

Challenges experienced by home based caregivers of HIV/AIDS patients in chifubukawama community, Ndola, Zambia

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ABSTRACT

Introduction: Home based care is an answered prayer in this era of HIV/AIDS, allowing the chronically ill people to spend their last days in familiar surroundings. Home based care was birthed for a noble cause such as this. As caregivers care for these patients, they experience challenges in terms of stress, burnout, stigma and discrimination among others, which could be due to social and psychosocial factors. The purpose of the study was to determine the challenges of home based caregivers for people living with HIV/AIDS in Chifubu-Kawama Community, concentrating on volunteer care givers. **Methods:** It was a quantitative study using convenient sampling methods. A questionnaire was used to collect data and the Statistical Package for Social Science (SPSS) version 20.0 aided in the analysis. **Results:** Of the 30 care givers, 66.7% were female and 33.3% were males. The common age range was between 40 and 49 years. 86.7% reported long distance walking as challenging while lack of food by the patients was at 83.3%. The major challenges were lack of food by the patients, limited support from the health institution both in logistics and counseling services. Other challenges included scanty supply of healthy kits and need for more training. **Conclusion:** The importance of home based care cannot be overemphasized in this era of the HIV/AIDS pandemic. Constant training and some stipends would motivate the care givers. Providing them with some staff support for monitoring and counseling would be idea, as everyone needs some encouragement from time to time.

KEY WORDS: HIV/AIDS, Home Based Care, Challenges

Introduction

Home based care is part of a larger form of health service called palliative care which uses a multidisciplinary approach to improve quality of life of patients with chronic illnesses like HIV/AIDS through prevention and relief of suffering [1]. This is achieved by assisting in performing various activities of daily living. Due to the types and amounts of work related to care giving, one needs to be in good health.

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The contribution made by home based caregivers takes a toll on their wellbeing as they may develop feelings of helplessness and frustrations when they do not meet the patients basic needs due to various challenges such as; lack of resources and poor working conditions [2]. As such, home based care giving is met with various physical, economic, cultural and psycho-social challenges which may ultimately affect the quality of care being delivered to patients and families [3]. Various studies in various countries have agreed that women and young girls are culturally the major contributors of care giving either as family care giver or as a volunteer care giver while multi tasking with various other duties [1, 4, 5, 6], as most men take the back bench as women get overwhelmed. This increases the burden of care on them leading to stress and work burn out [6, 7]. Many researchers have sited that stigma and discrimination against the PLWHA by family members and other community members has affected

and frustrated the works of care givers greatly, the discrimination tips most patients in depression and denial, affecting their response and compliance to medication [6,8, 9]. It has been seen also that as caregivers work and bond with some of these patients, when they see them suffer and even die, it takes a toll on their psychosocial health, it breaks them and therefore they need psychosocial counseling as often as they need it to help them cope with the grief and function well [10]. Having to care for a high load of patients and having heavy work load as it can be in some instances takes a toll on their physical health especially on the frail bodies of the elderly caregivers, walking long distances and caring for a lot of patients as well as having cared for patients for a long time are among other common challenges [11]. Most caregivers do not have formal jobs; therefore the economical challenge does not spare them as well as the patients they care for, whom they find without food most times making it hard for them to comply with medication taking on empty stomachs. They suffer financially because they are not paid and those that are given some form of payment, it's too minimal to sustain them [10, 12, 13, 14]. WHO has recommended formation of social support group sessions, having recreational breaks and rotation of care giver staff for a breather moment, so as to minimize on the burnouts [1]. Perhaps the main limitation to this recommendation as observed from various studies would be due to limited funds in running these programs, care givers are mostly few or usually stop because of none payments but also limited medical supplies like drugs, gloves and disinfectants.

Most researchers studying this subject have commonly used qualitative methods [2, 12, 13] and focus group discussions for data collection while sampling methods have been a mixture of random sampling [11, 15] and non-probability sampling [2, 16, 12]. Data analysis has ranged from descriptive statistics, regression analysis and Chi square analysis (16, 11). This study employed Quantitative methods with non probability sampling methods (convenience sampling methods). The researcher sort to find out if the volunteer care givers in Chifubu-Kawama faced similar challenges as seen from other studies as there is paucity of information regarding the challenges encountered by HBCGs for the PLWHA in Zambia and therefore make recommendation that are specific to these problems.

Methodology

Study design and study site

It was a quantitative cross sectional study carried out in Chifubu-Kawama area of Ndola. Quantitative research method is based on traditional scientific methods, which generates numerical data and usually seeks to

establish causal relationships between two or more variables, using statistical methods to test the strength and significance of the relationships [17]. Ndola town is the capital city of the Copperbelt province and has the second largest referral hospital in the country (Ndola Teaching Hospital). The Chifubu –Kawama community was chosen as it is one of its largest communities.

Sample size and sampling procedure and Research instrument

At the time of the study the Chifubu-Kawama home based care group had about 30 active voluntary care givers, therefore convenient sampling method was employed since the number was small. Convenient sampling method is a non probability and non random sampling method where members of the target population that meet certain criteria are included [11]. The members were over 50 plus but over time most of them have since stopped.

A structured questionnaire was used as the research instrument; this tool was used as most of them had gone up to secondary level of education and could read and write. For those that could not read and write the researcher and assistant interpreted and entered the responses on behalf of the caregiver. It had the profile section where the respondents' personal details such as age and gender were recorded. The other section contained questions on the logistical and psychosocial challenges. The tool was tested and adjusted accordingly after doing a pilot study of 9 caregivers in Chipulukusu community.

Data entry and analysis

The data was first entered in excel and then exported to SPSS software version 20.0 for further analysis. Descriptive statistics were used.

Ethical requirements

All the legal and ethical channels and protocols were observed. The researcher sort clearance from the Copperbelt University School of Medicine, the research ethics committee at Tropical Diseases Research Centre and also from the Ndola District Medical Office. The objectives of the study were thoroughly explained to the participants including its importance to them and the country at large. The participants were issued with consent forms that were signed by those who were willing to take part in the

research process. The researcher maintained dignity confidentiality and anonymity but also respondents were told they had the right to withdraw if they wished to at any point of the research and no incentives were to be given to them. Ethical issues on plagiarism, misconduct, falsification and data fabrication were totally observed.

Results

Socio-demographic characteristics

This section dealt with socio-demographic data of respondents. This data included information on respondents' ages, gender, marital status, level of education and employment status. From the findings the characteristics of the respondents in the study area were as follows. Of the 30 care givers interviewed, 66.7% were females while 33.3% were males. 43.3% were between the ages of 40-49 years, with 53.3% being married. 66.7% reported having attained a secondary school of education.

Table 1: showing socio-demographic characteristics

factor	number	percentage
Age		
20-29	5	16.7
30-39	4	13.3
40-49	13	43.3
>50+	8	26.7
Gender		
female	20	66.7
male	10	33.3
Marital status		
Single	8	26.7
Married	16	53.3
Widow	6	20.0
Level of education		
Secondary	20	66.7
Primary	9	30.0
Never been to school	1	3.3
occupation		
Part time	4	13.3
Self-employed	13	43.3
Unemployed	13	43.3

Logistical and psychosocial challenges

The summarized challenges into the following groups: logistical and psychosocial challenges. As shown in table 2. The main challenges were as shown

In terms of mode of transport used to travel to patients homes, 76.7% reported walking on foot while 23.3% reported the use of bicycles of which all these were Zone leaders, non reported the use of a vehicle in going to care for the patients. The study found that 60.0% took between 30 minutes and an hour walk to reach homes of patients, 33.3% took between 15-minutes to reach these homes while 3.3% was for those taking less than 15minutes and more than an hour to reach the patients homes. 86.7% of the respondents reported the distance walked to the patient's homes as challenging.

In terms of support from the government institution, 56.7% agreed to receiving some form of support while 43.3% reported no support. Staff support was at 17.6%, transport arrangements were at 6.7%, educational seminars and materials at 23.3%, while caregiver counseling provision services were at 37.5%. The availability of healthy kits was rated at 50% as yes while 43.3% reported that they only had them sometimes. About 86.2% reported to having some form of training, with basic facts about the HIV/AIDS topping the list at 92.3%, nutrition and hygiene was at 57.7%, precautions in caring for the patients giving was at 34.6% and the least was nursing and care training which was at 26.9%.

Table 2: showing logistical and psychological challenges

Challenges	Category	Subcategory
Logistical challenge	Transport and distance	Walking on foot Long distance
	Lack of health kits	Fear of contamination
	Lack of training support	Lack of skills and knowledge
Psychosocial challenges	Stress and burnout	Long time spent caring for patients
		Patients negative attitude towards counseling
		Patients negative attitude towards medications
		Lack of caregiver counseling services
		Lack of food by patients
	Stigma and discrimination	Family rejection of the patient with HIV/AIDS Community discrimination
	Unemployment/non payments	Care giver poverty

Table 3: showing the major challenges in frequency and percentage form

Challenge	Frequency	Percentage
Lack of food	25	83.3
Lack of payment	26	86.7
Stigma and discrimination	12	40
Family rejection	13	43.3
Stress and burnout	16	53.3
Inadequate training	25	83.3
Patients negative attitude towards medication	8	26.7
Patients negative attitude towards counseling	12	40
Failure of patients to easily access treatment	7	23.3

Discussion

Demographic findings

The findings of this study revealed that both males and females were part of the home based care giving program, this is a plus to the men in making an effort to be part of care giving, although the females were the majority at 66.6% as a common norm. The conclusion made from these facts is that women almost always in most cultures are taken to caring for the family and people around them. This finding is similar to what other researchers have found; in terms of women taking the leading role in home based caring [8, 18, 19]. Perhaps the males are much more involved in jobs that bring food to the table as most wives in communities are stay at home mothers, perhaps giving them a chance to spend time to care for people in the community but it could also just be that they leave it all up to the women. A Malawian study revealed that men traditionally left the care to women, similarly to an Indian study on care givers that found that women care givers cried for respite as men left it all up to them to

provide care even if they themselves as women are unwell [7, 20]. It was seen that the age range of most of the care givers was between 40 and 45 years old, leaving out the younger generation, perhaps because this work is voluntary. The youths would rather concentrate on what would bring them money to support themselves. However this was not the case in a study done in South Africa [8], which had more youthful caregivers. And the researcher concluded that it is a good thing that youths were much more involved as it would keep their minds off risk behaviour.

The study findings also showed that majority of caregivers (50.5%) were either self employed or unemployed. The self-employment perhaps are running small scale businesses of selling charcoal, sweets and vegetables around their yards, the addition of care giving to their schedule could affect their business or work leading to reduced productivity because of Less time to improve their business. Wringe et al [22] observed that caregiver's do suffer financial or income loss as they reduce their working hours so they can

care for the patients. Unemployment will be discussed later.

Logistical challenges

Transport and distance

As care givers move from home to home providing care, they cover miles and miles, before they could even reach and do specific chores depending on the needs of the patients. Walking especially for the older ladies as seen in this study who were the majority may be quite tiring and energy sapping, that by the time they reach their destination, they have no energy to work. Most of them in this study reported walking on foot as the common mode of transport, with only a few having access to bicycles as zone leaders. A high number of them (86.7%) reported being challenged by the distance they covered during these visits, provision of transport to most of them would be helpful with the movements to and fro the health centre to collect medications and delivering them to the patients, leaving them with some energy to interact meaningfully with the patient. Mohammed and Gikonyo [22] suggest that a calculated fund be allocated for transport assistance per client. A study by Ramuhahe & Erasmus [14] found that caregivers feared for themselves of being attacked along the way as they walked the long distances to some homes of clients.

Lack of health kits and training support

Health kits are a necessity in the home based care programme, they may include gloves and disinfectants among other things, they are important in infection control and keeping the caregivers feeling at ease. But in low income countries like Zambia health kits may be a jewel to have, 43.3% of respondents in this study reported to only having health kits sometimes, this could lead to a high rate of infections, putting the caregivers at risk. But also out of fear of being soiled, caregivers may avoid touching the patients, compromising the quality of care being provided. In a study in the rural North West province of South Africa the caregivers explained that lack of care-giving equipment such as surgical gloves, diapers, antiseptics and basic medication, which they had expected to be provided for by the government was not easily available making their work difficult [12]. Community care givers need constant training in their field. As seen from this study that none of the caregivers had tertiary education with about 66.7% gone up to secondary level while others with just primary school qualification. Therefore it would be difficult for some to grasp the medications and their schedules without thorough training from time to time. Qalenge [23] study found that most caregivers had low levels of education requiring continuous in service training, not just on

long intervals, to enable the caregivers though of low literacy levels to grasp the basic skills of writing or understanding the interpretation of doses of the medication for specific patients they care for. Cameroon et al [24] has recommended that community care givers be fully trained in home care, palliative care, infection control, psychosocial counselling and proper record keeping in order to improve their work outcome

Psychosocial challenges

Stress and burnout

A study done in Choma among home based care givers [25] found the levels of work related stress to be at 35.6% which compares well with this study, which found the stress levels to be at 56.3%. This could be speculated to be due to various reasons like family rejection and neglect, negative attitude of the patient towards the counsel and medication that is being provided among other reasons which could lead to work burnout. Kanye care givers in Botswana reported not receiving adequate psychosocial counselling to help them cope with the stress of care giving as such this was contributing to the poor quality of care those care givers delivered [26]. Much more of the frustration for the Chifubu-Kawama care givers would be coming from them seeing that patients are not improving despite their dedication in the care, for reasons such as lack of food by patients which was highly reported at 83.3% in this study. Patients Lack of food leads to difficulties in adherence to the medication, because of the side effects of these drugs leading to poor quality of healthy and even death [22]. Castleman et al [27] in his assessment of Food nutrition implications of antiretroviral therapy in resource limited settings concluded that care givers will find it nearly impossible to convince patients to comply with their medication on empty stomachs.

The support from the health institution was not adequate as seen that 43.3% reported not receiving support from the health institution. This means the quality of care by these care givers may be compromised at so many levels as the monitoring process is inadequate for these caregivers. they need trained personnel, nurse, doctor etc, to monitor them, every so often, providing them with educational seminars and provide them with counselling, in times that they feel so discouraged or overwhelmed with their duties. In Malawi Dippenaar [13] identified support from health professionals as the greatest need for lay care givers of patients living with HIV/AIDS in Lilongwe. In a similar study by Kang'ethe [15] in Botswana, 85% of the caregivers expressed disappointment in terms of lack of support and counselling by health personnel.

Sigma and discrimination

Stigma and discrimination that patients living with HIV face can be from family members but also the members of the community, when patients are discriminated, they tend to withdraw and go into depression, they will lack they drive to go on living and not take their medication, therefore not improving and making the work of caregivers difficult, meaning more visits and chores to do on behalf of patients that cannot care for themselves even in basic toilet use. Mohammed and Gikonyo [22] found that sometimes family members may not want to assist the PLWHA and therefore it becomes the sole task of the voluntary care givers to care for the PLWHA. Therefore they end up spending a majority of the time carrying out house chores and less counselling for patients.

Unemployment, poverty and lack of payment

Most care givers are from a low social economic status, with most of them unemployed as seen in this study that 43.3% were unemployed and with no form of business or income while 86.7% pointed out that they were not paid anything as caregivers and 13.3% agreeing to receive some remuneration just during specific programs. Going to work as a voluntary care giver with the work they have to do and distance covered on empty stomachs cannot be any easy while worrying about what the children left home will feed on. Caregivers are known to experience poverty, social isolation, stigma, psychological distress, and lack basic care giving education [13]. Qalinge [23] in her study in south Africa found that 88% of the voluntary care givers had no source of income, but wallowing in poverty, I suppose even the care giving is simply an act of humanity on their part. This degree of poverty can be discouraging and frustrating

Conclusion and recommendations

The importance of home based care cannot be overemphasized in this era of the HIV/AIDS pandemic. It buffers the government in a great way but also allowing the patients to be nursed in the comfort of their own homes. However to run this programme effectively, it should be improved from time to time, including looking into the plight of the care givers who are the driving force of this programme. Therefore the Zambian government should develop policies to deliberately identify difficulties and challenges faced by home based care givers, as they are key stakeholders providing alternative health care at home reducing the burden of care on health care facilities. Constant training will equip the caregivers more on what they need to do and improve their skills and some remuneration would motivate them and alleviate the poverty in their own homes which is a constant struggle. Health personnel should constantly monitor

the work of care givers and constantly provide them with counseling services. Providing some staff support for monitoring and counseling would be idea, as everyone needs some encouragement from time to time. In light of the findings, it has been recommended that community support groups be put in place for caregivers to share experiences and draw strength from one another and for professional health care providers to provide constant oversight and counsel of the caregivers to improve on the caregivers abilities which will ultimately improve the lives of the patients they are looking after. The home group could be provided with land and seeds to plant nutritious local foods, reserve some for food and sale some, the income could help both patient and carer or a business of running a hammer mill and the proceedings benefit the community. This may attract even more volunteers. They could even buy bicycles from the profits, to reduce on the long distance walks. A large scale research with different methods should be done for further understanding and evaluation of these challenges

Limitations

The sample size was small therefore generalization of these findings may not be accurate or a good representative of the population. The other problem or limitation could be that, the caregivers would have been untruth on some things as they were not watched working in action.

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