiatric symptoms such as the lack of concentration, isolation, negative behaviours, and disorganised communication and lack of self-care.

The rural area chosen for the study is large and has one community psychiatric nurse caring for individuals with mental disorders. She experiences problems like the lack of transport and of some drugs prescribed by the psychiatric hospital. When she goes on holiday there is often no one to relieve her. These factors lead to high incidents of relapses among individuals with schizophrenia. Another problem is that most people in this area believe that mental disorders are caused by witchcraft, thus their first point of consultation is the traditional healers, which delays patients' diagnoses and treatment. Families often reject individuals with schizophrenia when they do not understand their behaviour.

Caring for individuals with schizophrenia in the areas of Mpumalanga Province poses enormous difficulties for the caregivers. During crises the families get help from a district hospital, 6 km away. The psychiatric unit at the hospital accommodates only 24 acute patients, 16 males and 8 females. Patients who need long term care are transferred to a psychiatric hospital, 400km away, in the Gauteng Province. The patients' treatment, rehabilitation and subsequent discharge occur without family involvement because most families are too poor to afford travelling to Gauteng, to visit their loved ones.

PROBLEM STATEMENT

Schizophrenia is a psychotic state that can be frightening for everyone; especially the person experiencing the condition, triggering extreme stress, fear, loss of contact with reality and inability to distinguish between what is real and what is imaginary, including delusions and hallucinations (Frisch & Frisch, 2006:239). Researchers investigating the effects of mental illness on caregivers have identified various burdens such as financial expenditure, the disruption of everyday life and restrictions on the rest of the family (Jungbauer, Wittmund, Dietrich & Angermeyer, 2005:665; Sales, 2003:34; Saunders, 2003:177). However, studies done on people who suffer from mental illness themselves reveal that the individuals feel that natural social integration into the family cannot be replaced by any psychiatric care service, regardless of how good it may be (Martens &

Addington, 2001:131). Although the burdens of schizophrenic patients have been the subject of numerous studies, there are hardly any publications on the impact of caring for schizophrenic patients in rural Mpumalanga. The study was therefore a realisation of the need to explore and describe the experiences of caregivers of individuals suffering from schizophrenia in a rural area of the Mpumalanga Province.

RESEARCH PURPOSE

The purpose of the research was to explore and describe the experiences of caregivers of individuals suffering from schizophrenia in this rural area to share the findings with the mental health care authorities in Mpumalanga Province, and to make recommendations regarding improved service provision and support to caregivers.

Research objectives

The objectives of this study were to:

- explore and describe the experiences of caregivers of individuals suffering from schizophrenia in a rural area of the Mpumalanga Province
- offer the caregivers of individuals suffering from schizophrenia an opportunity to voice their needs with regard to caring
- make recommendations to the mental health authorities in the Mpumalanga Province regarding the improvement of health care and the support required by the caregivers.

RESEARCH DESIGN AND METHOD

A qualitative study was undertaken from a phenomenological viewpoint. According to Burns and Grove (2005:31) phenomenological research is ideal for researching and giving meaning to a person's experience in his/her context, in this case caregivers of people suffering from schizophrenia. Individual in-depth interviews were used to collect data. The choice of this method is based on the fact that the aim of an in-depth interview is to obtain access to another person's life in an empathic manner (Silverman, 2005:116).

Sampling technique

The population consisted of families of individuals with schizophrenia and the sample consisted of caregivers of the affected individuals. Potential participants were identified through clinic records by the community psychiatric nurse. Non- probability, purposive sampling (Burns & Grove, 2005:306) was used to select participants who met the inclusion criteria, who were willing to participate in the study and who would provide the most relevant information. In this study, the number of participants was

not important. The researcher collected data until saturation occurred (Terre Blanche, Durrheim & Painter, 2007:564); the sample comprised 12 caregivers of schizophrenic patients. The criteria used in selecting the participants in the study included that, they had to be able to communicate in English and/or SiSwati; as the primary researcher is proficient in the two languages; they had to be residents of the selected rural area and the individuals suffering from schizophrenia should not have been hospitalised at the time of data collection.

Ethical considerations

Written permission to conduct the study was sought from the Mpumalanga health authorities and ethical clearance was granted by the Faculty of Health Science Ethics Committee of the University of Pretoria prior to commencement of data collection. Informed consent was obtained from all participants by explaining the goals of the study and permission was obtained to audio-tape the interviews. The participants were assured of confidentiality and anonymity by explaining that their names will not appear in the research report and that the audiotapes and transcripts of interviews will be kept in a safe place for two years if the study is published or for six years if it is not published and then destroyed by burning. The freedom to opt out of the study at any stage, without incurring any negative consequences, was also explained.

Trustworthiness

Qualitative approaches are criticised because of their lack of rigour and credibility. Both reliability and validity are questioned since homogeneity of data and coefficients of determination cannot be computed (Lincoln & Guba, 1985:289). These authors have developed four precise criteria for qualitative inquiry that parallel the quantitative terminology:

- **Credibility (internal validity):** How truthful are particular findings? The researcher in the study ensured truth of the experiences of caregivers of individuals with schizophrenia, by dwelling long in the setting of participants. Each interview lasted 60 to 90 minutes with the people who were caring for people with schizophrenia. The interviews were conducted in a natural setting (Terre Blanche et al 2007:287), at the homes of the participants to ensure comfort and relaxation.
- **Dependability (reliability):** Are the results consistent and reproducible? Instruments that are assessed for consistency in qualitative research are the researcher and the informants, both of whom vary greatly within the research project (Krefting, 1991:216). To adhere to the criterion of dependability, the researcher gave an explicit description of how she went about to find the results in the study. The description provides information as to how repeatable the study might be or how unique the situation is.
- **Confirmability (objectivity):** How neutral are the findings in terms of whether they are reflective of the informants and the inquiry, and not a product of the researcher's

biases and prejudices? To adhere to the criterion of objectivity, the researcher gave the completed study report to two of the participants to read and verify its truthfulness.

Data collection

Data were gathered by means of individual in-depth interviews. A tape recorder was used to capture the data and transcribed verbatim for subsequent analysis (Burns & Grove, 2005:335). The researcher focused on issues of importance to the research question (Terre Blanche et al 2007:372; Wilson, 1989:437); and one central question was posed to all participants:

“How do you experience caring for a person with schizophrenia at home?”

Data were collected until saturation was reached; during the interviews experiences were not only communicated by the voice and tone but also through the facial expressions and gestures as the interviews continued (Ntswane & Van Rhyn 2007:88). Data were complemented with field notes that were taken during interviews. Field notes are notations generally made to document observations during an interview; observations, personal experiences, methodological issues and theoretical notes (Wilson 1989:434; De Vos, Strydom, Fouché & Delport, 2002:286).

DATA PRESENTATION AND DISCUSSION

Transforming data into research results is called analysis (LeCompte & Schensul 1999:102). The researcher familiarised herself with the phenomenon under study by becoming immersed in the data by listening to the tapes, reading the transcripts and identifying similar patterns (LeCompte & Schensul 1999: 104). The constant comparative method of qualitative data analysis by Tesch (1990:113) was used for the analysis. The data were co-coded by an independent, experienced qualitative researcher and consensus was reached with regard to the categories and themes identified.

Description of the sample

The sample comprised 12 participants, all women, related directly or indirectly like being cousin, aunt, and/or uncle’s wife to the individuals with schizophrenia (see Table 1.1).

Table 1.1: Demographic information of sample (N=12)

Criterion	Characteristics	Frequency	Percentage
Age	30 – 40	2	17%
	41 – 50	2	17%
	51– 60	8	66%
Marital Status	Married	2	17%
	Widowed	5	42%
	Single	5	42%
Relationship to schizophrenic	Mother	6	50%
	Sister	2	17%
	Child	1	8%
	Other	3	25%
Employment status	Fully employed	1	8%
	Part-time employed	2	17%
	Unemployed	9	75%

The raw data of ten participants were transcribed in SiSwati and translated into English; two participants spoke English during the interview. Five major categories emerged from the interviews, namely: emotions; physical burden; lifestyle changes; inadequate support and relationship burden. Table 1.2 illustrates a schematic condensation of the data analysis. The discussion will be highlighted by direct quotations from the participants and an accompanying literature control.

TABLE 1.2: Data analysis of interviews

Main categories	Subcategories	Themes
I. Emotions	Caregivers Immediate/extended family	Distress Anger and frustration Guilt Sadness Worry of what might happen next Blaming witchcraft Fear and shame
II. Physical burdens	Caregivers of individuals suffering from schizophrenia	Compliance with treatment Self-care Problems of role performance Poverty Unemployment
III. Lifestyle changes	Caregivers	A feeling of being trapped Dealing with violence

IV. Inadequate support	Caregivers	Financial and material Health care Conflict Spouse and partner rejection
V. Relationship burden	Caregivers	Patient unpredictable mood Stigma Rejection by community No sense of belonging Protection

Category I: Emotions

Distress

Emotions seemed to occupy the everyday lives of the caregivers of individuals with schizophrenia at the selected rural area. Distress was a significant theme in this study, with all participants describing distress in having a family member with schizophrenia. They also felt left out and believed that their caring role was not appreciated. Statements revealing these perceptions include:

“What is the government doing to relieve us from this burden?”

“I feel left out by the health system for not telling me when help is forthcoming, and what to do when my son becomes sicker here at home”.

In their research Martens and Addington (2001:129) measured the psychological well-being of families of individuals with schizophrenia. They observed that family members were significantly distressed as a result of having a family member with schizophrenia. In another study by Winefield and Harvey (1993:557), investigating needs of family caregivers of chronic schizophrenia, distress was found to be a major problem. However, they found that social support was important to relieve the distress.

Anger and frustration

Some participants acknowledged that they loved the individuals with schizophrenia and wished they would recover; but they were frustrated by not having the means to cope with the caring. Some participants expressed anger and frustration towards the government. This was evidenced by statements like:

“Government should build a special hospital for these patients here in Mpumalanga”

“Our government does not care for the mentally ill people; why can't we have a hospital?”

Frisch and Frisch (2006:240), as well as Martens and Addington (2001:129), noted similar feelings of anger and frustration when describing life with schizophrenic patients by their family members. They maintain that living with a schizophrenic relative can at times be very stressful and upsetting, to the family.

Guilt

The theme of guilt featured predominantly in participants who were the biological mothers of the individuals with schizophrenia. They expressed misconceptions about God or that ancestors were punishing them for something wrong they had done in the past. They added that the lack of improvement in their children was caused by not doing as much as they were supposed to do. The following quotations demonstrate this:

“If I did not leave to work far, my mother would not have died, and she wouldn't have punished me with my child's illness”

“If I listened to my parents, I wouldn't have had a child at such an early age. I used to leave him alone; this might be the cause of the disease”.

Frisch and Frisch (2006:240) were of the opinion that if families are to effectively help the client, they should receive help to manage their stress and guilt. Solomon and Draine (1995:422) studied the subjective burden among family members of mentally ill adults; they found that guilt feelings were severe where social relationships were stressful to caregivers of schizophrenic patients

Sadness and worries

Participants expressed worries about the future and about what might happen in future. They were upset when they had to pay for the damages caused by their schizophrenic relatives on people's property:

“I hide away, worried and sad when people come to my house; because he might have insulted someone or damaged property”

Winefield and Harvey (1994:560) investigated predictors of family burdens in caregivers of patients with schizophrenia and found that sadness and worries were among the most common emotions observed. In the same study it was found that parents worried a lot about the future of their schizophrenic children if the parents should die. Some participants expressed feelings of sadness and worry about the inadequate attention they received from the community psychiatric nurse especially when they needed her urgently. Statements to this effect included:

“I went to the clinic needing her help because my mother suddenly became aggressive and I feared for my younger children when I go to work but she only came after two days. She said that she was working at another village”

“The nurse appeared helpless and just encouraged me to continue to bring him for his monthly injection when my son told her in her eyes that he would not stop to smoke dagga”

Fourie (2004:39) studied the relationships between therapists and families of schizophrenic patients. Similar feelings of discouragement and sadness were found in the study, not only among family members, but also among their therapists. Ivarsson, Sidenvall and Carlsson (2004:398) measured the perceived burden of caregivers of individuals with severe mental disorders and found that the burden of caring was complex and included worries and social strain.

Fear and Shame

Caregivers accused the rest of their families for being afraid of and embarrassed by the affected member; ironically this made them feel the same way. Fear and shame are expressed in quotations like:

“I am shy to talk about my son to other people because I fear that they might think that he got the disease from me”.

“I feel bad when I must go with him to the clinic”

The shame prevented them from mixing with other people because of fear of having to answer embarrassing questions about the patient’s behaviour:

“I don’t go to community gatherings like weddings and funerals because people will be asking me about my mother’s condition”

Saunders (2003:176) studied families living with severe mental illness; he maintains that family conflict can reflect the degree of burden experienced by caregivers. On the other hand, Elder, Evans and Nizette (2005:364), describe the constant fear of families of schizophrenic clients for being harmed by the sick person. They also reported that families felt shameful about misbehaviours of the patients. They added that this could be the primary reason for their reluctance to keep these patients at home.

Blaming witchcraft

In this theme, a strong trend emerged of misconceptions about the cause of schizophrenia. Most participants blamed the illness on the girlfriends of their sons, in-laws of the patients and jealous neighbours. The belief was expressed in quotes like:

“When my son moved on to pay ‘lobola’ for another girl and not for her; that is when the problem started”.

“My mother’s illness was brought about by my father’s sisters, who hated her”

“The one neighbour was heard to be saying that it suits me just fine that my son got mad”

Witchcraft and mental illness have been documented in case studies of the middle ages. Mental illness has been often diagnosed as witchcraft. Erinosh (1977:158) investigated the belief system and the concept of mental illness among Nigerian medical students. He found that although the students had been sufficiently exposed to various specialities in the field of medicine, including psychiatry, many believed that mental illness can be influenced by witchcraft despite the modern influence of western education. Niehaus, Stein, Koen and Mbanga (2005:411) documented a case study of “Ifufunyane”, a Xhosa culture-bound syndrome similar to schizophrenia. They found that the Xhosa people felt strongly that traditional medicine is the only means to cure “Ifufunyane” (schizophrenia).

Category II: Physical burdens

Compliance with treatment

All the participants were women. Few of the participants had male relatives, who were heads of their families but none of the male relatives showed any interest in helping the caregivers. The caregivers had to take care of the entire household and the individuals with schizophrenia single handedly. They received occasional assistance when the affected individual needed to be forced to take medication:

“People get tired to help me force him to take his tablets. My child destroyed tombstones, windowpanes of a church and people’s houses. See these smashed window panes in my room? It is him”.

“Here at home he only smokes dagga; he takes medicines only when he is in hospital”.

Du Plessis, Greeff and Koen (2004:10) studied the role of the family as a support system for the psychiatric outpatient. They reported that the outpatients were dependent on the family for guidance regarding correct social behaviour. However, where there was no proper structure in the family, control became very difficult. These researchers emphasise the need for control over the individuals with schizophrenia. In their research on compliance with treatment Chamberlin and Rogers (1990:1241) emphasised that psychiatric outpatients need support of the families to encourage them to take medication.

Self-care

Most participants in this study mentioned that they were very cautious about instructing the patients to wash and change their clothes, as this provoked anger and aggression. Caregivers reported that it was difficult to persuade the individual with schizophrenia to wash and remove hoarded rubbish from their pockets. Some participants were forced to

build outside shacks for the affected member because they were too dirty and smelly to stay in the house. These quotes describe the theme:

“No one can go into that shack”.

“He sleeps in a rodent infested old car, and it is a ‘no go’ area; his feet have sores from rodent bites; he doesn’t want to go to the clinic for treatment because that would force him to wash”

Jungbauer et al (2005:666) investigated the subjective burden in spouses of individuals with schizophrenia and reported that deterioration in self-care and personal hygiene was a great burden to the caregivers.

Problems of role performance

Caregivers expressed the burden of having to do everything for the affected family member. The individuals with schizophrenia could not even participate in simple housekeeping chores. The burden was manifested in statements like:

“She needs complete care like a small child”

“I don’t know what will happen when I start to work; he cannot even pick up his clothes on the floor”

Jungbauer et al (2005:668) reported that the preoccupation with certain ideas, hallucinations and social withdrawal posed problems for the abilities of the patients to perform their expected social roles. Elder et al (2005:366) add that difficulties are compounded when families are poor and cannot afford to employ helpers.

Poverty and unemployment

The study revealed how poverty and unemployment compounded the burdens of caregivers of individuals with schizophrenia in a rural area. Most participants raised their concerns about money. They had to make ends meet from the monthly social grant and save some money for transport in case there was a need to transport the individual with schizophrenia to hospital. Some households were dependent on the small social grant. Financial hardships were expressed in quotations like:

“I sell goods at the bus terminus; I sell the whole day just to make enough to buy a day’s meal; at times I don’t get enough for even a loaf of bread”.

“At times we don’t even have food to eat because all of us are not working”

“He becomes sick every time from not taking his treatment regularly because when there is no food I cannot give him the tablets on an empty stomach”

Beebe (2002:45) cited financial concerns as a problem, because individuals with psychiatric disorders could lose their jobs. Ntswane and Van Rhyn (2007:92) are of the opinion that poverty is responsible for feelings of despair and isolation in mothers who cared for their mentally retarded children at home. In the study by Winefield and Harvey (1994:565), low quality of life in individuals with schizophrenia, evidenced by depression, psychotic symptoms and alcohol abuse, had been attributed to poverty and unemployment.

Category III: Lifestyle changes

Feeling of being trapped

In this theme some participants described feelings of being trapped; others described the experience as accepting less than ideal standards of life. They mentioned situations like:

“I have to be at home whether I like it or not. No one is prepared to assist when I want to go elsewhere”

“At times I feel cut off from the whole village, friends, community meetings, funerals, going to church”

“People don’t visit me any longer because they fear the sick boy; I can’t visit them too”

The theme is consistent with the findings reported by Ntswane and Van Rhyn (2007:93) about the life-world of mothers caring for mentally retarded children in a township. Participants reported feelings of entrapment and having no social life. Jungbauer et al (2005:669) found that informants in their study were affected particularly deeply by the loss of social contacts due to the schizophrenia of their spouses.

Dealing with violence

In this theme participants explained violence and aggression as the worst aspects of caring for individuals with schizophrenia. Most participants reported living with worries that the family member might cause trouble to other people. The caregivers described the first violent outburst as an extremely burdening and a catastrophic experience:

“It was frightening because I was not expecting it”

“He smashed all the windows and I ran out of the house, leaving my baby sleeping in the room”

“I felt powerless; I had never seen my mother like that”

“His girlfriend left him because she could not stand the violence and damaging of property”

Frisch and Frisch (2006:242) describe violence and aggression as the most difficult symptoms of schizophrenia with which the family must cope with. Some participants related how they incurred expenses by having to repair things damaged by the family member during a violent episode, in statements like:

“I will not replace the window panes because the same thing will happen again. I have decided to sleep without them. It is cold but there is nothing I can do about it”

“There are times when his entire social grant is spent on repairing people’s properties that he has damaged”

Category IV: Inadequate support

Burdens related to health care

Participants reported their concerns regarding the health care system, especially the inadequate community psychiatric services. They wished that the government could build a psychiatric hospital near their homes. Some reported the difficulties in finding the same drugs in Mpumalanga as those prescribed at the psychiatric hospital in Gauteng Province. This theme was expressed in quotations like:

“When I ask the police to help me take my son to hospital, they say it’s not their duty, theirs is to arrest criminals”

“The hospital is far and the people with cars charge us more than the usual price because the patient can damage their cars”

“Twice the clinic did not have the medicines that were prescribed in Gauteng”

Saunders, 2003:181 demonstrated that family caregivers of persons with severe mental illnesses suffer from significant stresses, experience moderately high levels of burden, and often receive inadequate assistance from mental health professionals. Hanson and Rapp (1992:186) studied families’ perspectives of community mental health programmes for their relatives with severe mental illnesses. They found that most families were guided by the affected member’s needs and demands, and the importance of providing the individual with schizophrenia with the prescribed medication. These researchers also found that families’ energies and resources were consumed in care giving, creating financial burdens.

Conflict

Participants reported that other members of the family provoked the affected individuals. Conflict arose from accusations that they disturb the peace and demanded that they

should leave the house. The individuals with schizophrenia were perceived as being manipulative and demanding, causing burdens to their entire families as evidenced by the following statements:

“We (my children and I) pretend that there is nothing wrong and ignore the provocations by my husband, just for peace sake”

“My other children threaten to leave home if he continues doing crazy stuff” “My husband hates the sick boy and wants him to leave the house”

This theme is consistent with the findings by Du Plessis et al (2004:13) who found that conflicting views can arise regarding the care of the mentally ill family member to the extent of causing conflict among family members; parents blame each other was common. Other studies revealed that family conflict and family intimacy reflected the degree of burden, or reward, experienced in the caring for the ill member (Saunders, 2003:177; Heru, 2000:93).

Stigma

Some participants kept the schizophrenics' problems and maladaptive behaviours secret, out of fears for people's gossip:

“I was humiliated at a community hearing because my son had vandalised people's graves”

“I asked them how could I have prevented the son's undressing himself in public”

Du Plessis et al (2004) refer to research by Zerwech (2000:54), of carers of people “on the ragged edge”, as he described schizophrenia. This study found that the lack of understanding and support, as well as singling out by neighbours, was largely ascribed to stigma, contributing to self-isolation of the affected families.

Breaks in relationships

Some participants mentioned that they realised that if they did not take care of the individual with schizophrenia, no one else in the family would. They sacrificed relationships for the sake of the schizophrenic family member. Some reported isolation by their extended families because of the sick member. The theme was expressed in quotations like:

“I was chased away from my husband's house because of caring for my sick mother”

“My husband took another wife because my boy is sick”

“They have stopped inviting me to family gatherings because of my child's illness”

Beebe (2002:39) as well as Solomon and Draine (1995:427), in separate studies found that problems in community living identified by people with schizophrenia, revealed that environmental stress related to social problems, family conflicts and financial concerns; led to relationship breakdowns among family members. In their research to investigate the subjective burden among family members of mentally ill adults, Solomon and Draine (1995:422) found that the family burden was severe among one third of the relatives, mainly in their social relationships.

Protectiveness

The participants who were biological mothers of individuals with schizophrenia showed a sense of love and compassion for their children more than other categories of caregivers. One participant was in tears when she expressed her wish to have her son protected against the community members. Other caregivers expressed mixed feelings regarding their affection – for the individual with schizophrenia, like relief when the patient died:

“I would feel relieved if they told me that my cousin has died because nobody will be harassing him anymore”

“I always worry about him; he is my only son”

“God can punish me if I failed to look after my mother”

“She is mine and I love her as though she was normal”

The protectiveness by mothers is consistent with the findings by Ntswane and van Rhyn (2007:92) who found that mothers were very protective of their children and did not trust professionals to replace them.

DISCUSSION OF FIELD NOTES

The researcher kept a written account of the messages heard, seen and experienced during the in-depth interviews. These notes were submitted to the independent coder and consensus was reached to include them in the discussion of results. Two of the observational and theoretical notes will be tabulated so as to show how opinions were formulated based on the observations:

Observational and theoretical notes

Observational notes	Theoretical notes
1. All the caregivers were females and only a few had husbands or partners.	1. Leaving women to care for schizophrenic family members unassisted seemed to be the trend among rural families in Mpumalanga.
2. The caregivers appeared to lack knowledge regarding the management of schizophrenia.	2. The caregivers seemed to think that individuals suffering from schizophrenia only needed medication and institutionalisation.

Methodological notes

The researcher is an experienced psychiatric nurse and familiar with the therapeutic process. However, she kept a protocol in each participant's file to remind her of the key concepts during data collection like, greeting; using communication techniques; bracketing and avoiding leading questions. The reminders served to critique her tactics and to avoid approaches that might jeopardise the outcome of the study (Wilson, 1989:435).

Personal notes

The researcher noted her reactions, feelings, reflections, and experiences during and about the interviews (Wilson, 1989:435). One of the personal notes described the researcher's feelings of sadness to observe women caring for individuals suffering from schizophrenia unassisted.

CONCLUSIONS

The findings of the study show that caring for individuals suffering from schizophrenia was not a pleasant or easy task; various emotions (anger, frustration, sadness, fear and shame) seemed to occupy the every day lives of the caregivers. Distress was a significant theme felt by all the participants. The emotional burden was compounded by physical burdens such as, poverty, affected individuals' lack of self-care, non-compliance with medication (individuals with schizophrenia preferred smoking dagga rather than taking their medications) with resultant relapses and psychotic episodes (outbursts of violence and changes in the patient's personality). Inadequate support and rejection by other family members and the community made caring difficult.

All the caregivers were women. This trend is contrary to the findings by Jungbauer et al. (2004:271), who found partnerships in caring for the mentally ill family member; to be a stabilising factor for managing the everyday lives and the patients' illnesses. Another was that most caregivers feared for the safety of the family member who suffers from schizophrenia because of the stigmatisation and hostility of the community.

Participants reported lifestyle changes that came with caring for these persons, like social isolation and feeling entrapped. They reported a lack of sensitivity by the health care service and the police when their interventions were needed. Some individuals with schizophrenia just disappeared from home. The greatest burden was the expense incurred when the affected family member became aggressive and damaged people's properties. The theme of protectiveness of mothers for their schizophrenic children was significant. Most caregivers wished that a psychiatric institution could be built in the Mpumalanga Province. The findings of the study underline the necessity to mobilise support and partnership in caring for individuals suffering from schizophrenia in rural Mpumalanga.

RECOMMENDATIONS

Based on the conclusions and results of the study, the following recommendations were formulated:

- Caregivers of individuals suffering from schizophrenia need information about the disease in general, signs and symptoms, importance of medication and how to cope with the patients at home
- There should be a mobile psychiatric clinic visiting rural areas with a complete psychiatric team (psychiatrist, psychiatric nurses, social worker, clinical psychologist) to monitor patients' progress and give support to the caregivers

LIMITATIONS OF THE STUDY

The fact that most of the interviews were conducted in SiSwati and then translated into English, might have led to loss of important meanings of caring for individuals with schizophrenia in a rural area by the participants. The study was qualitative and the results cannot be generalised; there is a need to conduct similar studies in other areas of Mpumalanga.

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