

## Voluntary Home-Based Caregivers' Perceived Needs for Support: A Study in the Mutale Municipality in South Africa

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**ABSTRACT** Voluntary home-based caregivers have become the backbone of home-based care programmes in Southern Africa where the public health care system is under severe strain. In this paper, a cross-sectional descriptive design was used to investigate home-based caregivers' perceptions of their need for support. A total of 77 randomly selected home-based caregivers were recruited. Self-administered questionnaires were used to collect data, which was analysed using descriptive statistics. The results revealed that 47 (61%) of the participants agreed that they were trained as home-based caregivers, whereas 62 (80.5%) indicated that they were not satisfied with the training they received. The results showed that 56 (72.7%) of voluntary home-based caregivers did not know where to get help when they felt stressed, whilst 39 (50.6%) voluntary home-based caregivers indicated that they get emotional support from their colleagues. Voluntary home-based caregivers are playing a critical role in providing care to people in their homes in rural areas and therefore it is essential that all stakeholders should participate in addressing their needs.

### INTRODUCTION

Globally there is great demand for palliative care services and governments are striving towards home-based care where people are cared for in familiar environments (Candy et al. 2015). In South Africa and other sub-Saharan African countries, home-based care organisations were developed in response to the HIV/AIDS epidemic (Valjee and van Dyk 2014). The World Health Organisation (WHO) developed guidelines for the effective provision of home-based care in resource limited settings (WHO 2002). Home-based caregivers visit the homes of the people in need of care and perform activities such as positioning and mobility, bathing, wound cleansing, skin care, oral hygiene, adequate ventilation and guidance, and support for adequate nutrition according to the needs of the person (WHO 2002). According to the WHO (2002), voluntary home-based caregivers experience various challenges resulting from limited resource settings whilst providing home-based care to people in their homes. Akintola (2008a) reported that majority of volunteers in home-based care programmes are unemployed and live in economically deprived settings.

Findings in a study conducted by Mashau and Davhana-Maselesele (2009) on the experiences of HIV/AIDS home-based caregivers in the Vhembe District of the Limpopo province

revealed that activities rendered by voluntary home-based caregivers included fetching water for their clients, as well as doing other household chores, such as cooking and cleaning. These activities are over and above the basic nursing care, such as treatment support, bathing and feeding that should be provided by voluntary home-based caregivers. The study further revealed that home-based caregivers are also contacted by the family members when a patient dies at home, so that they can assist in the removal of the body (Akintola 2008b; Mashau et al. 2009).

Resources such as home-based care kits, sanitation, water, poor roads and shelter are a challenge for home-based caregivers. Most countries depend on government and international funding to an extent that if there can be no funding, organizations could not be able to purchase kits for themselves. Most home-based care organizations in South Africa are struggling to get enough home-based care kits. Currently, up to five voluntary caregivers share a single kit, due to insufficient supply of home-based care kits (Mabude et al. 2008). The needs of the people under the care of voluntary home-based caregivers tend to overshadow the needs for the support of voluntary home-based caregivers. According to Akintola (2008a), voluntary home-based caregivers at times 'dirty their hands and become too involved', to the extent that they

use their own resources to care for their clients, and this, in turn, exacerbates stress and more poverty on the part of the caregiver.

Although government policies, legislative frameworks and guidelines meant to create an enabling environment for effective implementation of home-based care exist in South Africa, they fail to adequately address the holistic needs of the caregivers (Department of Social Welfare 1997; Department of Health 2001). Volunteers in home-based care play a positive role in assisting family members to care for the persons suffering from chronic illnesses (Lovatt et al. 2015). Lovatt et al. (2015) reported that even though home-based caregivers are not qualified health care professionals, they are able to work and provide the family caregivers and patients with the maximum support that they can offer. However, a study conducted by Rha et al. 2015 revealed a heavy caregiver burden, which in turn, has a negative effect on their quality of life. The same study recommended that the provision of support for caregivers might reduce the burden and positively influence their quality of life. A study conducted by Wattradul and Sriyaporn (2014) reported that family caregivers were in need of educational support. Therefore this paper seeks to investigate voluntary home-based caregivers' perceived needs for support.

### Objectives of the Study

- ♦ To assess voluntary home-based caregivers' perceptions regarding training in relation to their work.
- ♦ To determine voluntary home-based caregivers' perceptions regarding emotional support.
- ♦ To describe voluntary home-based caregivers' perceptions regarding financial support.

### METHODOLOGY

A quantitative cross-sectional, descriptive design was used to investigate voluntary rural home-based caregivers' perceived need for support while providing care to people in their homes. Cross-sectional studies involve selecting a sample from the population and collecting data at a specific point in time, in this case, to investigate voluntary home-based caregivers' perceived needs for support.

### Population and Sampling

The study was conducted in the Vhembe District of Limpopo Province in South Africa, with special focus on the Mutale municipality, which is located in the surrounding rural area. The population comprised of all voluntary home-based caregivers in Mutale municipality. A list of 26 home-based care (HBC) organisations in the Mutale municipality was obtained from the Department of Health and Social Development. Simple random sampling was used to select three home-based caregivers from each of the 26 HBC organisations. The sample was comprised of 78 participants and a total of 78 questionnaires were administered. All except one of these was completed.

### Instrument and Data Collection Procedure

A structured questionnaire was designed to obtain appropriate information from voluntary home-based caregivers. The questionnaire was developed in English and translated into Tshivenda by a language expert from the University of Venda and it was then translated back, by another language expert, to ensure English and Tshivenda equivalence. Participants were briefed on the purpose of the study before the questionnaire was administered.

The instrument was pre-tested on 10 voluntary home-based caregivers who were randomly selected from home-based care organisations that were operating in the neighbouring municipality with similar characteristics. The participants in the pre-test did not form part of the research sample. Questions which were found to be confusing were rephrased and restructured so as to suit the level of understanding of the participants. A test re-test was done to test the stability and reliability of the instrument over time on 10 participants by re-administering the questionnaire after one week. The results showed a correlation coefficient ( $r$ ) of 0.99. Data were analysed using descriptive statistics. Data was first coded and analysed using Statistical Package for Social Sciences (SPSS) version 20.0.

### Ethical Consideration

Ethical clearance was sought from the University of Venda Research Ethics Committee and permission to conduct the study was obtained

from the Limpopo Department of Health and Social Development. Permission was also obtained from the Vhembe District, Mutale municipality and home-based care organisations. Informed consent was obtained from the participants. Confidentiality, privacy and anonymity were respected throughout the study. Participants were informed that participation was voluntary and they were free to withdraw from participating at any time.

## RESULTS

### Demographic Profile of Participants

Out of 77 participants, 73 were females, and 59 (77%) were over the age of 35 years. The results showed that 53 (68.8%) participants did not have matric, whereas 24 (31.2%) had passed matric or grade 12. The majority of participants, 50 (65%) were staying with their partners, whilst only 27 (35%) were single parents. None of the participants had any formal employment except home-based care. Table 1 outlines the distance in kilometers travelled by voluntary home-based caregivers per day. These voluntary home-based caregivers travelled from five to more than 20km

per day to visit clients in order to provide home-based care.

### The Need for Training

Participants were asked whether they received training on various aspects (Table 1) of their work and whether they were satisfied with the training they received. The results revealed that 47 (61%) of voluntary home-based caregivers were trained in home-based care. However, 62 (80.5%) were not satisfied with the training they received. Only 19 (24.7%) agreed that they were trained on the conditions of the people under their care, whereas 43 (55.8%) said that they had not received training on the conditions of the people under their care.

### The Need for Emotional Support

Home-based caregiving is regarded as challenging for voluntary home-based caregivers. Table 2 presents the responses of participants regarding the emotional support they get during their voluntary work as home-based caregivers. The results show that 65 (84.4%) of the participants did not receive counseling from professionals, whereas 39 (50.6%) received emotional support from colleagues.

**Table 1: Training received by voluntary home-based caregiver**

<i>Training received by a caregiver</i>	<i>Agree</i>		<i>Disagree</i>	
	<i>Frequency</i>	<i>Percent (%)</i>	<i>Frequency</i>	<i>Percent (%)</i>
I was trained as a home-based caregiver	47	61	30	39
I receive regular training to update my skills.	33	42.90	44	57.10
I was trained on the conditions of the people I am taking care of.	34	44.20	43	55.80
I was trained to gain skills on how to generate income.	11	14.30	66	85.70
I received training on project management.	19	24.7	58	75.30
I received training on communication skills.	36	46.80	41	53.20
I received training on counseling skills	29	37.70	48	62.30
I am satisfied with the training that I have received	15	19.50	62	80.50

**Table 2: Emotional support received by voluntary home-based caregiver**

<i>Training received by a caregiver</i>	<i>Agree</i>		<i>Disagree</i>	
	<i>Frequency</i>	<i>Percent (%)</i>	<i>Frequency</i>	<i>Percent (%)</i>
I receive counseling from professionals	12	15.6	65	84.4
I always receive counseling every time I need it	12	15.6	65	84.4
When stressed I know where to get help.	21	27.3	56	72.7
I always get emotional support from my colleagues.	39	50.6	38	49.4

### The Need for Financial Support

Participants were asked to indicate if they were getting any financial support, and whether they were satisfied with what they were getting. The results in Table 3 reveal that participants need financial support to meet their basic needs, as well as for transport to visit their patients.

The results of this study further reveal that all 77 (100%) participants did not have their own home-based care kit, which is packed with the required equipment for home-based care. Whilst only three (3.9%) participants were provided with transport to visit their clients, the results showed that majority 74 (96.1%) of the participants were not provided with transport to visit their clients.

### DISCUSSION

The study findings reveal that majority of voluntary home-based caregivers do not have grade 12. However, the majority of these voluntary home-based caregivers were able to read and write. Education plays an important role in understanding the different health problems that people are suffering from in home-based care. The results of this study reveal that the majority of voluntary home-based caregivers were trained in home-based care. However, the results also show that the majority of voluntary home-based caregivers were not receiving regular training to update their skills, which could help them to understand the conditions of people that they are taking care of. In their study on the needs of community health promoters, Mthobeni et al. (2013), found that community health promoters wanted support in the form of in-service training, so that they gained knowledge in the field of HIV and AIDS. Moetlo et al. (2011) acknowledge that home-based caregivers received sufficient training initially, however, they indicate

that there is a need for refresher courses for new personnel, and management skills for supervisors, so that they are able to manage the organization properly. According to Akintola (2008a), the training that is received by voluntary home-based caregivers had limited effects because they found themselves being unable to administer pain-relieving or life-saving medication.

The need for continuous training is vital in home-based care since voluntary home-based caregivers deal with different conditions and chronic diseases in the community. According to Valjee and van Dyk (2014), home-based caregivers of people living with HIV/AIDS expressed their need for education and continuous training. A study conducted by Moetlo et al. (2011), on home-based care in the Vhembe District of Limpopo Province in South Africa indicates that voluntary home-based caregivers were interested in learning to get more information about the service they offer. It was also revealed that voluntary home-based caregivers regarded training manuals as the most required tool in their daily work. Therefore, literacy is essential in home-based care, because it enables home-based caregivers to read and understand instructions related to drugs and health promotion. According to Moetlo et al. (2011), voluntary home-based caregivers in the Vhembe District have enough knowledge on what they are doing because of the educational levels that they have.

The results reveal that voluntary home-based caregivers were concerned about the stipend they received (if at all), which was not enough to cater for their basic needs. The results of this study reiterate Akintola (2008a), who argues that since voluntary home-based caregivers were not receiving any remuneration, they had to develop strategies to cope with home-based care even if they were not getting any remuneration. The results of this study reveal

**Table 3: Financial support received by voluntary home-based caregiver**

<i>Training received by a caregiver</i>	<i>Agree</i>		<i>Disagree</i>	
	<i>Frequency</i>	<i>Percent (%)</i>	<i>Frequency</i>	<i>Percent (%)</i>
I have money for transport to visit my clients	0	0	77	100
We are provided with transport to visit clients	3	3.9	74	96.1
There is enough money in our household to pay for our basic needs.	0	0	77	100
I am satisfied with the stipend that I get every month.	1	1.3	76	98.7
I have learned other means of generating income for my family.	6	7.8	71	92.2
My HBC kit is always packed with the required equipment	0	0	77	100

that all participants were unemployed and were dependent on the home-based care stipend to meet their basic needs. Findings from a study conducted by Rödlach (2009) on voluntary caregivers in Zimbabwe revealed that voluntary caregivers who were preparing food for primary school pupils were tempted to steal from the supplies because they did not have food for their households.

The results of this study reveal that the majority of voluntary home-based caregivers did not always put on protective clothing when helping clients, because they had run short of equipment such as aprons and hand gloves. Material support was cited as a major challenge of community home-based caregivers in various studies (Department of Social Development 2006; Orner 2006; Akintola 2008a; Rödlach 2009; Moetlo et al. 2011).

The results of this study reveal that voluntary home-based caregivers were not receiving counseling from professionals; however, when they were stressed they relied on colleagues for emotional support. Lageman et al. (2015) and Kobos et al. (2015) reiterate that home-based caregiving is associated with caregiver burden, which may result in caregiver stress, because home-based caregivers become emotionally involved with their patients. According to Yikilkan et al. (2014), family caregivers of patients suffering from chronic illnesses at home experienced emotional stress. Home-based care is associated with emotional stress, which is exacerbated by suffering and dying of patients under the care of a home-based caregiver (Han et al. 2014; Valjee and van Dyk 2014; Lovatt et al. 2015). According to Rödlach (2009), home-based caregiving can be emotionally demanding resulting in burnout if there is no support offered. Akintola (2008a) claims that counseling of voluntary home-based caregivers on how to cope with stress in the context of home-based care is crucial. This study reveals the need for emotional support as perceived by voluntary home-based caregivers themselves. The findings of a study conducted by Mignone et al. (2015) reveal that nonhuman objects, such as animals, were regarded as sources of support in home-based care. Olwit et al. (2015) show that home-based caregivers relied on friends and relatives for support when emotionally stressed.

None of the participants in this study were employed, and therefore the issue of financial

support was very serious to them. This finding is supported by findings from studies conducted by Valjee and van Dyk (2014) and Yikilkan et al. (2015) who stated that home-based caregivers were confronted with challenges related to poverty, unemployment and poor salary. The findings of a study conducted by Thabethe (2011) reveal that the needs of voluntary home-based caregivers are often ignored while they are promoting the needs of people under their care. Voluntary home-based caregivers are also in need of clothes and non-perishable food donated to People Living with HIV/AIDS (PL-WHA). The same study recommended that voluntary home-based care should be valued as a job because voluntary home-based caregivers are providing free labour under stressful conditions (Thabethe 2011).

## CONCLUSION

Voluntary home-based caregivers in this paper expressed their need for support in the form of continuous training, and emotional and financial support. Voluntary home-based caregivers felt that some form of support should be provided so that they can provide quality home-based care. The burden of care of people with chronic illnesses such as HIV/AIDS, Tuberculosis, cancer, cannot just be shifted to home-based caregivers with the assumption that they would be able to cope.

## RECOMMENDATIONS

It is recommended that:

- ♦ A programme of support for community home-based caregivers which is community driven should be developed.
- ♦ Community stakeholders should be actively involved in the management and sustenance of their local home-based care programme by applying for national and international funding for their home-based care organization. Voluntary home-based caregivers should be encouraged to collaborate with community stakeholders so that they can receive continuous support from them.
- ♦ Voluntary home-based caregivers should be encouraged to form support groups wherein members from the religious structures and other volunteers from the members of the community can participate. Policies and

guidelines on home-based care should include the support programme for voluntary home-based caregivers.

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