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Exploring the Desires of HIV and AIDS Patients, Family Members and the Caregivers Associated with Zimbabwe's Community Home-Based Care Programs

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ABSTRACT This paper explores the desires of HIV and AIDS patients, their family members and caregivers associated with the Zimbabwe Community Home-Based Care Programs (CHBC). The study was explorative and descriptive in nature and it used a quantitative and qualitative design. The sample comprised of 100 HIV and AIDS patients, 50 primary caregivers and 10 secondary caregivers. Questionnaires and in depth interviews were used for data collection. The study found out that the desires of HIV and AIDS patients, family members and caregivers included the need for food, transport, treatment vouchers and other essentials. Also of high desirability were CHBC kits among primary caregivers and secondary caregivers, up to date knowledge or information about HIV and AIDS and various sustainability projects. It is recommended that the government and NGOs raise funds in order to provide the beneficiaries of CHBC programs with enough resources so as to improve their conditions and well-being.

INTRODUCTION

Zimbabwe is one of the African countries that has been heavily hit by the pandemic and it was the first country to reduce the spread of the pandemic. The devastating impacts of HIV and AIDS in the world have affected the people to a great extent, which steered the formation of community home-based care programs (CHBC). This was as a result of lack of funds and resources that have led to a failure in containing and supplying the special needs of millions of patients, resulting in the adoption of CHBC. CHBC programs have become a mitigating tool in extenuating the effects of HIV and AIDS, reducing the patients' suffering and pain so that they can have a better social functioning.

HIV and AIDS have become the most serious problem in public health internationally, and there is no continent that has not been affected with it. Many people have died because of its effects, and the number of orphans, widows and widowers has increased as well. However, with increasingly vigorous intervention programs being implemented, and more countries recording declines in HIV prevalence, including, Zimbabwe (UNAIDS 2008), the use of a standard and scientifically focused procedure for establishing the evidence for behavior change affecting the course of the epidemic should be of substantial value in the evaluation of the HIV prevention interventions (Hallett 2009). HIV and AIDS patients, primary caregivers and secondary caregivers are the most important people under CHBC programs because they are the benefactors of the program who need all the support and help.

Maslow's hierarchy reveals the behavior of humans in relation to basic provisions for subsistence and development and these supplies, or essentials, are organized conferring to their prominence for existence and their influence to encourage the individual. According to the National Guideline (2002), families and caregivers have their own needs also in order to help out the patients, these include physical, psychological and social/spiritual needs and they are essential to uphold family unity and well-being.

When patients are referred home to receive CHBC services without adequate assessment of their domestic environment, caregivers often find themselves struggling to accommodate patients in a home lacking adequate shelter, food, safe water, proper sanitation, and clothing (Phorano et al 2005; Shaibu 2006). Hence, every person needs all the above necessities in order to have a better life. HIV and AIDS patients, primary caregivers and secondary caregivers' needs should be met in order for patients to recover well and live a meaningful life like any other people in the world. If these needs are not met HIV and AIDS patients may die and their ill

health may deteriorate further, and the families of the patients and the secondary caregivers can be stressed as a result.

Objectives of the Study

- To identify the desires of HIV and AIDS patients, family members and the caregivers under CHBC programs.
- To investigate the challenges faced by HIV and AIDS clients, their family members and caregivers.

RESEARCH METHODOLOGY

Research Design

A research needs a plan or strategy. According to Creswell (2009), a research design is a strategy and method for a research area, the verdict commencing a comprehensive statement of in-depth procedures of data collection and analysis. The research design has provided a plan that may have stipulated how the research was performed in a way that permits the research questions to be responded to. The study used the mixed method, that is, the use of both qualitative and quantitative methods. Triangulation is defined as the mixing of information or methods so that different perspectives or opinions bring up light upon the subject (Olsen 2004).

The determination is to increase the reliability and accuracy of the results. The purpose is often indefinite in context to attain verification of findings through divergence of different standpoints. The researchers used a methodological triangulation of gathering data and using these two methods has provided a better understanding of the inquiry problem than both methods can alone. The qualitative method has covered the gaps left by the quantitative and vice-versa. Qualitative approach stood to gather the facts consuming in depth interviews. According to Cooper (2008), qualitative interviews put an effort to recognize the world from the participants' opinions and to explain the significance of the people's practices to discover their lives proceeding to methodical descriptions.

This method allows the researchers to study designated subjects in depth and try to fathom the groups of data that develop from facts. The quantitative method was also used to collect the data using survey questionnaires. It collects numerical data in response to the research questions. Therefore, these methods of research include the research method, design, population, sample, and sampling instrument, data collection and analysis methods. These methods allowed the researchers to gain attentiveness of the peoples' attitude, value system and concerns regarding the research topic. The methods for this study concentrated on real world situations of HIV and AIDS patients under the CHBC programs in Shurugwi rural area.

Research Instruments

The questionnaires and the interview schedule guide were the two instruments used to collect data from the respondents and participants. The first stage of the research conducted a survey by distributing 150 questionnaires to the HIV and AIDS patients and the primary caregivers. The second stage comprised of the in depth interviews with ten secondary caregivers and four key informants (CHBC officers' from NGOs and the government CHBC coordinators).

Selection of Participants

The study used two types of sampling methods: probability and non-probability sampling techniques. In the probability sampling technique, the respondents or sample were nominated by means of a random procedure, by a random number generator, thus every one person outstanding in the population had the similar possibility of being designated for the sample. In this study, the starting point was random by decisively selecting a beneficiary and the optimal afterward was a consistent interval; that is, every 6^{th} person that followed was carefully chosen. The study also used non-probability sampling technique and this was purposive sampling, where the population may or may not be accurately represented (Campbell 2004).

The judgmental sampling was used to select the sample and the type of sampling was established completely on the decision of the researchers. The participants were purposefully selected to obtain rich data enough to make conclusions. In this study, these two techniques were used to select the HIV and AIDS patients, caregivers, family members and key informants (CHBC officers from NGOs and the government

CHBC coordinators) who participated in the research study. The survey questionnaires and in depth interviews are the best method of data collection for this study as they enabled quick comparisons and addressed the aims, objectives and prompted questions. The tools helped to measure the effectiveness of CHBC programs on the services provided to patients. The researchers were assisted by two supervisors and other secondary caregivers who distributed the questionnaires to the patients and their primary caregivers, and the researchers later conducted the interviews.

Ethical Considerations

One of the researchers had worked with the caregivers during the attachment period therefore the caregivers helped the researchers to work with patients well. The researchers complied with the ethical guidelines of conducting the research by maintaining confidentiality and anonymity of the data that was collected. The researchers allowed the respondents to participate voluntarily and those who did not want to participate in a later stage were free to withdraw. The participants who agreed to take part in the research signed the informed consent forms. The study was conducted for academic purposes and the researchers were cognizant of the fact that HIV and AIDS is still a sensitive issue and participants were taken care of appropriately by respecting their privacy. The researchers obtained ethical clearance from the University as well as written permission from the Midlands Aids Service Organizations to undertake the research.

Data Generation and Data Analysis

The questionnaires and the interview schedule guide were the two instruments used to collect data from the respondents and participants, respectively. The first stage of the research conducted a survey by distributing 150 questionnaires to the HIV and AIDS patients and the primary caregivers. The second stage comprised of the in depth interviews with ten secondary caregivers and four key informants (CHBC officers' from NGOs and the government CHBC coordinators).

Data analysis is a method of collecting, modeling, and altering data with the goal of emphasizing valuable data, signifying conclusions, and supporting conclusion making (Welman and Fand 2005). The research study analyzed the data using both quantitative and qualitative methods. For quantitative data, the researchers presented the data using frequency tables and graphs while the qualitative data was presented according to key themes that emerged during the interviews. The quantitative analysis was used to apply prevailing data to inaugurate the effectiveness of CHBC programs in improving the conditions of HIV and AIDS patients. The Statistical Package for Social Sciences (SPSS) was used to enter the data in the computer for analysis.

Qualitative data analysis was used also to analyze data, as it required an approach, which is appropriate to analyze texts, visuals or narratives, such as content analysis or discourse analysis. The information was analyzed and interpreted according to the data collected using the thematic content analysis technique method. The information collected was summarized in any procedure of content by manipulating numerous features of the content as there is certainly no usual method for qualitative analysis but it does not mean it is not systematic. In thematic content analysis, the task of the researchers was to categorize a restricted number of themes, which sufficiently replicate their written data. Creswell (2009) considers that the method of data analysis and explanation can best be obtained by arrangement for recording data, data collection and preliminary analyses, managing or organizing data reading and writing notes, producing classifications, subjects, arrangements and coding data.

FINDINGS

Biographical Information

HIV and AIDS patients and their primary caregivers were the respondents to the questionnaires in this study. The outcomes of the study revealed that sixty-six percent of the respondents were females while thirty-four percent were males. The reason why there are many females is that most women stay in rural areas, especially the group between the ages of 35 and above and formed the largest component of the respondents in this study with seventy-two percent. This group was followed by respondents aged

26 to 35 years forming seventeen percent of the sample. The last group is those aged 18 to 25 years at eleven percent. Marital status was found to be crucial to the desires of HIV and AIDS patients.

Out of 137 respondents, sixty-two percent were married people and followed by twenty-one percent who indicated that they were single. The least percentage (17%) reported that they were separated. The educational qualification levels in the study were a contributing factor to the needs or desires of the beneficiaries where the majority of the respondents (47%) had secondary education, that is matriculation certificate, and some went to secondary but did not manage to finish school. Forty-five percent of the respondents indicated that they had primary education, which is a grade seven certificate. Those who responded to having no education were four percent, meaning that they did not go to school and the least number (3%) of respondents had some tertiary education qualifications.

The Desires of HIV and AIDS Patients under CHBC Programs

A desire or a need is something that is necessary for organisms to live a healthy life, which include food, air, shelter, clean water, good health, education and clothing. HIV and AIDS patients and the primary caregivers were asked about their desires or what their needs are. Table 1 shows the needs and desires of the beneficiaries of CHBC programs that can help improve their conditions and wellbeing if they are provided with them. The results show that the largest number (86%) of respondents as seen in Table 1 stated that they desired food because they experienced food shortages. This was followed by the sixty-five percent of respondents who showed that health kits were a basic necessity, which they lack. Table 1 also reveals that about fifty-one percent of the recipients mentioned that they needed treatment vouchers for medication and thirty-nine percent indicated that transport was another need. Four percent were the least number of beneficiaries who showed that they needed school fees for orphans.

Table 1: Desires/needs of respondents (multiple responses)

Desire	*Percentage*
Food	86
Health kits	65
Treatment vouchers	51
Transport cost	39

The Meals Eaten by the Patients

Furthermore, the respondents for quantitative instrument were asked how many meals the patients or they eat per day and their responses are shown in Table 2. According to the table, the majority (86%) of beneficiaries ate three meals and above per day, thirteen percent ate two meals per day and only one percent explained that she ate only one meal per day. Although most of the people manage to eat three meals and above, still they lack food to feed themselves than any other resources indicated in Table 2.

Table 2: Number of meals eaten by respondents

Meals eaten by patients	*Percentage*
Three meals	86
Two meals	13
One meal	1
Total	100

The Need for Food during the Year

The respondents were asked when they encounter food shortages and whether they desired food during the year. Table 3 shows this result. Out of 137 beneficiaries who responded, forty-two percent revealed that they encounter food shortages at any time of the month. This was followed by those who showed that they encounter food shortages before harvest (29% of respondents). In addition, sixteen percent of the respondents encounter food shortages at other times and the smallest number (7%) reported that they experience food shortages be-

Table 3: Frequency of the need for food during the year

Need for food during the year	*Percentage*
Any time of the month	42
Before the harvest	29
Other times of the year	16
Before the month ends	7
No need for food	6
Total	100

fore the month ends; hence, they desire food supplies. The food shortages encountered by the HIV and AIDS patients and the primary caregivers reveal that lack of education, poor rains, lack of agriculture and many other reasons contribute to affecting the patients' recovery during the year. Only six percent did not experience the need for food during the year.

The Causes of Food Shortages in the Household

The Zimbabwean country tries by all means to eliminate poverty and make people responsible enough by providing for their needs. In light of this, one of the objectives of the study was to find out whether the government and NGOs are helping the beneficiaries sustain themselves in order to improve their conditions. The results show the percentages of the respondents as seen in Table 4. Out of 137 respondents, fifty-eight percent lack agricultural inputs, thirty-eight percent mentioned that food shortage is affected by late rainfall and twenty-eight percent who explained that the food shortage was due to high temperatures. The study also exposed that twenty-three percent of the respondents indicated that the shortage of food was due to the death of the main provider, and sixteen percent mentioned that lack of food was as a result of loss of livestock due to drought. About thirteen percent of the beneficiaries revealed that the food shortage was caused by lack of water sources and reservoirs.

According to Table 4, eight percent of the respondents showed that the food shortage was caused by poor harvest due to pests and diseases, and five percent agreed that the food shortage was as a result of loss of livestock due to pests and diseases. The least (2%) of the recipients, mentioned that the food shortage was a result of lack of money and unemployment. The challenges mentioned above hinder the full recovery of the many recipients of CHBC programs in Shurugwi and it impedes the success of subsistence farming, which is the backbone of the district. Therefore, the respondents all expressed the desire or need for these items presented and discussed here, since they are needed for survival.

Table 4: Perception of the cause of food shortages in households (multiple responses)

Causes of food shortages	*Percentage*
Lack of agricultural inputs	58
Food shortage	38
Late rainfall	28
Death of the main provider	23
Loss of livestock	16
Lack of water sources	13
To Poor harvest due pest and disease	8
Lack of money and unemployment	2

Qualitative Findings for the Needs of the Beneficiaries

The qualitative analysis showed that all the ten secondary caregivers and CHBC officers had an awe-inspiring agreement that the needs of the patients are lack of CHBC kits, gloves, cotton, soaps, shortage of pain killers, and lack of transport cost, lack of school fees for orphans, lack of food and other resources like books to learn more about the pandemic. Furthermore, six participants indicated that the resources they are given to help the patients are not enough and they struggle to care for patients because CHBC programs do not supply the resources all the time. One female interviewee said that:

Sometimes we have to use our own resources when we are helping the patients and other times we seek help from the chiefs, counselors and headmen in the community and it's a good thing that they are supporting.

The other six participants revealed that the resources were fine and if they had problems they would visit the clinic for further help. Moreover, nine participants agreed that their needs as caregivers and as field officers were not met all the time because of lack of resources. In addition, three other participants agreed that their needs were met as they also received some money, uniforms, bicycles, soaps, and health kits although they were a few. It is very challenging for most secondary caregivers who provide care to patients to help them because they also experience food shortages and other problems in their own household.

DISCUSSION

The Shurugwi care program has been found to face many challenges regarding the needs of HIV and AIDS patients as well those of primary and secondary caregivers when they are assisting the patients to recover well. The results of the study revealed that sixty-six percent of the

women responded more than men in this research study because more women live in the rural areas than men. This also shows that more women are affected to a greater extent than men in many societies. Moreover, the needs of the patients show that food is the most important need for HIV and AIDS patients in the society followed by health kits, transport cost, treatment vouchers for medication and school fees for orphans. The study, therefore, shows a greater need for resources in order to improve the conditions of patients.

Furthermore, literature in support of the results contend that when patients are referred to receive CHBC services without adequate assessment of their domestic environment, caregivers often find themselves struggling to accommodate patients in a home lacking adequate shelter, food, safe water, proper sanitation, and clothing (Phorano et al. 2005; Shaibu 2006; Stegling 2000). On the other hand, the National Guideline (2002) asserts that families and caregivers have physical, psychological, and social/spiritual needs that must be met in order to maintain family solidarity and wellbeing. Because the burden of caring for someone who is very ill or dying is constant and heavy, the family may also need help with their household, farms, or other chores. This means that not only do HIV and AIDS patients lack the basic needs or desires, but also the family and the caregivers that provide the nursing care to the patients. Contrasting from the above researchers and the results of the study, resources are lacking in many countries and in many societies since the CHBC program started due to various challenges that include poor rains, lack of funds, lack of agricultural inputs and donor fatigue.

Empirically, the 2011 Zimbabwe Vulnerability Assessment Committee (ZimVAC) estimates that just over one million Zimbabweans are unable to meet their food requirements in the current lean season of 2012 due to the late green harvest. This is corroborated by the findings of this study, which show that most patients still lack food and other resources in the long run because of inadequate agricultural inputs and low rainfall as well in this district. The research also brought to light that most projects that are implemented in many rural areas are not sustainable enough to help HIV and AIDS patients overcome food shortages in their households, for example gardening projects are the only projects in effect to equip families to increase food in their families. It is argued that poverty alleviation projects have left a legacy of increased vulnerability and impoverishment amongst the displaced communities due to entitlement losses (Basilwizi 2010).

It is because most projects lack enough funds to make them last for a long time and due to other natural disasters and also due to dependency on donor aid. Moreover, as the study indicated, many people in rural areas are not educated, and as a result of lack of funds this also affects their living standards. As subsistence farmers, they are supposed to be knowledgeable enough to equip themselves for the better with good agricultural skills. According to MOCHW (2010), there is the lack of a national strategy or policy addressing food and nutrition insecurity in vulnerable households with PLHIV. This shows that the service providers are not receiving enough or continuous trainings because of shortage of resources and funds to train them more. The issue is that the government and NGOs are not reaching the poor of the poorest looking at food shortages or poverty of many HIV and AIDs patients.

They struggle to find food where NGOs and government distribute food, especially in Shurugwi. Furthermore, many donors come to issue food to all the people in the community affected by food shortages without considering those who are less privileged like HIV and AIDS patients and other debilitating sicknesses. Most of the strategies used to fight food shortages do not leave people empowered to do it for themselves, especially in rural areas because they concentrate more on gardening, which is affected by lack of agricultural inputs and poor rains.

Moreover the donors supporting the program sometimes leave or terminate before the beneficiaries are stable enough to stand by themselves, which becomes a barrier also for the implementation of CHBC programs. Therefore, it is vital to note that the needs of HIV and AIDS patients are very important in order to improve their conditions. There is a need for constant sponsorship from the NGO and government, other organizations as well as support from the community at large to increase the resources needed by HIV and AIDS patients, primary and secondary caregivers.

CONCLUSION

The needs and desires of HIV and AIDS patients, primary caregivers and secondary caregivers have become the most needed resource

in helping the patients associated with the CHBC programs to improve their resource base so as to sustain and support them. These resources include food, CHBC kits, bandages, soaps, transport cost, school fees, sustainable projects and treatment vouchers. These have become serious challenges, which most primary and secondary caregivers desire in order to take proper care of the patients. Without all the caregiving tools, and constant education on caregiving, the patients and other associated stakeholders find it a daunting task to uphold human dignity and worth, which are cardinal points for social justice.

RECOMMENDATIONS

Two pertinent recommendations are made so as to improve life quality of patients and program effectiveness. First, it is recommended that the government and NGOs as well as other organizations should support the program interventions to help restore the patients' dignity and quality of life. Finally, there is a need for a program monitoring and evaluation at specific intervals to gauge the progress of the program.

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