

CHALLENGES AND OPPORTUNITIES IN HOME BASED CARE AND TRAINING IN RESOURCE LIMITED SETTINGS

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ABSTRACT

This study sought to investigate the challenges and opportunities in home based care and training at Phuthanang Home Based Care in the Limpopo Province of South Africa. South Africa is a country with one of the highest HIV prevalence rates in the world. It is against this backdrop that home based care has become a national priority. The study was entirely qualitative. The case was selected because of its emphasis on training apart from offering home based care services and also its location in a poor township, Mankweng outside Polokwane. Data was collected from using open ended interviews, focus group discussion, observations and document review and was analysed using a data matrix. The major findings from the study were that, though Phuthanang Home Based Care is contributing fairly well in providing home based care; it faces several challenges in its operations these include lack of funds, stigmatisation of caregivers, poor collaboration and the burden on women caregivers. The research found out that Phuthanang Home Based Care offers training to its members, patients and also to the community. It was observed that training offered covers both theoretical and practical issues ranging from counselling, hygiene, and adherence to medicine to sewing, baking and market gardening; however there is emphasis on theory. The study concludes that Phuthanang Home Based Care faces challenges in offering home based care and training; however there are opportunities for improvements in service provision. The study recommends that there is need for more skills training sessions on the practical issues in home based care and fund raising. Stigmatisation of caregivers can be reduced if caregivers participate in information dissemination on HIV and AIDS using role play, drama and poetry within the community.

Keywords: Human Immunodeficiency Virus, Acquired Immunodeficiency Syndrome, Home based Care, Caregivers, training

INTRODUCTION

Home based care has become the alternative of choice in the wake of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS), this is especially the case in Sub Saharan Africa, the region with the highest prevalence rates in the world (Poku, 2005; World Health Organisation, 2005; UNAIDS 2008). Within Sub Saharan Africa; South Africa is the hardest hit country (Statistics South Africa, 2007). Owing to HIV and AIDS on the continent many countries across Africa are now witnessing reduced life expectancies, crumbling and over burdened health systems and fragmented socio-cultural coping networks. According to UNAIDS (2008) tuberculosis remains the most common opportunistic infection for people living with HIV, including those on antiretroviral therapy and a leading cause of death for people living in low income countries. HIV and TB have become co-epidemics in Sub Saharan Africa and in August 2005 the World Health Organisation (WHO) declared the TB epidemic in Africa to be a regional emergency. According to WHO (2005) the annual incidence of TB has risen two to three times in Sub

Saharan Africa since 1990 in line with the increase in HIV infections. The high rates of HIV and AIDS and other communicable diseases increases pressure on health resources; and health budgets are getting smaller.

The study was carried out to explore the challenges and opportunities that arise in the provision of home based care and training in the Limpopo Province of South Africa. Limpopo Province (previously known as the Northern Province until 2002) constitutes about 13 percent of South Africa's population. This Province is the fifth largest province in South Africa with a population of more than five million, of which 96% are blacks. Limpopo Province is one of the nine new South African provinces that replaced the previous four divisions and ten home lands after the first '1994' democratic elections. Limpopo Province is a result of a merger of three former homelands namely Lebowa, Gazankulu, and Venda after the demise of apartheid in 1994. This Province is bordered by three African countries namely Botswana, Mozambique and Zimbabwe (Statistics South Africa 2002; Mabasa 2002; Modiba and Zeleen 2004). The province contributes only four percent of the country's gross domestic product. Informal and personal services are the main employment outlets. Other indicators such as those related to life expectancy, unemployment, literacy, water and energy consumption fall far short of overall national average, especially for black households (Human Sciences Research Council; 2006).

The arguments for home based care are powerful. Hospitals in many countries are simply not coping with the increasing numbers of people in need of their services. Russell and Schneider (2000) argue that in most poor African countries the welfare system is often overstretched and it is common practice for health care facilities to limit services to people living with HIV AND AIDS. Most of the burden of care now falls on households and communities; this is also true for South Africa where home based care has become a national priority. In Lesotho, home based care was adopted to avert the ever increasing need for hospitalization of patients with AIDS related diseases. Continuity of care for patients and support for affected families were identified as the pillars of this strategy (Ministry of Health and Social Welfare and World Health Organisation 2002). According to (Akintola, 2004) in most countries in East, Central and Southern Africa, for example, over 50% of hospital beds are currently occupied by people with HIV and AIDS. In Zambia, over half of hospital patients and 70% of hospital patients with tuberculosis are HIV positive and the situation is getting much worse. Zambia expects a 15% annual increase in demand for hospital beds for people living with HIV and AIDS, while the actual number of beds available is expected to remain constant.

World Health Organisation (WHO, 2000) contends that between 70% and 90% of illness care takes place within the home. Research evidence demonstrates that most people would rather be cared for at home and that effective home care improves the quality of life for ill people and their family caregivers (WHO, 2000). Home Based Care (HBC) is one of the best ways for most people to receive quality care. According to Russell and Schneider (2000) home based care has become a national policy priority in South Africa as it helps those infected and affected with HIV and AIDS cope better with the pandemic. Most importantly, it makes a significant contribution to relieving the burden of care resulting from HIV and AIDS on the health sector. South Africa in 2001 developed a national home based care strategy which resulted in the introduction of guidelines to operate home based care programmes. According to the Department of Health (DoH, 2001) due to the HIV and AIDS epidemic, the increase in non communicable diseases and the complications thereof, it is necessary to plan how to care for people with disease and their families. The DoH (2001) argues that South Africa has limited health care resources, and situations arise where even if hospital or other institutional

care may be the best response to an individual's condition, it may not be available to him or her.

THEORETICAL FRAMEWORK

This study is grounded in constructivist theory and adult learning theory. Constructivism is a theory describing how learning happens, where learners use their experiences to understand a learning situation. The theory of constructivism suggests that learners construct knowledge out of their experiences. However, constructivism is often associated with pedagogic approaches that promote [active learning](#), or learning by doing. According to the constructivist approach, instructors have to adapt to the role of facilitators and not teachers (Bauersfeld, 1995). Gallagher (2006) notes that the HIV epidemic has reinforced to us that adult learning theory, interactive learning methods and active participation of people living with HIV and AIDS are important strategies for overcoming barriers to HIV education. Adult learning theory according to Knowles (1973) uncovered three important principles about adult learners: firstly, adults perceive themselves to be self directing in all areas of their lives, including their decisions about what they want to learn; secondly, adults have rich life experiences which they bring to the learning situation and finally they are pragmatic learners who learn to solve immediate problems.

SOURCES AND GENERATION OF DATA

In this study the case study design was chosen. A case study is an ideal design for understanding and interpreting phenomena for it retains the holistic and meaningful characteristics of real life events. (Descombe 2003, Cresswell, 1994) A case study design is employed to gain an in-depth understanding of the situation and meanings for those involved. The interest is in process rather than outcomes, in context rather than a specific variable, in discovery rather than confirmation; insights gained from case studies can directly influence policy, practice and future research (Merriam, 1998:19).

The use of multiple data collection methods is critical in attempting to obtain an in-depth understanding of the phenomena under study. This strategy adds rigor, breadth, and depth to the study and provides corroborative evidence of the data obtained (Denzin & Lincoln, 2000; Cresswell, 1994). This is especially critical in case studies. The researcher reviewed documents, carried out observations, open ended interviews and facilitated a focus group discussion for collecting data.

Written documents available at Phuthanang Home Based Care were accessed during field visits. Some of the documents the researcher intended to review include registers and proposals. One of the advantages of using written documents is that they have a broad coverage of events. The researcher did not manage to get all the documents he had hoped to review such as financial statements and minutes from their meetings this was because the organisation still has to start compiling such statements. Yin (1994) notes that documents can be used to corroborate and augment evidence from other sources. The data obtained from document analyses was used to augment the data obtained from fieldwork. Open ended interviews were done with the Project Coordinator, the Administrator and eight caregivers.

DATA ANALYSIS

After all the phases of data collection had been done; there was a mass of raw data that the researcher had to group and reduces into meaningful workable data. Firstly since the interviews were recorded on paper the researcher had to identify the categories of responses so that coming up with a data matrix would be easier. Miles and Huberman (1994) note that

when you are working with text or less organised displays, you often note recurring patterns and themes, which pull together many pieces of data. The methodology used in this research offered an opportunity to analyse the dynamics of the home based care programme in their holistic nature. The research questions were formulated to investigate a chosen focus in all its complexity in order to understand and derive meaning based on the experiences of the respondents as recommended by (Miles and Huberman, 1994).

Since this study was a single case study, the analysis of data took the form of making a matrix of categories and placing the evidence within such categories. A data matrix interlaces each respondent with each variable to produce a cell containing the appropriate value. According to Kent (2001) the columns in a data matrix are identified with the variables that are being measured and coded one column for each variable. The ultimate goal is to treat evidence as fairly as possible in order to produce compelling analytic conclusions and to rule out alternative interpretations (Yin, 1994). Responses collected from the interviewees were categorised under major themes and a data matrix was used for the analysis. The data from interviews, observations and documents were organised into major themes and categories through content analysis.

COMMENTS, CONCLUSIONS AND RECOMMENDATIONS

Data obtained from interviews and focus group interview revealed that Phuthanang Home Based Care offers a number of services and training programmes related to the provision of home based care in Mankweng Township. Caregivers at Phuthanang Home Based Care are not passive recipients of training; they are also community trainers in their own right. Findings from the interviews and document analysis revealed that Phuthanang Home Based Care helps many patients and community members within the Mankweng area. According to their patient register there were 85 patients serviced by the organisation at the time of data collection for this research; however these numbers constantly change as people move to and from the Mankweng area. Of the 85 patients 55 are women while 30 are men. The age range of patients in the home based care programme is from four to 75. Although training is available to patients of all ages, it is mostly the middle aged (adults) who usually participate; in line with the principle of adult learning that adults are motivated to learn relevant things which they can apply immediately to improve their life situations (Knowles, Holton &Swanson, 1998).

Findings from this study have confirmed previous findings on the disproportionate burden between men and women in terms of caring for the sick. According to UNAIDS (2003) there are a number of studies showing that HIV and AIDS underscores and exacerbates the unequal division of labour within households. This argument was also established by Ogden and Esim (2003) who contend that about 90% of AIDS care takes place in the home and women bear a disproportionate burden of those responsibilities. The researcher made the following conclusions and recommendations:

1. It can be concluded that caregivers' lack of practical skills required to provide effective home based care. There is also a lack of training in Ancillary Home Based Care, HIV and AIDS/Management and Voluntary Counseling and Testing. I recommend that more practical skills for all caregivers and their patients be offered by Phuthanang Home Based Care. Training packages must be developed for caregivers so that they increase their knowledge about how to deliver AIDS care in the most effective ways. Training in treatment literacy should be a compulsory component of Home Based Care training.

2. The Department of Health is the only source of funding for Phuthanang Home Based Care as a result the organisation has limited finance therefore cannot offer its services adequately. From the findings it can also be concluded that caregivers do not know how to fundraise for their project. Since Phuthanang Home Based Care has limited funds I recommend that they establish income generating activities, particularly those that generate resources such as chicken rearing and making herbal remedies. Caregivers can also participate through asking for donations (from companies etc) running a small business (*spaza*, selling services, selling products, sewing).
3. Collaboration is crucial in the success of Phuthanang Home Based Care. Currently there is no meaningful collaboration as a result of poor communication that exists between the organisation and its intended partners. There is need to establish, expand and manage strategic partnerships with other sectors in the community in order to enhance the integration of its services. Phuthanang Home Based Care needs to participate more in workshops that deal with home based care so as to meet and exchange ideas with projects doing similar work.
4. Stigmatisation is still a challenge in offering care for sick people at Phuthanang Home Based Care. It has been highlighted that still some people are reluctant to offer services as caregivers because of fear of being labeled as HIV positive in the community. I recommend that in order to reduce stigma in the community around Phuthanang Home Based Care there is need for information dissemination; factual and accurate information about HIV and AIDS through use of drama, poetry and role plays. Caregivers at Phuthanang Home Based Care must promote social openness about HIV and AIDS in the community as a way to combat HIV-related stigma and discrimination.

NB: The findings, conclusions and recommendations made in this research though they are an important pointer to the challenges faced by home based care organisations in resource limited settings; they are in no way exhaustive. With that in mind there is therefore a need for further studies by other researchers in the area of home based care and training; for example on the plight of old caregivers (grandmothers and grandfathers who are often left to care for the terminally ill members of the community in the era of HIV and AIDS.

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