SOCIO-PSYCHOLOGICAL CHALLENGES FACED BY VOLUNTARY HOME-BASED CAREGIVERS IN MUTALE MUNICIPALITY, SOUTH AFRICA

Ntsieni S. Mashau¹, Makondelela J. Mudau² and Vhonani O. Netshandama³
Department of Public Health¹; Institute for Rural Development² and Community Engagement³, University of Venda, South Africa
E-mail:ntsieni.mashau@univen.ac.za

ABSTRACT

The study explored the socio-psychological challenges faced by voluntary home-based caregivers in the rural areas of Limpopo province in South Africa. A qualitative approach was used to explore and describe the socio-psychological challenges faced by voluntary home-based caregivers. Non-probability purposive sampling method was used and data were collected through focus group interviews. Data saturation occurred after interviews with 46 voluntary home-based caregivers. Data were analysed using Tesch’s method of open-coding. The findings revealed that voluntary home-based caregivers were faced with challenges such as being chased away from households, religious beliefs of clients and shortage of home-based care kits. Recommendations described were based on the findings from the study and focussed on the development of a programme to support voluntary home-based caregivers.

Key words: challenges, home-based caregivers, socio-psychological, voluntary,

1.1 INTRODUCTION AND BACKGROUND

The establishment of home-based care programmes for people with chronic diseases such as tuberculosis and HIV/AIDS was found to be more attractive by many African governments because it was found to be a relief on the overcrowded hospitals (Uys, 2002). In its National guidelines the South African government has identified the increased demands on health care services due to HIV/AIDS epidemic. In South Africa it was noted that public hospitals were unable to cope with the increasing number of patients because hospitals are overcrowded with inadequate number of medical, nursing and allied health professionals (Department of Health, 2002). In response to these challenges, South Africa became one of the countries that signed a Declaration of Commitment of the United Nations General Assembly Special Session on Children (UNGASS) that was held in 2002 (Department of Social Development, 2005). One of the declaration was to: build and strengthen governmental, family and community capacities to provide supportive environments for orphans infected and affected with HIV and AIDS, including the provision of all basic needs as well as the protection of Children’s rights (Department of Social Development, 2005).

The South African government in its National guidelines on home-based care stressed the importance of community participation in caring for the sick in their home environment (Department of Health, 2001). Civil society responded to the need for community-based care services through non-governmental organizations (NGOs), community-based organizations (CBOs) and faith-based organizations (FBO), which collectively are known as Home and Community-Based Care (HCBC) (Department of Social Development, 2006). In South Africa, the African National Congress (ANC) (1994) in its Reconstruction and Development Programme (RDP) policy framework stressed the importance of community development through active involvement and empowerment of the people. In South Africa, Home-Based Care (HBC) organizations together with the government are responsible for training community members who volunteer to provide care to the sick in their homes, these people are known as volunteer caregivers (Akintola, 2008b).
Voluntary home-based caregivers are reported to experience frustrations and feelings of helplessness when they are unable to meet the basic needs of patients such as food and clean water. It is further worsened by the conditions under which they work in rural areas where they walk long distances to the households of people in need of care. Several studies reported physical, emotional and economic stress suffered by home-based caregivers as they carry out their day-to-day activities (Department of Social Development, 2006; Orner, 2006; Akintola, 2008b). This paper reports a qualitative study that explored and described the socio-psychological challenges experienced by voluntary home-based caregivers in rural areas.

1.2 PROBLEM STATEMENT

South Africa, like many of the other developing countries in Africa and the rest of the world has to rely on Home-based care models of care as a way to address the Health care crisis, particularly in rural areas. Most of Home Based Care (HBC) organisations are set up as volunteer programmes of mainly nonprofit organization. The result is that the services become overcrowded and depressed by the number of clients the voluntary home-based caregivers have to care for in settings which are indented with limited resources and abject poverty (WHO, 2002; Lindsey Hirschfield, Tlou, & Neube, 2003; Department of Social Development, 2006). It is reported that at times voluntary home based caregivers dirty their hands by becoming too involved and sometimes using their own resources to care for their clients, which in turn exacerbate stress and more poverty on the part of the caregivers (WHO, 2009). Therefore the study sought to explore the socio-psychological challenges experienced by voluntary home-based caregivers while providing home-based care to people in their homes.

1.3 RESEARCH QUESTION

In order to explore the socio-psychological challenges faced by voluntary home-based caregivers while providing care to people in their homes, the following central question guided the study:

What are the socio-psychological challenges experienced by voluntary home-based caregivers while providing care to people in their homes?

1.4 SIGNIFICANCE OF THE STUDY

Since this study sought to explore and describe the socio-psychological challenges experienced by voluntary home-based caregivers in Mutale local municipality of Limpopo province in South Africa, the findings may assist community stakeholders, non-governmental organisations and the government in planning strategies for effective and sustainable home-based care programmes. Support programmes for voluntary home-based caregivers may be developed based on the findings from this study.

1.5 THEORETICAL PERSPECTIVE

The study departed from Lazarus and Folkman’s (1984) theory of stress and coping. According to Lazarus and Folkman’s theory there is a relationship between the person and the environment. Psychological stress results when individuals appraise their environment as demanding or exceeding their resources and endangering their well-being (Lazarus & Folkman, 1984).

Primary appraisal is a process in which a person perceives risks related to an encounter, thus resulting in stress. In primary appraisal a person may perceive a stressful situation as a benefit, challenge, threat and harm or loss (Lazarus & Folkman, 1984). A stressful situation is appraised as challenging if it results in physical and psychological activity involvement. The theory describe secondary appraisals as the individual’s available coping options for dealing with stress. In the process of dealing with stress the individual evaluates his/her competence, social support, material support and other resources in order to readapt to the circumstances and to reestablish equilibrium between the person and the environment. According to Lazarus and Folkman (1984) coping is related to cognitive appraisal and to stress-relevant person-environment transactions.

Various studies revealed that home-based caregiving results in physical, emotional and psychological stress on the voluntary home-based caregiver (Akintola, 2008a; Jack, Kirton, Birakurataki & Merriman, 2011). Voluntary home-based caregivers are in an interactional relationship with persons and the environment, and therefore the study sought to explore how they describe the challenges that they experience while providing care to people in their homes.

2.1 RESEARCH DESIGN AND METHODS

A qualitative approach which was exploratory and descriptive (Creswell, 2009) was used to explore and
describe the socio-psychological challenges experienced by voluntary home-based caregivers while providing care to people in their homes. Qualitative approach allows participants to freely present their daily experiences using every day language Creeff in (de Vos, Strydom, Fousché and Deport 2011).

2.2 POPULATION AND SAMPLING

The population of this study comprised of all voluntary home-based caregivers providing care to people at their homes in Mutale local municipality of Limpopo province, South Africa.

Non-probability purposive sampling was used to select participants in this study. Participants who met the following criteria were included in the study:

- trained as a home-based caregiver
- experience of more than one year working as a volunteer in a home-based care organisation
- be a resident of Mutale local municipality.

The size of the sample was determined by data saturation which occurred after interviewing 46 participants. According to Neuman (2011), qualitative data saturation is reached when there is no new information coming from participants during interviews. Out of 46 participants only 4 were males and the rest were females.

2.3 ETHICAL MEASURES

Ethical clearance was obtained from the University of Venda, Health, Safety and Research Ethics Committee. Permission to conduct the study was obtained from the Department of Health, Limpopo province, South Africa. Furthermore, authority to conduct the study was obtained from Mutale local municipality and from the managers of all home-based care organisations that were included in the study. Informed consent was obtained individually from the participants after providing them with detailed explanation of the purpose, scope and procedure of the study. The rights of the participants were protected throughout the study. Participation in the study was voluntary. Participants were informed of the right to withdraw from the study. Codes instead of names were used to ensure anonymity and raw data was not exposed to anyone except the promoters of the study. Participants were assured that the information they provided would not be used against them.

2.4 DATA COLLECTION

Five focus group interviews comprised of an average of 9 participants in each group were conducted with community home-based caregivers. Community home-based caregivers were asked the following main questions were asked: “What are the socio-psychological challenges that you experience when providing care to people in their homes?” Probing questions were asked as a follow up on the responses from the participants. An interview guide was used to guide the researcher during data collection. Data were transcribed verbatim in order to record accurately the information provided by participants.

2.5 TRUSTWORTHINESS

Efforts were made to ensure trustworthiness using the four criteria identified by Lincoln and Guba (1985). Strategies were utilized which helped to establish credibility, dependability, transferability and confirmability of the findings.

Credibility

Credibility or the confidence in the truth of the findings was ensured through prolonged engagement with voluntary home-based caregivers, member checks and peer reviews.

Dependability

The strategy of dependability was utilized to ensure consistency which was enhanced by coding and re-coding of data by an independent coder who has a doctoral qualification, with experience in qualitative research methods.

Transferability

Transferability was ensured through thick description of research methodology. Sufficiently detailed descriptions of data were collected in context and reported. Purposive sampling was used to maximise the range of specific information that could be obtained from and about the context.

Confirmability
The strategy of conformability was utilized to ensure neutrality. Transcriptions, audiotapes and field notes were made available to promoters to confirm the findings.

2.6 DATA ANALYSIS

Data were analysed using Tech’s (1990) method of open coding. All transcriptions were read carefully and a list of all topics was recorded with similar topics clustered together and arranged into the main theme and sub-themes (Creswell, 2009).

3. RESULTS AND DISCUSSION

The following theme emerged during data analysis: socio-psychological challenges experienced by voluntary home-based caregivers. The theme was further divided into sub-themes.

3.1 Socio-psychological challenges experienced by voluntary home-based caregivers

It was clear from the discussions with voluntary home-based caregivers that they were extremely stressed and affected by the experiences in their everyday work. Experiences entail being chased away from households and cold receptions associated with stigma and religious beliefs. Voluntary home-based caregivers in this study expressed that being chased away from household, stigma associated with HIV/AIDS, religious beliefs, delay in health and social service delivery and shortage of home-based care kits were the main cause of their frustration.

3.1.1 Voluntary home-based caregivers chased away from households

Voluntary home-based caregivers in this study explained that sometimes family members would tell them not to get into the household even when they are still at the gate. They further expressed that they felt emotionally hurt because they would know that there was a sick person in that household who needed their assistance. A study conducted by Jack et al. (2011) in Uganda on community volunteer programme revealed that some patients were found isolated by their family members and neglected in their rooms. According to Akintola (2008a) home-based caregiving is demanding on home-based caregivers physically and emotionally. A study conducted by Moetlo, Pengpid and Peltzer (2011) on home-based care services in Vhembe district reported that one of the common problems and barriers in caregiving includes problems with the community. The study reported that community home-based caregivers are sometimes not welcomed by patients and family members (Moetlo et al., 2011).

Participants in this study explained that they are sometimes called during the night or around midnight to assist in emergencies. They further explained that it becomes emotionally traumatizing for them when a family that has denied them entrance in the afternoon is the one seeking for their assistance at midnight. This finding is illustrated by the following statements:

“In some households we are not allowed to enter even if there is a sick person, we are told: ‘go away!’ We know that we are volunteers........ (pause, takes a deep breath), but they hurt us when they chase us from their homes.”

“It is very painful when you have visited a household with the aim of helping, and end up being chased away. A person will talk to you in an unacceptable manner, and later on when they are desperate they need our help. That person will even wake me at midnight around 12am and during that time I do not feel safe, but, because I am committed to work and I love my job, I am forced to wake up and help.”

The findings in this study revealed that voluntary home-based caregivers have passion of the work that they are doing in the community. The study showed that voluntary home-based caregivers were sometimes used by the families in the community to their advantage without considering the feelings of voluntary home-based caregivers. However, in this study voluntary home-based caregivers explained that their love to help the community keep them going despite the problems that they encounter. A study conducted by Akintola (2008a) on voluntary home-based caregivers in Kwazulu Natal province, South Africa revealed that volunteers tend to develop a thick skin in order to cope with the unreasonable demands from patients and their families. Some participants explained that some community members still associate community home-based caregivers with HIV/AIDS and therefore the stigma that is attached to it also affects volunteers in the context of home-based care.

3.1.2 Stigma associated with HIV/AIDS

The findings in this study revealed that community home-based caregivers were associated with diseases
like TB and HIV/AIDS by the communities. Therefore the stigma associated with these diseases was attached to community home-based caregivers resulting in families not welcoming them into their households. Voluntary home-based caregivers in this study expressed the emotional pain that they felt when people do not welcome them into their households and call them by names. A study conducted by Akintola (2008a) also revealed that voluntary caregivers are denied access to the families due to the fear of stigma. In the same study it was reported that families were afraid that the presence of voluntary caregivers would make it easy for the community to identify and stigmatize them (Akintola, 2008a). Voluntary home-based caregivers explained that even though they end up passing on to the next household, they felt hurt by the manner in which people talk to them. This is supported by the following statement:

“What I can say is that when we visit people in their homes with the aim of giving advice about diseases (TB, HIV/AIDS and Malaria), some people do not allow us; instead we are told: ‘You are the ones who are suffering from the diseases that you want to teach us about’. It hurts us a lot”

The findings of the study on home-based care in Zimbabwe conducted by Rödlach (2009) revealed that some patients were hidden from voluntary caregivers by family members due to the HIV/AIDS stigma. According to Akintola (2008a), stigma makes it difficult for the people in the community to get help because they will not seek help due to fear of stigma. It was further indicated in the same study that stigma hinders the work of voluntary caregivers because they will not be able to access patients, therefore volunteers who have to serve as advocates for stigmatised patients, find it very stressful for them not to be able to assist. The study further revealed that the problem is that if the sick person dies in hospital after being referred by a community home-based caregiver, the family members blame the community home-based caregiver (Akintola, 2008a).

The findings of this study revealed that voluntary home-based caregivers were sometimes blamed for the death of a patient who dies in hospital after being referred by a voluntary home-based caregiver. According to Akinsola (2006) it is common for African black people to blame health care workers especially nurses if the condition of the patient does not improve within the expected period in the hospital. Voluntary home-based caregivers in this study expressed that they felt emotional pain resulting from the blame placed upon them. This is how a participant explained:

“The other thing is that people delay to go to the clinic to be checked earlier before they complicate. Sometimes they even say that we are killers after we have referred the patient to the hospital and if that patient dies, you will hear them saying: you took my patient to the hospital to die. It hurts because you are offering your help and then they will call you a killer, it hurts.”

Some indications of change were reported in this study because participants explained that some families even call them when they are passing by and invite them to their families. Voluntary home-based caregivers in this study explained that they think that people are becoming aware of their knowledge and they know that voluntary home-based caregivers will assist them. This how a participant expressed it:

“Since we started in 2000, it was very difficult for us because when walking in the villages we were called ‘people with AIDS’……………..But today they invite us and say: ‘May you come to us!’

It was clear from the discussion with voluntary home-based caregivers in this study that stigma is not yet completely eradicated from the community members even though voluntary home-based caregivers indicated that HIV/AIDS is becoming less stigmatised. In this study religion was found to have a profound effect on members of the community and therefore affected the roles of voluntary home-based caregivers in a positive as well as a negative manner.

### 3.1.3 Religious beliefs

The findings of this study revealed that voluntary home-based caregivers expressed the emotional pain that they felt when people refuse to take their advice of taking treatment or going to the clinic because of their religious beliefs. Participants were concerned that parents discontinue treatment of their children as a result of their religious beliefs. This is how it was expressed by some participants:

“It hurts, especially for children! I am hurting, that is why I was referring them to the clinic. One can even write a referral, it is a way of assisting them, I want them to live. I really feel hurt, and the parent some other time regret why he/she did not take the advice on time, and blame his/her religious beliefs.”
“Let me start here, what I encounter…….maybe without being negative or something else….. there are people, who because of their religious beliefs, when we advise them to take treatment and to go to the clinic, they resist because of their beliefs.”

The findings of this study revealed that voluntary home-based caregivers were given referral forms by the clinic nurses which they should complete and refer people whose conditions need medical attention by professional health care officials. However, they felt frustrated when people refuse to go to the clinic. The following response supports the findings:

“Up to this far, as I have already said, we cannot be able to solve this problem because they have stopped taking their treatment, and maybe we have referred them to the clinic for check-up, and it was found out that stopping to take their medications has its adverse effects which make the sickness to be worse again and complicates, so it means starting the treatment therapy from the clinic again.”

A study on home-based care services in Vhembe district of the Republic of South Africa reported that voluntary home-based caregivers experience emotional stress when patients are not taking the prescribed medicine regularly (Moetlo, et al., 2011). According to Akinsola (2006) most African black people still believe that traditional healers are more effective in the treatment of chronic diseases and therefore tend to stop taking the western prescribed medicine and continue with the traditional medicine. A study on adherence to antiretroviral therapy conducted Capricorn District of Limpopo province in South Africa revealed that people default treatment and opt for faith healing or the use of traditional herbs (Jali, Mothiba, Maputle & Lekhuleni, 2011). On the other hand voluntary home-based caregivers in this study explained that they believed that by serving the community, they are serving God and therefore they can feel inner comfort. Similarly, in a study conducted by Rödlach (2009) in Zimbabwe on voluntary home-based caregivers, religion was found to be a source of inner strength and comfort for voluntary caregivers who were mostly from various Christian denominations. It was further reported in the same study that voluntary home-based caregivers found their strength to cope with human suffering that they are faced with everyday from their Christian beliefs.

3.1.4 Delay in service delivery

Voluntary home-based caregivers in this study explained that they cannot solve social problems that they come across in the families. However, they referred families with problems to social workers, but they experience emotional stress when families in need do not get assistance on time.

It was found that despite the fact that volunteers were successful in assisting people in need to access grants, there were still many people who were not successful. The findings in this study revealed that in order for the families in need to get assistance from the social workers, they were required to travel to the social worker’s offices which may require several trips. Voluntary home-based caregivers explained that they offered no other help to the families except to advise them to have patience and go to the social workers even if the process may took very long. Therefore voluntary home-based caregivers in this study felt that people no longer trust them because of the delays in other services that are necessary for their survival. This is how it was expressed by a participant:

"We do tell them to be patience and go to the social worker, however, the process is very long and it is like running in a circle without any success. The people end up losing trust in us, because we only help them with advice and not giving them a tangible solution such as mealie-meal. Since they are tired of travelling to the social worker’s offices, they may think that we can perhaps go and collect such items for them............. It is very painful to us.”

Delay in getting assistance in case of emergencies was also cited by voluntary home-based caregivers as frustrating. Voluntary home-based caregivers in this study expressed the frustration that they experience when they cannot get ambulances during emergencies. It was revealed in this study that there were no ambulances waiting for emergencies in community clinics, as a result participants explained that they felt frustrated when they are faced with emergencies in the community and cannot get an ambulance. Instead they advise family members to hire a car to take the patient to the hospital; however, they experience emotional pain if the family cannot afford to pay for transport. Findings in this study revealed that clinics in rural areas are dependent on ambulances which may delay or not come at all. It was revealed in this study that there was no hospital in Mutale local municipality and the villages that are
situated in the deep rural area of the municipality were dependent on one community hospital located in another municipality. They explained that the challenge becomes worse during rainy days where there was no access due to muddy roads since the roads were not tarred or not developed at all. The following responses support the finding:

“We make telephone calls to Donald Frazer hospital for an ambulance because there is no ambulance in the clinic, but sometimes we are told that there is no ambulance or it has gone to Niani (villages next to Zimbabwe boarder). We once had an emergency patient who did not have money and there was no ambulance”

“We experience a great pressure especially during rainy days; we experience a lot of stress you see.......................(pause) and for us to go to the police station for assistance when it is raining whilst leaving a patient behind with no one to assist, it causes a lot of stress on us.”

Service delivery in South Africa is a problem which is also affecting the community caregivers since they cannot be able to offer a complete assistance to the community without the support from other stakeholders such as the Department of Health and Social Development. Voluntary home-based caregivers in this study expressed concern for not getting help on time when their clients needed it. Similar findings were reported in a study on home-based care conducted by Akintola (2008a) in KwaZulu Natal province where it was reported that voluntary home-based caregivers referred social welfare issues to the social workers. The problem of transport for patients was reported to be a cause for despair on home-based caregivers who find themselves entangled in problems related to poverty at household level (Kipp, Nkosi, Laing, & Jhangri, 2006). It was reported in a study by de Figueiredo and Turato (2001) that in Brazil family caregivers were burdened with the transportation of patients to hospitals during emergencies.

3.1.5 Shortage of home-based care kit

Voluntary home-based caregivers in this study expressed the challenges that they experienced due to the shortage of home-based care kit. They explained that they often find themselves working without having the necessary personal protective equipment such as hand gloves and face masks. Voluntary home-based caregivers explained that sometimes they find themselves working with insufficient hand gloves to an extent that they find themselves assisting patients with bare hands. Palliative care in sub-Saharan Africa is provided with limited resources (Harding & Higginson, 2005). A national survey of home-based care kits for palliative HIV/AIDS care in South Africa revealed that supplies are limited to an extent that in most organisations more than five caregivers share a single kit (Mabude, Bekinska, Ramkissoon, Wood & Folsom, 2008). The findings in this study revealed that voluntary home-based caregivers feared that they may contract infectious diseases if they were not provided with sufficient home-based care kit. They further indicated that it seemed as if the Department of Health did not care about their health because they have reported the problem of shortage of home-based care kit several times without getting any help. The study findings further revealed that participants find themselves helping people who were suffering from cancer with offensive discharges without face masks. Similarly, the findings of a study on home-based care services in Vhembe district of South Africa reported one of the challenges that voluntary home-based caregivers are faced with is the lack of supplies to carry out community home-based care (Moetlo, et al., 2011).

Voluntary home-based caregivers explained that the situation becomes worse when they request for a supply of gloves and face masks and they would find that the clinic also did not have enough stock. They further expressed a concern of not having plastic aprons which can protect them from secretions or blood from patients. Voluntary home-based caregivers explained that every day when they go to work, they feel that they are putting their lives in danger of infection because they do not have the necessary equipment to protect themselves from infection. This is how a participant expressed it:

“We just carry our bags with some papers and go to work, we don’t have kits”

Voluntary home-based caregivers in this study recommended that their work would be much better if each one of them can be provided with a home-based care kit which is filled with the necessary equipment regularly. They also suggested that it would make their work better if they were also supplied with thermometers and portable baumanometer machines which they might use in the community to monitor the blood pressure of patients.
in their homes since they have been trained. Therefore they could provide quality home-based care if they were supplied with the necessary equipment.

Findings from this study revealed the socio-psychological challenges that affect voluntary home-based caregivers when providing care to people in their homes. However, despite the socio-psychological challenges expressed in this study, voluntary home-based caregivers expressed their love and passion for the people which make them to continue with the provision of home-based care to families and individuals in the community.

4.1 CONCLUSIONS

It was found from the study that voluntary home-based caregivers experience socio-psychological challenges that may affect their health and the provision of quality home-based care. The study brought to the fore the issues in home-based care that were perceived as emotionally stressful by voluntary home-based caregivers.

4.2 RECOMMENDATIONS

Caregiving inevitably challenges the health of voluntary caregivers in a significant and holistic way because it impacts on their daily living and satisfaction from caregiving. Therefore the study recommended for policy makers and other stakeholders to develop programmes aimed at supporting voluntary home-based caregivers.

Voluntary home-based caregivers should be included in the review of programmes and the development of home-based care policies.

Government and other stakeholders such as non-governmental organisations and community stakeholders should work together in support for voluntary home-based caregivers. They should collaborate in the provision of resources for home-based care and recognize the unique contribution of voluntary home-based care in the community.

Support groups for voluntary home-based caregivers should be formed and home-based caregivers should be encouraged to attend and participate.

Voluntary home-based caregivers should be encouraged to attend monthly debriefing sessions offered by a professional clinical psychologist organised by a responsible committee from the community.

Voluntary home-based caregivers should be encouraged to attend monthly debriefing sessions offered by a professional clinical psychologist organised by a responsible committee from the community.

4.3 ACKNOWLEDGEMENTS

We would like to thank the research and publication committee of the University of Venda and the National Research Fund (NRF) for funding this study.

5.1 References


