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DEINSTITUTIONALISING THE MENTALLY ILL IN RURAL AREAS: A CASE STUDY OF THE OFFICIAL CAREGIVER¹

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INTRODUCTION

Following political transformation in 1994 and in the light of fiscal planning and severe budget cuts by the state, South Africa is stepping up efforts to deinstitutionalise mentally ill patients and rationalise psychiatric services. In order to reduce expenditures, patients are often discharged from psychiatric hospitals back to their families and communities. Families are expected to take care of these patients without receiving the necessary training and support for this task. It is especially families living in poor rural areas that experience caregiving as a severe burden. Based on information obtained through employing a qualitative methodology, the aim of the paper is to demonstrate and highlight the plight of caregivers of the mentally ill within poor rural areas in South Africa. It does this through an exploration of the role and responsibilities of caregivers living in the Fort Beaufort district in the Eastern Cape Province. It also examines possible ways to empower these caregivers and the role that communities should and can play in such empowerment efforts.

The paper is divided into different sections the first of which contextualises the role of caregivers in poor rural areas. It provides an overview of South Africa's health care system which is increasingly being characterised by an emphasis on primary health care, deinstitutionalisation and building the capacity of communities to be full partners in policy and implementation processes. The following two sections briefly describe the methodology used to obtain information from caregivers, the profile of caregivers and the behaviour of mentally ill patients they have to contend with. The two main sections examine the role and responsibilities of caregivers in caring for the mentally ill and some of the negative consequences caregivers experience in fulfilling their task. The last section emphasises the idea of community involvement as a partnership relationship and the dire need for community programmes to assist caregivers in their task if a primary health care approach is to succeed. In an attempt to give voice to caregivers, the paper relays their experiences by using their own words and stories.

PRIMARY HEALTH CARE AND DEINSTITUTIONALISATION IN SOUTH AFRICA: AN OVERVIEW

Until 1995 no comprehensive mental health or psychiatric policy document was forthcoming other than the Mental Health Act (1973). Following the 1994 elections, representations to the new Minister of Health resulted in the establishment of a National Directorate of Mental Health and Substance Abuse and a policy document. Most of the nine provinces had adopted their mental health policies by the end of 1995 and all policies conform to the principles of the new health policy that is primary care oriented. The Primary Health Care approach includes goals such as intersectorial collaboration and empowerment of communities with an emphasis on care in the community (Freeman & Pillay 1997:35-36). The integration of mental health into primary health care is one of the priorities proposed. What is envisaged is a shift from a curative, institution-based approach to a more user-centered, preventative one.

Integral to the Primary Health Care policy is the deinstitutionalisation and community integration of the mentally ill and disabled. Although there are variations in the usage of the concept deinstitutionalisation, the idea underlying this concept is that optimal treatment of long-standing and chronic behavioural conditions will take place, not in an institutional setting, but in "situations and under conditions most closely approximating the social and cultural norms that apply everywhere else" (Johnson 1990; 1994:215). A more complex understanding of the concept is offered by Surles (1994:221). The latter defines deinstitutionalisation as the "shifting of responsibility for persons believed to be mentally ill and disabled from a fixed location, a state hospital, to a variety of settings which might be operated by state government, local government, or nonprofit corporations". Despite varying definitions, however, most notions of deinstitutionalisation seem to assume the existence of a wide-range of community-based programmes for its realisation.

In 1974 responsibility for psychiatric service provision and policy responsibility was transferred from the provincial departments of health to the Department of National Health. This was aimed at consolidating and developing psychiatric services. While psychiatric hospitals were upgraded, primary and general secondary level psychiatric care and training of general health workers were insufficiently addressed (Robertson *et al.* 1997:69). To the extent that services were established at community level, it was staffed by specialists from psychiatric hospitals. Thus, psychiatric services were characterised by "overuse of institutional care, inequity of service provision between population groups, and underdevelopment of community based mental health services" (1997:70). In 1988 psychiatric service provisions once again became provincial responsibility, but overall, primary and secondary health care practitioners remains minimal.

Partly in response to South Africa's integration into global markets the present government's macro-economic policy (GEAR) is emphasising decentralisation, privatisation and a greater reliance on market forces. This means that government is transferring many of its previous welfare and health service deliveries to the private sector and local communities. Although lagging behind other countries in the process of deinstitutionalisation in the past, South Africa is increasingly adopting developed countries' route of rationalising psychiatric services and deinstitutionalising the mentally ill in response to tough fiscal planning and severe budget cuts. In the absence of primary psychiatric services these financial constraints will, of course, make it extremely difficult to develop community facilities for those who have populated state institutions and hospitals. Deinstitutionalisation, say Robertson *et al.* (1997:85), requires primary and regional psychiatric services to be in place. This would include the availability of a range of rehabilitation programmes, housing options and chronic care facilities in the community.

In their review of the history of mental handicap in South Africa from the early nineteenth century, Foster and Swartz (1997) have characterised it as racist and discriminatory. An important feature of the South African scenario was the virtual lack of facilities for the black mental handicap. Special institutions, education, vocational training and sheltered employment were primarily created for white persons. It was only in the last decade or two that persons belonging to other racialised groups were able to access these facilities. Molteno (1997:116), of course, has maintained that deinstitutionalisation within the South African context could be more of a problem for whites as community care with minimum support is by default, the usual form of care for other racialised groups. He points out that, while it is now especially progressive to argue for the "inclusion" and "mainstreaming" of persons with special needs, black people have always, even by default or discrimination, been "mainstreamed" (1997:113).

The absence of community-based programmes and facilities is especially evident in poor rural areas in South Africa. There appears to be an increased proportion of chronic mentally ill people in some rural areas due to the mentally healthy seeking employment in urban areas, and the return of the chronic mentally ill to rural areas because of the lack of safety in urban areas (Robertson *et al.* 1997). This inevitably places a large burden on families, communities and health services in rural areas, compounded by the relative shortage of mental health workers in these areas. Thus, while provincial governments in South Africa purport to create "mentally healthy" communities in their respective provinces, the lack of infrastructure and programmes usually results in the families of mentally ill patients having to take the responsibility for caring for the mentally ill.ⁱⁱ It has also been suggested that, if deinstitutionalisation and the Private Health Care system are to work, psychiatric patients who are admitted to psychiatric hospitals in future need to be discharged as soon as possible back into the community. This will only be successful "if rehabilitation is actively pursued both in hospital and in the community" (Robertson *et al.* 1997:86). At the present time, however, families take on responsibilities of caregiving without receiving the necessary training and support to undertake such a task.

Caregiving is also gendered in that it is usually women within families who end up being the caregiver. In many ways women's "double burden" of paid work and domestic labour is replicated at other levels of family care (De la Rey & Eagle 1997). Women are expected to assume responsibility in the main for any "infantilised" or "disabled" family member. Research into psychiatric outpatient care at a Soweto clinic (located in the Gauteng province) found that the bulk of primary family caretakers were elderly women. De la Rey and Eagle (1997:152) have suggested that, while the role may not be unacceptable to these women, the burden it places on them tends to go unrecognised and unsupported. Women in these household "alleviate much of the cost of institutionalisation and treatment for the state, in a manner that goes largely unrecognised".

The research on which this paper draws was undertaken in the Fort Beaufort district,ⁱⁱⁱ which is located in the Eastern Cape Province - the second largest province in South Africa and also one of the poorest. Of all the provinces of South Africa the Eastern Cape has the second lowest HDI, the highest poverty gap, the second lowest per capita income and the highest percentage of households and individuals living in poverty (Welfare Statistical Report 1996:6). As noted by its Premier, the Eastern Cape Province faces enormous challenges if it is to rise from the ashes of its Bantustan legacy. The rural population represents 65 percent of its total population and in two of the regions 90 percent of the population are classified as rural (Bennett *et al.* 1996:9). While the provincial government spent R1.7 billion on infrastructure during the 1998/9 fiscal year, only R180 million was allocated to building and maintaining a health infrastructure (ECSECC May 1998:3).

RESEARCH METHODOLOGY

According to 1996 Census data the total population of Fort Beaufort managerial district is just over 27 000. The district is sub-divided into urban, rural and farm villages populated by different racial groups, i.e. Africans, whites, coloureds and some Asians.^{iv} However, the vast majority of residents are African (Xhosa). Patients admitted to Tower psychiatric hospital come from all over the province.^v Annual statistics obtained from the hospital indicate that some mentally ill patients have been admitted more than once. During 1996 most of the patients who had been re-admitted came from the magisterial district of Fort Beaufort. The study focuses on the latter district, given the high percentage of re-admissions. Thus, the patients as well as their caregivers are not necessarily representative of all patients admitted to Tower hospital and their respective caregivers.

Given that the objective of the study was to explore, interpret and obtain a deeper understanding of the role of caregivers, a qualitative methodology using in-depth interviewing was chosen as the most appropriate. From a population sample of seventy-three mentally ill patients re-admitted to Tower psychiatric hospital in 1996, twenty-five were randomly selected.^{vi} Addresses of these patients were obtained and the caregivers of the respective patients were contacted by home visit. For the purpose of the study caregivers were seen to include people living in the same household with a mentally ill patient and who assume the responsibilities of caring for and supporting this person. Where the patient lived with more than one family member, the family member who allocated the most of her/his time to caregiving was interviewed.^{vii}

A semi-structured questionnaire was used to obtain biographical data of caregivers as well as information pertaining to family interaction, family leisure and physical health of mentally ill patients. The caregiver burden scale used by Zarit *et al.* (cited in Futter 1995:159) to assess caregivers' attitude towards patients also provided guidelines and pathways for interviews.^{viii} The interviews were conducted in Xhosa with African and in English with coloured caregivers.^{ix} Since most of the caregivers were unemployed and over 60 years of age, the interviews took place during the day at their homes.^x In an attempt to give voice to these caregivers, their experiences and burdens are relayed in their own words.

PROFILE OF CAREGIVERS AND BEHAVIOUR OF THE MENTALLY ILL

Of the 25 caregivers interviewed, 22 are African (Xhosa) and 23 women.^{xi} The majority of caregivers are the mothers or sisters of the mentally ill person, while others include sisters-in-law, grandmothers, nephews and foster parents. Caregivers range in age from 20 to 85 years, with eleven being 60 years and older and nine between 40 and 59 years. Those over 60 receive an old age pension grant from the state in order to support themselves, given that they are no longer in employment.^{xii} In accordance with research elsewhere, gender and age structure the profile of caregivers.

The impact that mental illness has on family relationships is largely disruptive and tends to cause interpersonal difficulties. The effects are particularly devastating for the person acting as caregiver. Caregivers who participated in this study (predominantly older women) characterise the behaviour of the mentally ill as aggressive, violent and destructive; rude and wasteful; suicidal; being stingy with money. The mentally ill are also seen to withdraw from interaction with others for long periods of time.^{xiii}

Patients often behave violently in their homes as well as in public. Some have been known to kick doors, throw stones at people and passing cars as well as break chairs and windows. Commenting on her brother's behaviour, one caregiver has the following to say:

"My brother is very dangerous, cruel and notorious in the township. He always carries a big knife that he stole from the house. I cannot ask him about it because I fear that he would stab me. He once stabbed his younger brother and other people in the township. He also hates children. He always swears at people. While people get annoyed they usually remain silent."

It is especially males who tend to assault others. This kind of behaviour is often directed at children and other male adults in the family household. Thus, according to caregivers, children often exhibit nervousness in the presence of the mentally ill and run away when approached by the latter. One caregiver relates the following:

"My husband always shouts at the mentally ill patient who likes fighting. One day my husband attempted to discipline him with a stick. This resulted in the patient chopping

the door with an ax. This episode ended in a fight between them and my husband broke his finger that day."

The destructive nature of some mentally ill patients' behaviour is emphasised by a number of caregivers. They are reported to break windows, doors, crockery, furniture and household appliances. Destructive behaviour also takes place in other people's homes resulting in the family of the mentally ill patient having to pay for damages inflicted upon other people's belongings and property. One caregiver mother relates the following story about her son:

"My son was reported by the school master for breaking the school's windows and I had to fetch him immediately. On another occasion he visited his friends with a guitar, as he was very fond of it. That evening I received a telephone call from his friends telling me that he was violent, breaking their glasses and fighting with them."

The term "dual diagnoses" is increasingly being used in psychiatric practice to describe the combination of severe mental illness (mainly psychotic disorders) and substance misuse (Weaver *et al.* 1999:137). Caregivers included in the study report a similar pattern regarding the abuse of alcohol and drugs. One caregiver comments:

"My son begs and sometime even demands money from his sister, strangers and us to buy dagga. He also exchanges clothes (his and others') and household belongings for money to buy the stuff."

Substance abuse is vehemently opposed by caregivers as they believe that especially dagga aggravates the patient's aggressiveness. They fear that alcohol and drug abuse leads patients to rape and even commit murder. Caregivers also view abuse as being conducive to the exploitation of the mentally ill by others.

Patients often develop sleeping and eating disorders that disrupt the family household (Hamber 1995). Sleeping disorders result in family members not being able to sleep. This is especially hard, not only on neighbours but also on young family members who have to study at night. Patients also wander at night, leading one mother to comment:

"Sometimes my daughter wanders and never returns on a specific night. I will not sleep that night. I first wait hoping that she will step in at any moment. If she does not return, I have to get up and look for her in the neighbouring villages. During this time I fear nothing, but worry about her, thinking she might have been raped or murdered. Sometimes I find her and sometimes I don't."

Eating disorders entail either eating "too little" or "too much". Food intake is often reported to be excessively high when, for example, dagga is used. One caregiver relates how the mentally ill patient would come in the evening and demand breakfast, lunch and dinner that he had missed that day. While he was unable to finish his food and grabbed food from each plate, he left the rest looking like a "pig's dish". Caregivers are also concerned about food intake when patients tend to wander from home. One mother "solved" this problem by giving her son uncooked meat which enables him to cook wherever he is. This excludes the possibility of having to steal to obtain food.

Research has posited a link between alcohol abuse, drug abuse and suicide by mentally ill persons.^{xiv} Generally, most studies predict a life-time suicide rate of fifteen percent for all alcoholics (Miles cited in Talbott *et al.* 1988). Mentally ill patients are reported by caregivers to lock themselves in a room and threaten or attempt suicide. Caregivers often panic not knowing what is happening inside the room, how the patient is relieving him/herself and whether the

house is going to go up in flames, given that the patient often has access to a paraffin stove and matches. Suicide threats and attempts cause extreme anxiety and panic on the part of caregivers. Three caregivers had to deal with suicide attempts. One mother, for example, relates that her son seemed depressed but that she had to leave him for a short while. On her return she was informed that he had swallowed all his pills. She had to rush him to a doctor. Another relates the following:

"My son was found drowning himself in the dipping tank and I took him to the hospital immediately after the family was informed about this by the herd-boys."

THE ROLE OF THE CAREGIVER: RESPONSIBILITIES AND BURDENS

The above overview illustrates the range of behavioural problems that caregivers have to contend with in their role as caregiver. It would appear that the most basic goal throughout the process of caregiving is to ensure, to some extent, the patient's physical comfort and safety. The work of a caregiver is largely concerned with observing the mentally ill's behaviour, problem solving and explaining the mentally ill's behaviour to others. Caregivers also have to make decisions regarding the future of the patient as well as her/his own. Often it is about finding ways to maintain the patient's ability to act in a relatively autonomous way. Thus, caregiving can be an occupation with no clear goals, no description and no limits. The following section explores some of the responsibilities identified by caregivers as particularly burdensome.

(i) Medication and less conventional forms of treatment

Although patients are provided with medication by the hospital and despite being encouraged by caregivers to take medication, seventeen of the twenty-five patients involved in the study refuse to take medication when discharged from hospital. This leads many caregivers to prefer injections as an alternative. This is explained by one caregiver:

"My brother receives injections monthly. He is always calm, that is, after he has taken his breakfast he goes outside and sits under the tree until he is hungry again. I always notice when he is due for the next treatment. He becomes restless; for instance, he would go in and out of the house demanding food. Sometimes he does not wait for me to prepare the food for him. He will cook and leave the food there. He once stirred the boiling pot with his hand. When I tried to stop him he nearly threw it at me."

Another caregiver says:

"I prefer injections because my son refuses to take pills. When I force him to do so, he pretends to have swallowed them while he hides them under his tongue. The next day I will find the pills under his pillow, meaning that he spit them there."

Some caregivers resort to blackmailing the patient to get the latter to take the medication. One caregiver explains:

"When she refuses to take treatment, I always threaten to return her to the psychiatric hospital and she would take it because she hates the place."

Others appear to develop a more philosophical approach concerning this matter:

"I do not force her (patient) to take treatment. She takes it when she likes and leaves it when she does not want to take it. That is all."

Caregivers utilise different sources in an effort to successfully treat mentally ill patients - some of which are less "conventional". These include traditional healers as well as witchcraft doctors.

Some caregivers invest a lot of trust in traditional healing, as is evident from the following comments:

"I took her (mentally ill) to a traditional healer who said the mentally ill needs a ritual to be carried out on her behalf (amasiko akowabo). She will never get better until this is done."

"We have been to many places seeking assistance for the health of our son. We have tried both medical doctors and traditional healers, and we are still trying. Even now, we are coming from the traditional healer's gathering next door. We hope that we might eventually get help."

Other caregivers are less optimistic and hopeful:

"There are three mentally ill patients in this house. They are all my children, two sons and one daughter. We have spent a lot of money on their health, using both western and traditional medication but that was all in vain. We would own a big house if we did not spend so much money on their health."

(ii) Protecting and supervising the mentally ill

The mentally ill are at risk of endangering either themselves or other people, or being endangered by other people, all of which impact on the caregiver's daily life. Caregivers report, for example, that they have to be continually alert to ensure that the mentally ill patient is not exposed to dangerous materials such as matches, paraffin or petrol. Children especially tend to make fun of mentally ill patients as is evident from the following account:

"The mentally ill patient once pulled the females who were passing through the house by their dresses. He hugged them and also attempted to kiss them. They shouted, scolded and even beat him. I intervened by appealing to them to understand that he is sick."

CONSEQUENCES FOR CAREGIVERS

In caring for the mentally ill, caregivers suffer many consequences. This section examines the following consequences: exploitation; social isolation; financial constraints and public embarrassment. From the interviews held with caregivers it would appear that caregivers experience three forms of exploitation, that is, by mentally ill patients, by other people as well as by the situation itself. Thus, while caregivers protect patients from being abused, they are often abused themselves.

(1) Exploitation of caregivers

Caregivers are often threatened, beaten or ill-treated by patients. As a result they leave their homes only to return hours later in the hope that the mentally ill have calmed down. More often than not, they find refuge with neighbours. Some choose to live elsewhere. One caregiver explains her situation:

"I am not staying with my husband (mentally ill) any more. He stays alone in the house and I rent a flat at a distance of about 100 meters from the house. I left him because he was ill-treating me, for example, beating me up. One day he went to the police station to demand that I move out of the house because I am not his wife. The children are at school and when they return from school they stay with their father in the house. They visit me anytime they want."

One caregiver had the following to relate about her son's behaviour:

"My son (mentally ill) once forced me to go and tell the magistrate that he is not my child and that is the reason why I bewitched him. I had to go because I feared that he would beat me as he normally does. One day he missed me with a sharp weapon. I believe that God saved me that day. I could not sleep at home that night, but at my next door neighbour's place. I could not even sleep that night as I was thinking about what could be happening at home."

Exploitation by the mentally ill often results in caregivers being exploited by other persons as well. People sell goods to patients on credit with the intention of claiming the money from caregivers. While the latter may not be involved in the initial arrangement, they ultimately do become involved. Caregivers experience these situations as very problematic. They are not entirely sure whether the mentally ill has in fact bought these goods. One caregiver relates the following incident:

"One day my son was chased by a group of men into the house. I asked them what the problem was. They claimed that my son owed them money for meat he had bought on credit from them. I asked how much money he owed. One man said R100 and I gave them the money. A few weeks later they returned demanding money for the same reason. I reminded them that I had already paid them. They said my son had again taken meat. I gave them R100 again and asked them to bring me the change. They said there was no change because he (mentally ill) also owes money to another person. I was unhappy about this but I gave up and asked them not to give him meat again. There was nothing I could do. I did not report the incident to the police because I feared that they might kill him."

In some instances patients break other people's belongings and owners demand to be compensated by caregivers. Caregivers do not budget for these expenses.

"My brother once broke our neighbour's couch and wall unit. The neighbour demanded a new one from my mother. My mother does not earn much money. Her salary is insufficient for the household needs, but she had to buy that furniture on credit and is still paying for it today."

(ii) Social isolation and sacrifices made by caregivers

The presence of mentally ill patients within the family household may also affect relationships between family members and members of the community. Families taking care of a mentally ill family member often fear social discrimination on the part of the community and several studies have confirmed the restriction on interaction with members of the community. The social and leisure activities of the whole family are hindered. This reinforces the social isolation of the family as well as the patient (Lefley cited in Hamber 1995:20). One caregiver explains:

"There is no traditional function at my elder brother's place this weekend. Customarily we are all supposed to attend. But we cannot go with my eldest son (mentally ill) because he will be unruly and disturb the function. We cannot leave him alone here. His younger brother will have to stay and look after him."

Most caregivers' social life has suffered from their responsibilities towards the mentally ill (Forster & Young 1990). They cannot attend church services, funerals and other important traditional functions while the young cannot attend their social clubs or visit their friends. Instead, friends visit them at their homes. In general, caregivers report that since becoming involved with the mentally ill, they have forgotten what it means to have a good time. One caregiver relates:

"I am not her mother but her sister, and I sacrifice my social life for her. One day I will get married and my husband might not want to look after her. Even if I hire somebody to look after her that person might not do what as I would do."

One caregiver was quite tearful about her socially isolated situation, whilst another stressed the economic consequences of being isolated:

"When my friends visit me I always say to them, 'Aye, by the way, I shall never be happy in my life because my relatives (mother and two uncles) are sick.' I am unemployed and do not receive any support from the state or other family members. Most of the time I have to look after my sick daughter and other younger children. I do not find the time to seek a job."

Caregiving also means sacrificing dreams and expectations of the future:

"I do not know where I would be, if it were not for these three mentally ill patients. I have spent a lot of money on their health but there is no improvement. I could have built a big house with that money."

(iii) Financial constraints

As suggested by Farkas *et al.* (1987:864-70), psychiatric outpatients generally fare badly in the labour market and are either unemployed or require substantial support to maintain employment. Financially, says Clark (1994:808-13), this and additional costs related to psychiatric illness can place a significant burden on the family.^{xv} Financial constraints are particularly burdening for poor rural families. As mentioned earlier, eleven of the twenty-five caregivers included in the study are sixty years and older and depend on an old age pension grant to survive. However, only ten of the caregivers receive this pension, while fifteen do not. Those who do qualify are extremely dependent on this income. Caregivers use this money to support not only the mentally ill, but also their entire families. Expenditure includes buying groceries, clothes and furniture; school fees and rent as well as - in some cases - paying for damages caused by the mentally ill. Most caregivers are thus dependent on the mentally ill's disability grant as they have no other sources of income.

Of the total number of mentally ill patients, twenty-two receive disability grants. However, some of these patients monopolise their grant and do not allow caregivers to have any say in how they spend their money. In fact, while mentally ill patients demand food from caregivers every day, they often spend their own money on items like cigarettes, alcohol and dagga. They have also been found to be giving money to other people. The financial burden in caring for the mentally ill is illustrated by the following two comments:

"We are a family of four: my daughter (mentally ill), myself as well as two young children. I do not have any source of income but rely on the mentally ill's disability grant. She is very stingy with it. She refuses to give me any money to buy food and rebuild the room. Recently, I received an account for R300 from the municipality for sewerage services and I had no money to pay it."

"Shoo, both the mentally ill and her son are receiving the disability grant but the money is not enough at all. They keep it to themselves and do not allow anyone to interfere with it. If I can be permitted to control their money, I could improve their condition."

Most mentally ill patients are accompanied by caregivers when picking up their disability grant from pay points. Some caregivers try to save patients' money by opening bank accounts for

them. However, they often experience serious problems when attempting this. This is illustrated by the following stories told by two caregivers:

"I opened a bank account for her (mentally ill), trying to save her money, because she was wasting it on alcohol, cigarettes and other people. But, one day she reported me to the police saying I am keeping her money and that she wanted it back immediately. The police suggested that I withdraw all the money and hand it over to her with the bankbook because I will never be happy as she will always accuse me. I did as the police said."

Another says:

"My son likes money a lot. He spends his money mainly on dagga and buying alcohol for other people in the village. His father decided to save this situation by opening him a bank account. But, the mentally ill demanded the bankbook and the father gave it to him."

Some rural families cannot afford to buy groceries cash and have to buy on credit. They complain that other family members do not support them, although their children stay with them (caregivers). Some families have resorted to selling paraffin, sweets and other small items at their home in order to generate income.

Victimisation of mentally ill patients by other people often contributes to the financial constraints experienced by caregivers. The latter relate how patients are frequently robbed of new clothes as well as money. It is especially the "independent" mentally ill patients who experience this problem. Their houses are broken into and belongings are stolen. One mother says the following concerning her son:

"My son is very humble and he has been taken for a ride on many occasions. Firstly, he took R50 to buy himself a packet of cigarettes. His sister noticed that he returned with R30. We knew that cigarettes do not cost R20. We believe that others might have robbed him."

(iv) Embarrassment experienced by caregivers

Some caregivers report being embarrassed by the behaviour of the mentally ill rather than by the disability itself. Mentally ill patients are known to sometimes undress or urinate in public, leave the house naked, masturbate and bath in public, spit on the floor, pull at women's dresses, beg money from strangers and pray for caregivers at church services. Two caregivers relate their stories:

"The mentally ill always prays about me at the church, accusing me of witchcraft. This worries me because some people believe her. She once tore my blouse in church claiming it to be hers. In fact it was identical to mine."

"My son likes attending church and always travels with the congregation wherever it goes. The congregation, accompanied by the priests once paid a visit to another church. I received a report that he (mentally ill) had beaten the priests on their way back and I was so embarrassed."

Despite the consequences and sacrifices discussed above, there seems to be an acceptance and tolerance of the burden on the part of caregivers. They emphasise the appreciation that the mentally ill have for their help and care. One mother explains: *"I once explained to him (son) what he did when he was sick. He said 'I thank you very much, Mama, for your support. Please*

do not give up in despair. I am dependent on you.'" However, appreciation is not always forthcoming. As one caregiver says:

"My brother is sometimes dissatisfied with the way I treat him. He blames me for paying more attention to his siblings. But, he is sometimes satisfied saying 'I do not mind if you do not care for me. The only person who cares for me is Robert.'"

PRIMARY HEALTH CARE AND COMMUNITY-BASED PROGRAMMES

The previous sections demonstrate the heavy burden that is being placed on caregivers in poor rural areas in caring for the mentally ill. To an important degree caregivers are expected to "manage" a disability and perform various roles – those of executive and financial managers, lawyers and advocates as well as nurses and housekeepers. They are predominantly older women left to cope with the emotional, physical and financial burden of caring for mentally ill family members - often lacking sufficient knowledge as to how to cope with these burdens in the most appropriate and effective way.

The Department of Health Provincial Task Team assisted by the Hospital Transformation Project reviewed the current Mental Health Service and drew up a Provincial Transformation Plan for this service in October 1999. The proposed key points are:

- To move away from institution-based care towards a more community-based service, integrated into the rest of the health service;
- To shift the emphasis away from long-term care towards acute care, incorporating a more psycho-social, rehabilitative and humane approach to delivering mental health services;
- To accurately allocate beds and staff to the service, which will address both the current geographical inequalities and ensure the effective functioning of a reorganised service;
- To establish a clear and agreed upon vision and mission statement for the future of the service, with clear definitions of the various types of care, resulting in more a more consistent functioning of the service;
- To introduce basic quality-assurance systems, including performance indicators, and an understanding of the roles and individual responsibilities at each level of the service;
- To ensure that other agencies, including the private sector, contribute to the provision of mental health services;
- To secure financial means to provide high-quality mental health services;
- To address the capacity-building and training implications arising from the deinstitutionalisation process;
- To address policy recommendations to facilitate the deinstitutionalisation process.

Despite the emphasis being placed on deinstitutionalisation and the involvement of communities by the Provincial Transformation Plan as well as the National Department of Health's newly adopted Primary Health Care approach, there appear to be no community structures and programmes in place in Fort Beaufort to empower caregivers and provide them with a support base. Even if community programmes were to be established, the concept of community involvement in health programmes is not as straightforward as one might assume. Community involvement can take on different meanings depending on the interpretation of primary health care, the approach adopted in its implementation and the programme objectives of the implementing agency (Chimere-Dan 1996:13-20). This has resulted in viewing community

involvement as a programme instrument, as community empowerment and as a partnership with a local authority.

The idea of community involvement as a partnership relationship between community and health authorities advocates a compromise between exclusively community-managed self-help programmes and paternalistic government-sponsored programmes. This would entail recognition of self-help programmes, respect for the individual, a willingness by the authorities to cooperate with community initiatives, and "the realisation on the part of the community that government initiatives can have merit" (Chimere-Dan 1996:19). Thus the potential assets in both government and the community are recognised.

However, the success of this approach requires a responsive public sector and successfully addressing the power relationship between health officials and the community (in its geographic and relational or identificational meaning)^{xvi} so that it does not constitute an obstacle. Communities need to be involved in choosing community representatives and identifying their own priorities if community involvement is to empower the community. This will ensure the sustainability of health programmes. Thus, community perspectives should be the focal point in any model of community involvement in health programmes.

CONCLUSION

The purpose of the paper was to explore the role of and highlight the problems and burdens experienced by caregivers in caring for mentally ill family members in a poor rural area. Although the paper does not offer workable solutions - especially within a context characterised by extreme poverty - it nevertheless supports Chimere-Dan's (1996) view that community involvement as a partnership relationship between community members and health authorities is the most appropriate model for addressing health problems in the South African context. Thus, community involvement as a partnership might be the most appropriate model for addressing the plight of caregivers of the mentally ill in poor rural areas.

Although aimed at abused and neglected children, the "Eye of the Child" - "Isolabantwana" community-based Child Protection Programme reported on recently (Doran 1999), for example, provides valuable lessons on how to successfully involve communities in addressing pressing issues in poor and high-need localities. While social workers attached to the Cape Town Child Welfare Society spearheaded the initiative, the success of the programme can be attributed to the role played by key community leaders and community volunteers taking ownership of the project. Not only has the programme facilitated community participation and empowerment, but co-operation with formal resources has also been established. Similarly, Mokone's (1999) suggestions regarding strategies in caring for the elderly could be helpful. These strategies involve caregiver support programmes, respite care as well as day care and luncheon clubs. In the final analysis, however, it is those professionals who are active in the area of mental health service delivery who need to come up with workable strategies.

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NOTES

- ⁱ The research on which this paper is based was undertaken by VLL Magaqa. It also formed the basis for an MPhil dissertation completed at the University of Stellenbosch.
- ⁱⁱ Desjarlais *et al.* (1995) claim that families manage the greatest burden of caring for the mentally ill world-wide and the most crucial community resource for the mentally ill is the family.
- ⁱⁱⁱ Bordering the old Transkei, Fort Beaufort is situated 50 km north of Grahamstown and 20 km west of Alice with a total area comprising 968 sq/km. It was used as a military base during the frontier wars from the 1830s to 1860s.
- ^{iv} The South African population was officially categorised into four "racial" categories, that is, African, White, Asian and coloured. Although the use of these terms does not imply support for racial classification, it is also true that people have a particular history resulting from this classification.
- ^v The skills and abilities of these patients vary. While some are seriously impaired, immobile and incontinent, others are able, for example, to read, write and count.
- ^{vi} Of a total of 32 villages in the Fort Beaufort District, the following nine villages were involved in the study: Tinis, Dorrington, Hillside, Swide, Newton, Mpolweni, Mazoka, Lower Brink Water and Emdeni.
- ^{vii} Other family members were also allowed to participate in the interview if they so wished. However, patients were not allowed to participate as caregivers found it difficult to speak in the presence of the mentally ill.
- ^{viii} During interviews non-verbal messages were interpreted and information regarding the environment, living conditions and the problems they experienced were observed and recorded. Observations were also made regarding relationships and interaction between family members and caregivers, on the one hand, and those between the mentally ill and their respective caregivers, on the other hand.
- ^{ix} Interviews conducted in Xhosa were translated into English by the researcher.
- ^x In a few cases mentally ill patients lived by themselves and were visited by family members. In these cases caregivers were interviewed in the evening in their own places of residence. Interviews lasted about two hours on average and were tape-recorded and subsequently transcribed.
- ^{xi} Three of the participants were coloured.
- ^{xii} Not all those who qualify receive this grant. Some have applied but have not received any response from the Department of Welfare.
- ^{xiii} It is evident from studies such as those of Gibbons *et al.* (cited in Orford 1987:9-12) that the kind of behaviour which relatives of the mentally ill find most distressing and difficult to cope with is that which is directed at them, for example rudeness and aggression.
- ^{xiv} Roy (cited in Talbott *et al.* 1988), for example, places the risk for suicide in male alcoholics who have had psychiatric hospitalisation at seventy-five times that of the general population within a five-year period following the last psychiatric admission.
- ^{xv} Financial costs can be "direct" or "indirect". The former includes cash expenditure on the relative's (mentally ill) behalf. Indirect costs are more difficult to measure and can include missed career opportunities, psychological stress and stress-related illnesses. Financial burden is not only an "objective" burden on the family's finances, but financial constraints may adversely affect the inter-personal relations between the family members concerned.
- ^{xvi} Homan (1999:109) and Peterson *et al.* (1997:56), for example, differentiate between geographical and relational/interest communities. While the former refers to a group of people living within a defined geographical area who share some values, interests and needs and within which a sense of community prevails, the latter refers to communities defined by shared interests and activities.