

CHALLENGES EXPERIENCED WHILE PROVIDING HOME BASED CARE: A COMMUNITY ORGANISATION'S EXPERIENCE

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Abstract

Introduction: The large and ever-growing number of people being infected with HIV/AIDS, led to health professionals being unable to cope with these increasing numbers. To combat this challenge, an alternative strategy such as home based care needed to be implemented. When attempting to attend to this need, a deeper understanding of the challenges facing community organizations when providing home based care is necessary in order to formulate these effective and relevant care services. The aim of the study was to explore the challenges faced by Umtha Welanga Community Organization in the provision of HIV/AIDS home based care.

Methods: A case study using a qualitative approach with in-depth interviews as the data collection method was used. The Umtha Welanga Community Organization constituted the total population therefore no sampling was applied. All the members of the management team and all the home-based caregivers were interviewed. Informed consent as well as consent for recording interview was obtained prior to data collection. Respondents were informed that participation is voluntary and that they can withdraw at any time. Data analysis began immediately after completion of all the interviews by transcribing and translating the audio-taped data. Thematic analysis was used in which data was coded and categorized.

Results: The main areas of concern were gender inequality, insufficient funding, lack of disclosure and trust, risk faced by caregivers and lack of recognition

Conclusion: Finances appear to be, both for the organization and the home based carers, a specifically influential obstacle in the implementation and maintenance of the services. Lack of recognition by the government and lack of trust and disclosure towards care workers; create difficult conditions for them to perform their tasks and duties. Care services also present risks and dangers to caregivers such as being susceptible to criminal activity, feeling unsafe and vulnerable.

Keywords: Challenges, Community organization, Home based care, HIV/AIDS.

Introduction

An overwhelming number of people infected with HIV/AIDS forced programmers and policy makers to consider shifting their focus of clinical care from only health services, to the community where patients are cared for with dignity by their own families and friends (Ogden, Esiman & Grown, 2004). Limited health care services highlighted the need for services rendered by home based caregivers (mostly family members & friends) (Campell, Nair, Maimane & Sibiyi, 2008). These included a shortage of hospital beds, inadequate numbers of

medical, nursing and allied health professionals in the public sector. Ankitola (2004) highlighted other factors such as a lack of resources for treatment and drugs, the often high cost of institutional care, crowded hospitals which are often unsuitable for managing patients with terminal or long term disease.

The involvement of community based, non-governmental and faith-based organizations has been promoted as a cost-effective strategy that can rapidly expand HIV care services (USAID, 2002).

Home Based Care (HBC) is viewed as a solution for caring and supporting people with HIV/AIDS and affected families (Sadler, Bahwere, Guerrero & Collins, 2005). It furthermore provides a supportive, familiar environment of home setting for care, and appears to be a cost effective option that enables the stabilization of individuals with chronic conditions (National Association for Home Care and Hospice, 2006).

The advantages of home based care are influenced by its relationship with the services offered by others, such as the government. In efforts to balance the delivery of services, and to reduce the amount of strain placed on either service provider, the aim of Community Based Organizations (CBO) is not to replace the work performed by the public health sector, but rather to support and working closely with the public sector so that the efforts of both parties are reinforced (UNAIDS, 2005). The resources, skills, time and energy of both government and community organizations, are required to meet the total requirements and challenges of home based care. The advantage of a mutually beneficial relationship between the private and public sectors is that effective and cheaper home based care can relieve the burden on hospitals and have additional social benefits for the clients and their families (Nsutebi, Walley, Mataka & Simon, 2001).

Supplementing the above reasoning of a mutually beneficial relationship, community/home based care and support should not be used as a replacement to the care and support provided by the formal health sectors, but should be viewed as one element in a co-coordinated and integrated continuum of care (Russell & Schneider, 2000). In a similar vein, community based organizations should not be expected to shoulder the majority or full responsibility for what is really an obligation of the state. CBO's must aim to develop partnerships with the government, private sector, schools, communities, families and individuals to ensure effective service delivery in the fight against HIV (UNAIDS, 2009). In addition, home-based care programs for resource-poor settings play a significant role in providing access to comprehensive palliative and supportive care for a large proportion of individuals and families affected by the HIV disease (US: Department of Health and Human Services, 2006). When communities are involved in

the role of HBC, the more likely they will have a sense of ownership and responsibility (UNICEF, 2004).

It has been argued that in Southern Africa, home based care for HIV/AIDS clients is being promoted as a cheaper substitute to hospital care by the policy makers (Ankitola, 2008). The author further argued in contrast that cheaper forms of care can only be drawn by assessing all of costs, benefits and utility derived by all stakeholders in home based care. With respect to this, an important asset of the CBO is the volunteers who willingly offer their time and energy to care for the families that are infected and affected by HIV/AIDS. Focusing on the case of the Umtha Welanga Community Organisation (UWCO), this article seeks to reports on the challenges as experienced by this organisation.

Methodology

Research design

A qualitative approach using a case study design, with the Umtha Welanga Community Organization (UWCO) as constituting the case, was used.

Population and sampling

The population in this study consisted of all the employees of the UWCO.

Data collection methods and procedure:

In-depth interviews through an unstructured interview schedule were conducted with both management and home based care workers. Observation and field notes were administered during the data collection. An audio-recorder was used to capture the interview sessions. Data was collected at the UWCO office in Masiphulisan Centre in Khayelitsha. An appointment, for the interview, was scheduled with the employees of UWCO as well as the home based carers. All the interviews were conducted after informed consent was obtained from the interviewees. The interviews lasted between 40 to 60 minutes. Permission to audio-record the interview was requested and obtained from the participants before entry.

Data Analysis

Data analysis started with the transcription of the information from the audio taped recordings. The interviews were transcribed immediately after completion of data collection. Thematic analysis was

employed to analyze or make sense of the data gathered. The transcripts were read thoroughly several times, broader categories were sorted into clusters and categories and from this, the themes emerged and relationships between them could be identified (Braun & Clarke, 2006).

Findings and Discussion

Demographic information

All employed caregivers were all black females living in the township of Khayelitsha. The participants' home language was reported as IsiXhosa. Their age ranged between 20 and 40 years. Fifty percent of the respondents were married and all have completed Grade 12. Christianity was the dominant religion practiced. The themes identified were education and training as provided by UWCO, finances, support systems and the benefit of care giving services.

The themes derived from the challenges experienced were gender equality, finances, voluntary service, overwhelming and demanding experience, risks faced by caregivers and lack of recognition.

Finances/funding

UWCO's greatest challenge, acknowledged by management, is the lack of funding which makes the operation of and the provision of services by the organization difficult. The organization experienced in particular negative responses with funding applications. They continuously and consistently apply for funding to different institutions and in most cases are turned down. The coordinator reiterated this challenge:

“Actually, finance is the greatest challenge that we experience. Actually it is the biggest challenge to any organization, and those who can say we don't have the challenge I can say they are very lucky. But you have got to work very hard on that one. We keep on applying almost all the time, some gives us regrets. The solution is to keep on knocking until someone opens the door”

It has been reported that the stability of finances in a community home based care organization is very critical in creating a secure work environment for staff, most of who have families and other

commitments (UNAIDS, 2008). Home based care is time and resource consuming and has difficulties such as travel costs and travel time (Campell & Foulis, 2004). Lack of funding jeopardizes the sustainability of community organizations, thus leading to a dependence on volunteer caregivers (Browning, 2008).

In addition to the organization having problems with funding the workers also indicated that they were not being paid enough. The majority of caregivers involved are largely women, and poverty and a high rate of unemployment were found to be the driving force behind women's involvement in home based care. Caregivers expressed dissatisfaction regarding the kind of payment offered and complained that it is insufficient to meet their basic needs. However, most of the care workers felt that if offered better salaries elsewhere, they would resign from their current position within the CBO:

“The most challenging issue is only money or the salary. The salary is not sufficient to meet our basic needs but can only help you to survive” (Home Carer 2)

“There is no money in this kind of job. Otherwise, I console myself by saying that things will become better one day. The other reason is that you have volunteered by yourself to offer care services without anyone forces you. Finance is a big problem when you are doing this kind of job.” (Home Carer 5)

Furthermore, it is also revealed that some organizations have fears that they can lose their staff for better employment opportunities (Kang'ethe, 2009). Besides committed and well trained volunteers, CBHC organizations also require effective support systems to provide adequate care to its clients and their families (UNAIDS, 2008). If home based care programs are to be sustainable in playing a vital role of caring and support of people with AIDS, proper remuneration arrangements and support structures must be put in place (Campell et al, 2008).

Gender inequality

Gender imbalance in people providing home base care services is reflected by the all-female component of home based carers of the UWCO

organization, with two males involved in managerial positions. The coordinator confirmed this statistic:

“Actually, most of our staff operating in this organization is female. The same with the client, it is the females who normally disclosed their status. We do have few men who are helping. You find that they are two or three. We have just started a program called gender health specifically focusing on the father to do HIV awareness campaign.

We do door to door visit to ensure that men are involved in great numbers because the HIV/AIDS does not only concern women but affect us all regardless of whether you are male or female”. (Coordinator)

Traditional gender norms result in more women and girls providing care and it also creates social barriers to men and boys becoming caregivers (UNAIDS, 2008). It has been demonstrated that the work of caring for people who have HIV/AIDS is primarily the responsibility of women and girls (Ogden et al, 2004) who spend active days and nights providing care to ill relatives, coupled with their general domestic chores (Opiyo, Yamaano & Jayne, 2008). Home based carers execute complex roles in adverse conditions (Campel & Foulis, 2004) and face challenges such as burn out and impoverishment, vulnerability to diseases and emotional and physical burden (Ogden et al, 2004). Furthermore, issues such as poor supervision, lack of appropriate incentives, and an unsupportive environment (Schneider, Hlope & van Rensburg, 2008) as well as poverty, social and cultural issues, inadequate health knowledge, lack of palliative services, transportation problems and feminization of the care giving have been challenges facing home based care (Odek & Odoo, 2007).

Overwhelming and demanding experience

The tasks and actions performed by care workers are found by them to be both physically and emotionally demanding, and for many it becomes an overwhelming profession. Some families that are being cared for live in extreme poverty. Home based care workers do not only suffer maltreatment and distress from the clients and family members, clients sometimes also refuse to disclose their status and insist that they are not sick due to lack of trust.

“The most worrying thing is that when you visit

people in their houses, you find that living conditions are very poor. This is one of the most troubling experiences you face”. (Home Carer 3)

Caregivers are subsequently confronted with psychological and emotional challenges from both the client and family (Ankitola, 2008). Feelings of guilt and self blame are experienced by caregivers due to the overwhelming experiences they encountered.

“It is challenging out there in the community because you work with different people. The emotional experience that I once experience was after I have tried to help the client by washing him, the next thing he died. Emotionally, I was disturbed and started to feel guilty, for I did not understand how that person can pass away after washing him”. (Home Carer 4)

Caregivers experienced feelings of emotional drain, being stressed, exhausted and overwhelmed (Dangeid, Sedumedi & Duckert, 2009). Home care is a process which has its ups and downs brought about by the condition of the patient and his/her functional level and it calls for the total dedication on these responsibilities (Ndaba-Mbata & Seloilwe, 2001).

On occasion, the case family is not welcoming toward the caregiver and they are even insulted by frustrated household members. At times clients also refuse to be assisted by care workers whom they are not familiar with. Evidence of this kind of behavior was documented by a caregiver through the following quote:

“The client will refuse to be helped because the one she knows didn't come. She will tell you that I will only bath when that one comes. So it is a challenge really. You really need to be down until the client agrees. They will take advantage of us because they think we get paid for such services. We are only there to assist”. Sometimes you are not welcomed and they will ask you many questions such: Who said we have got a sick person in this house? Who said we need your help? They can also close the door to show that you are not

welcome". (Home Carer 5)

Lack of disclosure and trust

Lack of disclosure and trust from the family and clients toward the care workers, creates difficult conditions for them to perform their tasks and duties. Without being granted the permission or given the consent to perform care duties, care workers are unable to operate. The following quote demonstrates this:

"Otherwise most of them don't disclose their status, and you can only get the \ information next door. Still you need to wait until they disclose and allow him/her for the permission to do home care. Other instance the client will be in denial. This is not easy at all. (Home Carer 5)

Openness and disclosure creates a significantly more comfortable atmosphere, and make work easier for the care workers. The appropriate disclosure of one's HIV status results in a sense of empowerment and leads to a decrease in stress (Tufts, Wessell & Kearney, 2010).

Risks faced by caregivers

It is mentioned that they feel unsafe, vulnerable and exposed to rape by the male clients who are staying without family members. Furthermore, care services present many risks and dangers to home based caregivers of UWCO who are females and had to conduct home visits mostly unaccompanied. Sexual harassment can be directed to both male and female; however, women are the most targeted. A home carer states her experiences regarding this risk:

"There was one time when I visited the male client who was living on his own without family members or friends around. I was afraid of being raped". (Home Carer 3)

Preventive measure can be used such as sending two home based caregivers for a home visit instead of one caregiver to minimize the possibility of a woman becoming a target opportunity of rape and robbery, since the offender usually waits until the potential victim is vulnerable or isolated (UNAIDS, 2008).

Another participant also highlighted that it is not safe

to walk in the location alone because there is a high rate of unemployment in the location which results in a high rate of crime and violence.

"When we are doing visits, it is very risky sometime, because you are visiting the person for the first time and it is very risky and dangerous to ask people because of the crime rate around the location. The other thing is that it is not safe to walk around the location". (Home Carer 2)

The distance travelled by foot can be far and isolated without public transport. Caregivers sometimes even get lost while on their way to visit a client since they are afraid to ask people on the street for directions. As a result, caregivers become vulnerable to the crime in the location and their safety is therefore compromised. The following comment was voiced:

"I think with home visit we do experience lots of challenges. We are in great risk because sometimes you don't know the address to that particular home. You will travel long distance asking people of the direction, trying to find the location. We even get lost sometimes and it is very dangerous because in the location it is not very safe, there is high rate of crime. Some places are very far and isolated" (Home Carer 5)

Home care workers are faced with considerable and huge tasks related to health and safety risks (UNAIDS, 2000). Care work is performed under threatening conditions and care workers are exposed to infections. The caregivers can contract HIV/AIDS while on duty if not properly covered and protected by gloves and therefore compromise their own safety and security for the sake of their clients; however, the organization ensures that they are using protective measures such as gloves and masks when performing client care. Health risks are created when caregivers come into close contact with client faeces, vomit and other bodily fluids and tuberculosis infection (UNAIDS, 2000).

Lack of recognition

The caregivers' principal concerns stem from a lack of recognition which is a prerequisite for the acknowledgement of another human being of one's

emotions, knowledge or skills, all founding competencies in health and care work (Liveng, 2010). It is the service which is undervalued and they experience exploitation without normal rights or benefits such as leave, maternity benefits and a pension by healthcare authorities and communities (Schneider et al, 2008). The following citation supports the above comment:

“My concern is that the government should start to recognize the services of home care seriously by ensuring that we are registered, recognized and paid well because this task drains a lot of energy”.(Home Carer 2)

The roles and responsibilities assumed by caregivers are clearly unrecognized and undervalued (Pallangyo & Mayers, 2009). Ogden, et al (2004) supported that the home based care work is the kind of service usually taken for granted and undermined by the government and the NGO's because it is usually viewed as the activity or role to be performed by women to sustain their families, communities and nations. Therefore, when care work remains invisible to the society, even the care workers are taken for granted. Caregivers, whether doing formal or informal care work need to be acknowledged as part of the health care system to the response of epidemic requiring financial, medical and social support (UNAIDS, 2000).

Conclusion

The study concluded that there is gender imbalance in UWCO as the organization is predominantly constituted by women. The greatest challenge that the organization experience was the lack of sufficient funding for the smooth running of the operation and provision of services.

However, a lack of proper recognition and appropriate remuneration by the state exist. Lack of disclosure and trust from the family and clients toward the care workers, creates difficult conditions to perform their tasks and duties. Caregivers experienced negative treatment by clients and family members. Their safety and security is compromised as they are susceptible to contracting HIV/AIDS while on duty if not properly covered and protected by gloves, criminal activity and robbery and being raped, feeling unsafe and are vulnerable to gangsters in the community. This study highlights

however, that the role of home based caregiver's will continue to be essential to the care of PLWHA in South Africa.

Recommendations

Following the afore-mentioned challenges experienced by home based carers, it is recommended that:

- The government should acknowledge care as a priority human need, encourage a gendered approach and ensure that home based care workers get recognition, credit and support for their valuable contribution, through various channels that address the issues surrounding the sustainability of such a profession.
- A system of registration and specific quality control measures are to be implemented in an effort to ensure both a sense of job security and better management of home based care schemes.

The security, safety, and subsequently too moral and, if needs be, financial support of volunteers should be properly facilitated, to ensure a sustainable volunteer culture in home based care.

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