

## **SUPPORT FOR LAY CAREGIVERS OF PATIENTS WITH HIV AND AIDS IN LILONGWE, MALAWI**

**J.M. Dippenaar**, D Cur  
University of Limpopo, Medunsa Campus  
Nursing Science Department  
**Corresponding author:** joand@ul.ac.za

**G.F.Chinula**, M Cur  
University of Limpopo, Medunsa Campus  
Nursing Science Department

**B. Selaledi**, M Cur  
University of Limpopo, Medunsa Campus  
Nursing Science Department

### **ABSTRACT**

This study explored the experiences of lay caregivers for patients with HIV and AIDS in relation to the support that they received and wanted from their communities. In the context of HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) home-based care is a strategy that could reduce the burden on the health care systems, also in resource-limited conditions.

A qualitative research design used a purposive sample of three traditional authorities with home-based care programmes, in peri-urban and rural communities in Malawi. This included 15 lay caregivers registered for home-based care at these institutions. Data were gathered through semi-structured interviews.

Thematic support (social, financial, material, technical and psychological) categories (types of community members) and sub-categories (types of assistance) emerged from the data analysis. The findings indicated that the gateway to support lay caregivers was 'visits and chats'. Providing support to the patient made caregivers feel unsupported. Support from healthcare professionals was the greatest need identified.

Based on the findings, recommendations for a comprehensive collaboration of stakeholders to support the varied needs of lay caregivers are proposed.

**KEYWORDS:** Acquired Immune Deficiency Syndrome, HIV/AIDS in Malawi, home-based care, lay caregiver support

### **INTRODUCTION AND BACKGROUND INFORMATION**

Throughout the world, most caregivers at home are family members. (Chimwaza & Watkins, 2004:795; WHO, 2000:9). Within the context of HIV (Human

Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome), home-based care is a strategy to reduce the burden on the healthcare system.

The prevalence of HIV and AIDS in sub-Saharan Africa (SSA) remains the highest in the world (estimated at 8.6% of the adult population (WHO, 2002). This places a burden on the poorly resourced and financially constrained healthcare delivery systems in many developing countries, including Malawi (Jackson, 2002:234). The provision of care for persons with HIV and AIDS is often the responsibility of their loved ones. This implies that families and lay caregivers are burdened with the care of their loved ones; often with limited resources and under substandard conditions (Jackson, 2002:234). This puts the survival of the patient at risk and also affects the well-being of the caregiver.

### **Community home-based care**

Spier and Edwards (in Uys & Cameron, 2003:3) consider home-based care as a reality in most healthcare systems. Governments in developing countries advocated home-based care as a strategy to relieve the healthcare system, which contends with a lack of resources. For these reasons, care shifts from hospitals to homes. Lay caregivers, as unremunerated workers, find themselves burdened and commissioned with the care of their loved ones (WHO, 2002:15--16). This places an added strain on them because they are emotionally involved with the patient (Zimba, 2000:17; WHO, 2002:40–42).

Home-based care is defined as care at a patient's residence to supplement or replace hospital-based care (Uys & Cameron, 2003:3). The Botswana Ministry of Health (Lindsey, Hirschfeld, Tlou & Ncube 2003:489), describes home-based care as “care given to individuals in their own natural home environment by their families; supported by skilled welfare officers and communities to meet spiritual, material and psychosocial needs, with the caregivers playing a crucial role”.

### **Healthcare provision and home-based care in Malawi**

Malawi has a comprehensive health provision system consisting of maternity units, dispensaries, health centres, district and central hospitals linked through a well-defined referral system. Malawi's Ministry of Health (MoH) delivers 60% of the country's healthcare services. In addition, there are facilities which are managed directly under religious missions, co-ordinated by the Christian Health Association of Malawi (CHAM), providing 37% of the services, while the Ministry of Local Government (MLG) provides 1% of healthcare. Not-for-profit non-governmental organisations (NGOs) and the private sector provide 2% of health services. At grassroots level, community health services are based on the delivery of services by a network of community nurses, traditional birth attendants (TBAs) and volunteers. However, the exact numbers and extent of these services are unknown.

The AIDS Control Programme in Malawi recommended in 1995 that the management of AIDS patients should be undertaken in the community using locally available resources. The Malawi National HIV and AIDS Policy adopted a home-based care

approach as one of its major components (Office of the President and Cabinet, National AIDS Commission, 2003:20–21). Most Malawians, especially in rural areas, do not have access to home-based care services. Many patients still come to hospital during the terminal stages of their illnesses as their family members fail to cope with the demands of their illnesses.

## **PROBLEM STATEMENT**

The psychological and sociological experiences of lay caregivers in home-based care need to be researched and considered in healthcare service delivery programmes (Orner, 2006:236). Only a few studies investigated the full range of care giving practices and cultural values of lay caregivers, including their needs in Malawi and in other African countries (Chimwaza & Watkins, 2004:795; Ndaba-Mbata & Soloilwe, 2000:218).

## **PURPOSE AND OBJECTIVES OF THE STUDY**

The purpose of the study was to explore the experiences of the lay caregivers of patients with HIV and AIDS in relation to the support that they received from and wanted in their communities.

## **RESEARCH METHODOLOGY**

This study used a qualitative phenomenological research design to explore and describe lay caregivers' experiences in relation to the type of support that they received from and wanted in their communities.

## **POPULATION, SAMPLE AND CONTEXT**

The study was conducted in the Lilongwe district of Malawi, due to its high prevalence of HIV and AIDS. Three traditional authorities, served by three different hospitals covering peri-urban and rural communities were involved in the study. All the areas had home-based care programmes and different institutions such as NGOs, the government, and mission hospitals supporting each area.

Purposive sampling was used to select participants. Five participants were selected from each setting. Fifteen lay caregivers of patients with HIV and AIDS were selected at household level regardless of age, sex and the duration of care giving. The only inclusion criterion stipulated that they should be registered for home-based care at a hospital and should be caring for a person suffering from HIV/AIDS at home. Written permission was obtained from all participants and institutions.

## DATA COLLECTION

Data were collected during July/August 2005 in the homes of all participants through initial in-depth interviews and frequent follow-up interviews. All interviews were audio tape-recorded with permission of the interviewees.

### Interview protocol

The semi-structured interview schedule comprised two major sections: biographics to determine the composition and variables of the sample, and the qualitative semi-structured questions. The individual interviews were conducted in the participants' homes in their home languages. Three questions were used to gather qualitative data.

**Table 1:** Questions asked during the interview

Question 1 What are your experiences as a caregiver in relation to the support you receive in the community?
This question translated into the vernacular means:
Tell me exactly what you do in caring for your mother/husband/wife/daughter/brother/sister?
Question 2 What type of assistance do you get in your community as a caregiver of your mother/husband/wife/ daughter/brother/sister?
This question remained the same in the vernacular.
Question 3 What type of support would you like to have as a caregiver? Translated into the vernacular the question means:
Tell me what assistance you would like to have when caring for a mother/husband/wife/daughter/ brother/sister.
The following probes were used to gather more information and also to seek clarification:
<ul style="list-style-type: none"> <li>• What is your experience in caring for people living with HIV and AIDS? This question translated into vernacular was:</li> </ul>
<ul style="list-style-type: none"> <li>• What do you need when taking care of your mother/sister/daughter/brother?</li> </ul>
<ul style="list-style-type: none"> <li>• What are your roles and responsibilities in caring for this patient? This question translated was:</li> </ul>
<ul style="list-style-type: none"> <li>• What do you do for the patient?</li> </ul>
<ul style="list-style-type: none"> <li>• Tell me about the help and support you are getting. This question translated was:</li> </ul>
<ul style="list-style-type: none"> <li>• Tell me about the assistance that you get when caring for this patient.</li> </ul>
<ul style="list-style-type: none"> <li>• In your opinion what could be the best way of caring for a patient like this one? Translation did not change this question.</li> </ul>

Field notes of observations during the visits were used to provide more insight into the circumstances that influenced the responses.

The duration of the interviews of caregivers were adjusted after the pretest from the initially planned 30 minutes to the actual sixty minutes.

## DATA ANALYSIS

Quantitative analysis of the biographical data was done. A protocol for the analysis of the qualitative data was based on Collaizzi's (1978 in Holloway & Wheeler 2001:125) method of data analysis. The recorded responses were transcribed *verbatim* in the vernacular and quotations were translated into English by the researcher, who is fully conversant in both languages.

The qualitative data were analysed through multi-phase manifest coding and a dense description of the findings. Similar responses were extracted from the raw data in the transcripts. Based on these findings, a thematic structure was developed of themes, categories and subcategories. This framework was used to interpret all the data.

## QUALITY OF DATA

Gobi (1981) as well Gobi and Lincoln (1994 in Streubert & Carpenter 2003:29) developed four criteria of credibility, transferability, dependability and conformability to use for assessing the data's trustworthiness. Table 2 demonstrates how these were applied.

**Table 2:** Trustworthiness of quality of data

Credibility	The following strategies were used to increase credibility
Bracketing	The biases, views, beliefs and opinions of the researcher were bracketed by maintaining an open minded approach.
Selection of participants	Purposive selected participants were unfamiliar to the researcher.
Triangulation	Multiple sources of information were triangulated. These were: in-depth interviews, observations, field notes and literature control. Biographical data served as quasi statistics.
Prolonged involvement	After two months in the field, the researcher continued with member checking.
Persistent observations	Throughout the interviews, observations of participants and their environments continued and field notes were taken.
Member checking	The tapes were played soon after completing the interviews. The transcriptions were checked with participants for the real meaning.

Peer debriefing	Regular discussions with colleagues and significant others about experiences in the field and ideas about the findings served to challenge and inform interpretations. The co-coder and supervisors accessed field texts.
Transferability	The findings in the study are contextual but might be generalisable to similar contexts.
Dependability	Correlation with other studies confirms dependability.
Audit trail	Clear records of decisions and rationales were kept. The inquiry audits (scrutiny of data) were the preferred methods used in this study. The inquiry audit was limited because of the use of the vernacular in the verbatim transcripts. Only the coder and assessors that understood the language (Chichewa) were able to audit the information obtained during the actual interviews.
Co-coder utilisation	A co-coder was used.
Conformability	An audit trail and the use of a protocol for coding through a co-coder ensured conformability. Manifested coding and a dense description of data were used to improve conformability.

## BIOGRAPHICAL DATA

All 15 participants were included in the study because of their biographic differences, which might have influenced the participants' experiences. Therefore, interviews continued until all 15 participants had been interviewed, although saturation had been reached after the ninth interview.

Vulnerable groups were young girls, males, the aged, persons with low literacy levels, as well as poor persons. Young girls needed to go to school. Two young girls' education was jeopardised by providing home-based care to HIV and AIDS patients. They stated, *"If people could come to stay and chat with my mother...I want to go to school..."* *"I am always late for classes...it is very difficult to cope with content that was already covered"*.

Two participants were male caregivers. Caring for the sick is viewed as a woman's role in Malawi (Chimwaza, & Watkins, 2004:795; Ndaba-Mbata & Solozlwe, 2000:220; Jackson, 2002:249; Zimba, 2000:40). Responses included, *"....In addition to caring for my wife, I have to care for the children and do the other household work. Children are better looked after by their mother.... have to also take the children to hospital when they are sick, it is not easy"*.

Of all participants, 47% were older than 50 years. The young and old were more affected by the demands of care giving. A participant commented, *".....Sometimes I become very*

*tired as there is no one to assist me ... my patient leans on my chest the whole night because when she sleeps in the sitting-up position she breaths much better...”* .

Of these respondents, 47% never attended school. This could influence their understanding of HIV/AIDS, their ability to generate income and follow instructions on how to care for these people and to read instructions on medication. One caregiver noted, “...I have heard about HIV and AIDS at the clinic...I want to know...I wanted to use gloves...I am frustrated ... no one is telling me anything”.

As 66% of participants were of low socio-economic status, they lacked access to transport. Their ability to feed their loved ones and the people they are caring for caused concerns. Some complained: “ *If I could be helped with child caring so that I go for piece work to earn money....*” “...I need money to buy some items to use in caring...” “...If organisations would help us get loans for small businesses, the problem would lessen”.

Caregivers and the patients were related on various levels-- brother and sister, husband and wife and child and mother/father and vice versa. The degree of commitment might be influenced by the nature of the relationship. The duration of care varied from one to six years. An elderly person said: “... I left my husband at our home for one year now... I have come here to take care of my daughter.... I do not have friends in this area. ...”.

## **DISCUSSION OF QUALITATIVE DATA**

The qualitative data were developed into themes, categories and subcategories.

Five themes relating to support received and wanted emerged from the categories identified from the data through the coding processes (table 3 columns 1 and 2). Subcategories that emerged relate to the providers of all the kinds of support reflected in the themes and categories. These included church members, chiefs, relatives, friends, volunteers and healthcare workers (table 3 column 3). A summary reflecting the experiences of lay caregivers appears in table 3 column 4.

### **Themes**

Themes identified with regard to support received and wanted related to social, financial, material, technical and psychological aspects. The most important support received in terms of the themes was social support in the form of visits, chats and prayers. This was also identified as the gateway for financial, material and psychological support, although this type of support was received exclusively for the patient, not for the caregiver. This social contact became the tool to connect lay caregivers to the community --and even though their own needs were not met the connectedness gave them a sense of security-- as stated: “*The church leaders come to see the patient... some come every day, others twice and others three times a week ...all the same, I feel happy when they come ...*”

*“...the church members to come see my wife, at times they chat with me after seeing my wife ...I get encouraged...”*

The lowest level of support received was the practical support, and this also had, (without overriding the importance of social visits), become the most desired support—as explained: *“...at least if once a month healthcare workers could visit and teach me how to care for my mother...”*

Caregivers required assistance to meet their psychological needs as they experienced anxiety, worries and despair. Only one caregiver stated that they needed psychological counselling, *“...I think nurses should also visit and listen to my issues. Sometimes I become confused.....I need mental support”*.

## **Categories**

The categories identified represented the community tasks and activities that participants considered supportive or non-supportive. Categories were identified for each theme (see table 3 column 2). The most important categories were chats and visits which also remained the primary aspect under support wanted. Others categories included the following:

**Practical assistance:** “Sometimes people from church come and help....they fetch water, firewood and clean the house.”

**Money:** “The chief gave me money and he told me to use it for transport of patient to hospital....I am worried she cannot go alone.”

**Food:** “Friends help by giving me money to buy my husband’s food...sometimes he wants nice foods...the money is not enough...I get frustrated.”

**Relief of rendering physical patient care:** “If her sister could come and help to take care of my wife at night, this is my second week without good sleep... I feel very tired.”

**Treatment and education:** “I have observed that he vomits everything and now it is blisters...I am concerned because no nurse has visited since they gave her the medicine.”

**Infection prevention:** “The volunteer tells me to keep good hygiene...I do not have anything...no bed sheets, no blankets, no basin.”

**Prayers and counseling:** “The female chief comes...the first time she visited, she prayed with me and my wife...I got encouraged.”

## **Subcategories**

Subcategories identified were the providers of support from a variety of sources. They were church members, relatives, chiefs, volunteers and health care workers. The most important supporters were the church members followed by relatives. The relatives who visited gave support in terms of food, money, practical assistance and relief of



**Table 3:** Themes, categories and sub-categories developed from qualitative data analysis

Themes	Categories	Sub-categories	Participants' experiences
Social support	Visits and chats	Church members, relatives; friends, chiefs, health care workers	Participants felt excluded from chats during visits, but relieved and encouraged after inclusion in visits and chats.
	Practical assistance (household tasks)	Church members, relatives, fiends	Participants felt exhausted, burdened, overwhelmed, frustrated, and stated that caring was difficult
Financial support	Money	Church members, relatives, friends, chiefs	Participants felt excluded because they did not benefit from the money given to the patients; helpless and frustrated because the money was inadequate to meet the patients' needs.
Material support	Food (mainly maize flour)	Church members; relatives; friends; volunteers	Participants felt excluded because benefits were only for the patient. Caring was physically demanding and due to poor nutrition the caregivers were exhausted
	Relief of the burden of physical patient care	Volunteers; relatives; friends	Participants felt unsupported and anxious with irregular assistance with basic nursing care and night relief especially when their patients were very sick and they did not know how to assist them.
Technical support	HIV and AIDS treatment education	Health care workers	Participants felt concerned because they lacked drugs. They were also unsure of the effects of some drugs. Health care workers (HCW) did not follow them up.
	Infection prevention		Participants noted that no one taught them about HIV and AIDS. They had only heard about HIV and AIDS mentioned at the clinic, over the radio and at their church. They lacked confidence.
Psychological support	Prayers	Church members, chiefs	Participants who were included in the prayers felt encouraged, hopeful and empowered. The majority of participants felt excluded from prayers that were offered for the patient only.
	Counselling	Volunteer, health care worker	One of the two participants who benefited from counselling felt emotionally empowered.

physical patient care. The chiefs assisted with money and transport. Each subcategory seemed to provide for a different kind of need.

Church members chatted and prayed, *“Members from our church come...they pray for the patient...if they could be praying with me...I feel sad that they cannot pray with me...”*

Assistance from relatives, *“...If relatives visited, they could help look after my wife and the children ...”* *“...Relatives help by giving money, they tell me I should use it for the patient’s needs which I use to buy food, sometimes I have to buy soap, some drugs ...”*  
 .Support by chiefs, *“The chief gave me money and he told me to use it for transport of the patient to hospital....I am worried she cannot go alone....”*

The lay caregivers expressed the need for all kinds of support of which the most important support wanted from the providers was visits and technical support from the health care workers. *“The chief could assist by organising people to help me work in my garden... I need to produce my own maize...but have no time... least if once a month nurses could visit and teach me how to care for my mother...”*

The lay caregivers mentioned that they received most support specifically for the patients and not for the caregivers. Lay caregivers experienced a lack of support in this regard and stated, *“...Relatives help by giving money, they tell me I should use it for the patient’s needs which I use to buy food, sometimes I have to buy soap, some drugs ... The chief gave me money and he told me to use it for transport of the patient to hospital....I am worried she cannot go alone....”*

Participants also indicated that the support was irregularly provided. This included visits, prayers, food and money. Support they received was thus inconsistent and unstable.

## **CONCLUSION**

There appeared to be adequate social support for the lay caregivers from church members but insufficient support from health care workers. The spin-offs from the social support, through visits, mainly benefited the patients in terms of prayers, food and money but had no benefits for the caregivers as such. Therefore it could be inferred that the lay caregivers were unsupported and their needs remained unmet because support was inconsistent and uncoordinated coming from a variety of sources focusing on the needs of the patients, not on those of the caregivers. This lack of support could be translated into a disconnectedness described by Sowell, et al. (in Wood & Harper, 2002:264) in a study of AIDS sufferers where the essence of the researched phenomenon of lost lovers was found to be the isolation and disconnectedness from the support of others.

The central meaning in this study resonates with this meaning of connectedness and disconnectedness while their lived experiences are reflected in the emphasis on social support. Through the social visits and chats, the participants were connected to different

types of support although these were insufficient and irregular. The social visits became the gateway for other forms of support, although these social visits could not replace the health care workers' inputs desired by the caregivers.

The high level of social support experienced from the church indicated that the participants experienced support through such social contacts although all their particular needs as caregivers were not acknowledged nor met. Although they did not benefit directly from the visits, and additional money and food for the sick, the social contact benefited them indirectly.

The five supportive themes and the subcategories involved in the support of the lay caregivers suggested that one provider alone cannot meet all the diverse needs of lay caregivers. Although all the caregivers had similar needs in spite of income, age, gender and literacy differences, some had particular needs. For example, young people who needed to go to school and male participants who, in Malawi, were not accustomed to performing household chores.

The support mostly needed and wanted was the support least received, namely the technical support from the health care system. It can be said that the caregivers experienced disconnectedness from the health care system.

## **RECOMMENDATIONS**

Formal social networks are required to mobilise and coordinate community resources to support lay caregivers, with emphasis on inputs from the healthcare sector. Each stakeholder had a specific function that could render support to the caregiver if healthcare workers could regularly visit the patient, the caregivers could obtain regular information and drugs and support.

The development of guidelines for a collaborative supportive network of stakeholders is recommended to support lay caregivers. Further research is recommended to establish formal structures to this end. A future study should investigate the challenges encountered by healthcare providers concerning lay caregivers in Malawi.

## **LIMITATIONS OF THE STUDY**

Because of limited resources, only 15 lay caregivers participated in the study. Consequently the findings might not be generalised to other lay caregivers in Malawi. The lay caregivers' verbal responses were accepted as shared during the interviews. No attempts were made to confirm/refute the lay caregivers' information with healthcare providers.

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