

Challenges Faced and the Coping Strategies Adopted by Family Caregivers in Dealing with People Living with HIV/AIDS in Thika District, Central Province, Kenya

Lucy Njoki KATHURI-OGOLA

Department of Community Resource Management and Extension
Kenyatta University
P. O. Box 43844-00100, GPO, Nairobi, Kenya.

Olive MUGENDA

Department of Community Resource Management and Extension
Kenyatta University
P. O. Box 43844-00100, GPO, Nairobi, Kenya.

Francis P. KERRE

Department of Sociology
Kenyatta University
P. O. Box 43844-00100, GPO, Nairobi, Kenya.

Abstract

This paper documents the challenges and coping strategies family caregivers (FCGs) of People Living with HIV and AIDS (PLHWA) encounter based on a study conducted in Thika District. One hundred and seventy-seven primary FCGs of PLHWA, drawn through proportionate stratified random sampling from three divisions in the study area, were used. Data was collected using interview schedules and Focus Group Discussions and analyzed quantitatively and qualitatively. Quantitative data was analyzed with the use of Statistical Package for Social Sciences (SPSS) where descriptive statistics and inferential statistics were computed in order to understand the patterns and nature of relationships. Qualitative data was analyzed using content analysis, where labels were assigned to various categories and themes of the data. In addition, the data was presented where possible through the use of verbatim quotation. The results showed that the FCGs face numerous challenges in care provision, the most prominent ones being financial, food provision, stress and stigma. Consequently, they adopt coping strategies to ensure economic endurance, psycho-social wellbeing and spiritual support. The study recommends that policies and interventions be put in place to ensure that the FCGs are empowered economically, given psychosocial support and their capacity strengthened. These are fundamental in enhancing their adaptation. The result of which would be quality care for the PLHWA.

Keywords: Quality Care, Family Caregiver, Home Based Care, Person(s) Living HIV/AIDS

1. Introduction

More than 1.4 Million Kenyans are living with HIV and AIDS. This represents 7.4 per cent of Kenyan adults aged 15-64 years (NASCO/MoH, 2008). Death rates from HIV have reached an unprecedented level in Kenya, at about 150,000 per year. Even with the scale up of treatment, death rates in Kenya are likely to continue to rise because of the large number of people who were infected in the 1990s (NASCO/MoH, 2005). Over two decades since the first AIDS case was diagnosed in Kenya, HIV and AIDS remains a huge challenge for the country in its efforts for social and economic development. Responses to the pandemic have evolved over time as people became aware of this new disease, as they experienced illness and death among family members, and as services have developed to confront this epidemic (MoH, 2005).

According to the National Aids Control Council (2000), Thika District has been a region of high HIV prevalence with rates of 20-29 per cent for the 15-49 year olds. It is estimated that 55,335 had been infected in the District (MoH, 2001). However, the district has had a steady decline in HIV prevalence from 39 per cent in 1994 to 31 per cent, 11 per cent and 8 per cent in 1998, 2001 and 2004 respectively but stabilized in 2003 (NASCO/MoH, 2005).

In 2006, Thika District had the highest number of HIV infected people and AIDS deaths amongst the seven districts in Central province. It had total of 17,541 HIV infected persons and 1,968 AIDS deaths (NACC/NASCOP, 2007).

1.1. Care Giving of PLWHA

The experiences of relatives and friends who are caregivers of PLWHA in Africa and particularly in Kenya are important to examine since informal care giving is stressful and has social, economic, medical, and psychological implications to both caregivers and society (Raveis & Siegel, 1991). The HIV and AIDS epidemic has strained the health sectors of most developing countries, reducing their capacity to respond to the pandemic. As the number of PLWHA increased, the gap between demand for and availability of healthcare services continued to widen. Consequently, home-based care was adopted for its benefits for the person living with HIV and AIDS and for family members in the sense that it allows the sick person to be cared for in a familiar environment and affords them opportunity to prepare for their death and die with dignity at home (Akintola, 2006). Jackson (2002) observes that, as the epidemic expands, caring for people with HIV-related diseases is increasingly taking place in the home and community. She asserts that PLWHA are often discharged to die at home because the hospital staff can do nothing further for them or because they feel the scarce supplies are better utilized on someone with greater chances of recovery. Moreover, she argues that patients in the last stages of the HIV/Aids ailment might prefer to be at home rather than in the hospital provided they have access to the medication, nursing care, nutrition, material support and psychological and spiritual care they need.

1.2. Statement of the Problem

Most families, according to Reuben & Jonathan (2001), take care of sick members at home and this is often the best way to care for PLWHA. Consequently, FCGs are (and the situation seems to suggest that they will continue) offering the bulk of care to the infected (Limanonda, 2004; UNAIDS, 2004; Jackson, 2002; Reuben & Jonathan, 2001). In spite of the numerous advantages of family care giving and the heavy care giving work placed on families and households by the HIV and AIDS epidemic, FCGs may not be adequately prepared in terms of support and resources.

HIV and AIDS care support programmes usually tend to concentrate on the care of PLWHA and not on the caregivers, especially the family members. As Limanonda (2004) observes, not much attention has been paid to the needs of family members who act as caregivers, most of whom are women. Yet, these caregivers are in a vulnerable position since they have to carry out other household chores in addition to providing care for PLWHA. The author therefore sought to investigate the challenges family caregivers face and the coping strategies they adapt when dealing with PLWHA in Thika District, Kenya.

1.3. Justification

According to UNAIDS (2008), while the percentage of people living with HIV has stabilized since 2000, the overall number of people living with HIV has steadily increased as new infections occur each year, HIV treatments extend life, and new infections still outnumber AIDS deaths. Moreover, the number of people who have already been infected by HIV in the past years is contributing to AIDS prevalence rates. This in turn is overwhelming capacities of health facilities. According to Shebi (2006), a serious consequence of this is that PLWHA care is compromised due to premature discharges from hospitals. The increased demands placed on medical budgets, combined with the prolonging of PLWHA lives through antiretroviral therapy (ART), has led to HIV being classified as a chronic disease best suited for home-based care (Hickey, 2001). Notably the increased access to ART is likely to result in PLWHA living longer and consequently they may require care giving for longer too. Indeed, Leake (2009) contends that despite the fact that PLWHA can be healthy, strong and live perfectly 'normal' lives they can experience a range of symptoms that will affect their day-to-day life, and for which they will need care and assistance.

Home-based care programmes for PLWHA were introduced in a number of African countries, including Kenya during the late 1980s and early 1990s in an effort to reduce the strains experienced in the formal health sector (Sims & Moss, as cited in Uys, 2003). Although the services of Community Health Workers (CHWs) are available within the HBC programmes, it is the informal caregivers (specifically FCGs) who provide most of the care for the PLWHA in the homes. These caregivers are, typically, the spouses, parents, children, siblings or other family members of someone diagnosed with HIV and AIDS.

They usually have little or no training in home-based care. Any training they may have is offered to them by CHWs and it is presumed that it will enable them to cope on their own when these “professionals” are not present.

1.4. Limitations the Study

The study focused on selected FCGs of PLWHA in Thika District only and therefore generalizations of results to other non-familial caregivers or other areas should be done with caution. Owing to the difficulty in identifying and accessing the FCGs, as well as the sensitive nature of the subject of study, the sample included selected caregivers identified through community health workers organizations in Thika District.

1.5. Theoretical Perspective to Family Care

The author perceives family care from the four components of the double ABC-X model and three elements of the systems theory. The double ABC-X components adopted were the “pile up” concept (aA factor), the resources (bB factor), the perception of the situation (cC factor), coping as a bridging factor and the adaptation levels (xX factor) with specific focus on the FCGs of PLWHA.

The stressor is in this case non-normative in nature (unexpected) and basically chronic in form of HIV and AIDS infection of a family member. The pile up of stressors, the resources and perception of the situation as well as coping influence/affect the adaptation level. For this study, the ‘pile up’ component is considered as the HIV and AIDS in the family and the resultant care giving stressors, demands and hardships encountered by the FCGs. The conceptual framework is summarized in Figure 1.

1.6. HIV and AIDS in Kenya

When the first case of AIDS in Kenya was reported in 1984, the pandemic was considered a Ministry of Health issue. Even with increasing incidence and death due to the epidemic it was not until the late 1990s when it was declared a national disaster. As one of its responses to the epidemic, the Government of Kenya set up a structure of AIDS control committees at provincial, district and constituency levels to help communities organize to assist PLWHA and their families to fight the spread of the epidemic (NAS COP, 2002).

The epidemic in Kenya peaked in the late 1990s with an overall prevalence of 10 per cent in adults and declined to 7 per cent by 2003. The peak incidence (new cases) of infection in the country occurred around 1993, with over 200,000 new adult infections (NAS COP, 2005). The Kenya Demographic Health Survey (2003) indicates that 6.7 per cent of Kenyans aged 15-49 years are HIV infected. The same report shows that prevalence is 8.7 per cent for women aged 15– 49 compared to 4.6 per cent for men aged 15-49. Infection levels among urban residents peaked in the mid-1990s; this occurred before a similar peak among rural residents. Infection levels in rural populations subsequently dropped, though at a slower rate than the urban ones (MoH, 2005). In addition, data reports from sentinel surveillance sites throughout Kenya show that there is an overall decline in HIV infections from 1999 to 2002. The most recent sentinel surveillance evidence indicates that adult (15-49 years) prevalence has now fallen to 6.1 per cent as of end of 2004 (NACC 2005) and as low as 5.1 in 2007. However, according to the preliminary results of the 2007 KAIS, which is a population based survey, for the same age group, an estimated 7.8 per cent were infected (NAS COP, 2008).

In Thika, the first recorded case of HIV and AIDS was in 1986 (Kinyanjui, 2007). The district has been an area of high prevalence as shown by the prevalence rate among pregnant women visiting ante-natal clinic at the surveillance site (NACC/NAS COP, 2007). The high HIV prevalence in Thika over the years defied geographical explanation. It was geographically located far from what were then considered ‘high risk’ or entry points of HIV and AIDS, like the towns of Mombasa and Busia (ibid). For many years, the HIV and AIDS pandemic was associated with truck drivers and Commercial Sex Workers (CSWs) and Thika is off the main international highway of Mombasa to Busia. However, according to Lyons (2004), over the years, HIV and AIDS has been viewed as resulting from ‘risky practices’ but this has changed in recent times and the concept of ‘multiple contingent of risk’ has been adopted. This concept factors in the multifaceted nature of the life situations of individuals such as unemployment, underemployment, poverty, forced separation from family and kin, lack of access to health services, war and displacement.

Thika has had a vibrant industrial sector since the 1920s made up of agro-processing, chemical and textile industries. Consequently, it has a highly mobile population as migrants come to seek for employment.

According to Barnett & Whiteside (2002), migration and mobility leading to concentration of large numbers of unaccompanied spouses in certain parts of the district created patterns of sexual behaviour and mixing which are perfect for the spread of STDs. Generally, Thika District attracts a large number of unskilled and casual labourers and those who do not find employment end up offering sexual services (RoK, 1994). Moreover, findings of the KDHS (2003) showed that prevalence was higher among men who slept away from home (9 per cent) than those who did not (3 per cent).

Therefore, the high HIV prevalence rates in Thika can be elucidated by the presence of high migrant labour, low economic status of a substantial number of its resident due to collapse of the coffee industry, presence of plantations, being a stopover for truck drivers, consumption of illicit brews and intergenerational sex between young girls and older men. All these factors are catalysts to the spread of the virus since the concerned parties engage in casual sex. Over and above, in these kind of sexual liaisons the persons more likely than not, engage in unprotected sex.

1.7. Family Care Giving for PLWHA: A Synthesis

Caregivers may be family members, volunteers, or health and social workers. They are on the front line in dealing with the epidemic and they need to be cared for themselves and supported in their work, lest they become overwhelmed by the work of grief and despair. Many of the FCGs are women, volunteers who are unemployed, they come from the same community as the PLWHA, often are poor, contribute from own (possible) income earning time, frequently lack empowerment and recognition among other features.

In spite of this, the effectiveness of the family/home based care approach depends on many factors, the most critical of which is the readiness of the family to cope with their own challenges, such as the work of care provision, the cost of providing care and medication, the capability of coping with discrimination, the psychological effects associated with illness and the eventual death of the ill member (Limanonda, 2004). Taking care of an infected family member at home has numerous advantages but it often can be challenging because it is time and resource intensive. Also since the FCGs are taking care of their own members their work and efforts may not be noticed and as a result, they are not supported fully by society. Besides, individuals may be cared for in overcrowded and impoverished conditions (FHI, 2001). According to Jackson (2002), home care can actually mean home neglect because PLWHA are out of sight of the medical services, their suffering is unseen except by relatives and friends and many PLWHA in poor families lack access to the most basic medication, nursing care and relief of symptoms.

2. Materials and Methods

The study was carried out in Thika District. It is one of the seven districts of Central Province in Kenya. It has six administrative divisions: Thika Municipality, Gatanga, Kakuzi, Ruiru, Gatundu North and Gatundu South (Thika District Poverty Reduction Strategy Paper, 2001-2004). According to the 1999 Population and Housing census, its population stood at 645,713.

Thika District, according to NACC (2000), has been a region with high HIV prevalence with rates of 20-29 per cent for the 15-49 year olds. It is estimated that 55,335 people had been infected in the District by 2000 (MoH, 2001). However, the district has had a steady decline in HIV prevalence from 39 per cent in 1994 to 5 per cent in 2006 (NACC/NASCOP, 2007). According to the same report, in 2006, Thika District had the highest number of HIV infected people and AIDS deaths amongst the seven district in Central province.

Thika District was purposively selected for the study. The target population included all primary family caregivers of PLWHA working with registered groups in Thika District. The survey design was used for this study. The study sample was drawn from three divisions namely Thika Municipality representing urban population, Ruiru representing peri-urban population and Kamwangi representing the rural population in Thika District. These divisions were also purposively chosen because Ruiru is the largest division in the district and has the largest number of organizations of CHWs while Thika Municipality boasts of being the largest town (urban area) as well as industrial area and is central point for jobseekers in the District and Kamwangi for its rural orientation and according to NACC/NASCOP (2007) it had the highest HIV prevalence in 2000 in the district. In addition, the divisions lie on the higher and lower potential areas of the district and are therefore deemed to offer varied characteristics especially with regard to socio-economic backgrounds.

Through the District office of Social Services (D.S.S.O) a list of organizations working with families of PLWHA at the community level was obtained. From the list, five organizations were purposively chosen for the study. The selection of the organizations was based on evidence of having been in operation in the study area for at least two years. These organizations included three Community Based Organizations (CBOs), one women's self-help group and one Faith Based organizations (FBOs). The individual respondents were randomly selected from a list provided by each of the five organizations. The selection of the respondents was done with the aid of the random table. The respondents were selected using a proportionate stratified random sampling as is presented in Table 3.2. Proportionate sampling is where the numbers in the groups selected for the sample reflect the relative numbers in the population as a whole (Robson, 2004).

After the respondents were selected, the CHWs under whose jurisdiction the FCGs fell were enlisted to introduce and accompany the researcher to the homes of the selected FCGs. Two visits were scheduled to each FCGs home. The first visit to the home was to; seek consent of participation, explain objectives, the procedure and requirements of the study, and to book an appointment for the interview date. The subsequent visit was to ensure informed consent and to carry out the interview. However, some of the FCGs participated in the interviews on the first visit. This enabled the researcher to reach almost all of the 183 sampled FCGs. Six caregivers were not able to be interviewed since they were committed elsewhere even on subsequent visits. Because of the time constraints it was not possible to get replacements and the return level of 177 respondents was considered to be relatively high at 97 per cent.

2.1. Inclusion and Exclusion Criteria

The study sample comprised of primary FCGs of PLHWA who were the primary respondents. The primary caregivers were chosen because once a person develops AIDS or starts falling ill even before developing full blown AIDS s/he requires intense care and hence the care giving at this stage is quite tasking. Only caregivers who had given care for more than 6 months were used. These were considered to be in a position to give a valid account of their situation since they had provided care for a substantial amount of time. Of the sampled FCGs, the willing and available ones were interviewed.

2.2. Instruments and Data Analysis

Data was collected using interview schedules and Focus Group Discussions (FGDs) with the assistance of two research assistants. Interview schedule was the main data collection tool targeting the primary respondents who were the FCGs. The questions for the interview schedule were both open (for qualitative data) and closed ended (for quantitative data). The interviews were administered in either English or the Kiswahili translation based on the respondent's preference. The interviews lasted between one and a half hours to two hours and the responses were recorded through note taking.

Data was analyzed both quantitatively and qualitatively using Statistical Package for Social Sciences (SPSS). Descriptive and inferential statistics were used. Descriptive statistics of frequencies and per centages were used to summarize the data. Inferential statistics utilizes sample data to make estimates, decisions, predictions or other generalizations about a larger set of data (McClave & Sincich, 2000).

Qualitative analysis was also done to enable the researcher to analyze the respondents' perceptions, views and opinions in a meaningful and useful way. Qualitative data was transcribed to enable the researcher to capture fully all the information gathered. Codes and labels were assigned to various categories and themes to draw conclusions and conduct content analysis. Coding was used because it reduces information gathered through narrations to something useful.

3. Results and Discussions

The study established the challenges that the FCGs faced in caring for the HIV infected family members. Over four fifths (93%) of the respondents admitted experiencing challenges as caregivers. Figure 2 gives a summary of these care giving challenges.

The study indicated that the FCGs face numerous challenges as they provide care to the PLWHA the most critical of which related to insufficient finances (83%, food provision (56.4%), stress (52.1%) and stigma (32.1%). This relates to the observation by Limanonda (2004) that, caring for the PLWHA at home has many advantages as well as a number of limitations.

3.1. The financial Challenge

This was the most prominent challenge. The caregivers asserted that their income and that of their households had gone down significantly because the number of dependants had increased. This increment was attributable to the care recipient falling ill, hence becoming a dependant and/or his/her children becoming the caregiver's dependents. Besides, some of the caregivers attested to abandoning income generation from jobs /businesses or reducing their person-hours at their workstations to engage in care giving. A study by Steinberg et al (2002) found out that where someone was either sick or had recently died due to HIV and AIDS related illnesses, more than 20 percent of the caregivers had diverted time from work or informal income generating activities to provide care in the home. They also asserted that paying for medicine or hospital bills especially once the opportunistic infections strike had taken up most of the income. According to NACC (2008), ARVs are free in Kenya since early 2005 but the user bears that cost of medical support services such as tests, medication and treatment for opportunistic infections as well as transport. The caregiver more often than not met these costs. The response of one caregiver during an interview epitomizes this challenge.

“My economic status has gone down...I have stopped building rental houses I had started...When I get a little money or a loan all goes to medication and feeding of the sick (care recipients)”
(Woman taking care of son, daughter in law and grandson)

On the other hand, facing financial difficulties has resulted in some of the FCGs engaging in various activities to earn income and this tends to compromise their care giving to some extent. The main income generating activities engaged in included casual labour, farm work, and household work (such as washing clothes). These activities therefore tended to consume time and energy of the FCGs and thus limiting their attention to care giving. As one CHW put it;

“They have to do other work to make ends meet so they (caregivers) do not care well for the PLWHA.”
(FGD session)

The general view of the FCGs was that household economic difficulties had intensified as they used a large proportion of their income to support care giving needs such as medical costs, hospital bills and transport to health facilities. In other cases there is lost income of the FCG as well as that of the PLWHA as they become dependants. This particular challenge concurs with observations by Leake (2009), UNAIDS 2008, Steinberg *et al* (2002) and Neufeld (2002) on financial costs of care giving.

3.2. The challenge of Food provision

Food is a basic human need and the intake of a nutritious diet is crucial in the management of HIV and AIDS as part of ART. This may explain why these FCGs experienced this challenge as they endeavored to meet the nutritional requirements of the care recipients. This challenge in many cases closely interlinked with finances since in most instances they had to incur an extra cost to meet the dietary requirements as illustrated by the response of a FCG during an interview.

Mrs. N, who said, “I have money challenges...I need money to take mgojwa (care recipient) to hospital and other basic needs... and the food that the care recipient demands.... I have borrowed a lot of money.”
(FCG interview)

3.3. The challenge of stress

The main source of stress was thinking of the ill person and their children and/or the inability of the caregiver to adequately provide for or help the PLWHA as well as the other dependants in the family. Factors used to portray instances of stress in this study were sleep problems, anxiety, persistent headaches, feelings of frustration, loss/increase of appetite and poor concentration. An indication of stress, Mrs. F, teary said,

“Sometimes I get stress but I just pity myself.... But she's my child....I know she'll never get cured and I really feel bad about it ...and about my grand children. I sometimes think and I feel my head spinning.... Especially when I see her and her children going without food.”
(Woman providing care to her daughter)

This particular response brings to the fore aspects of helplessness and despondency that some of the caregivers may feel as they provide care to their chronically loved ones within a context of inadequate resources. This kind of stress is likely to impact negatively on the FCGs as well as on their care giving and can be counterproductive as a CHW observed;

“They [caregivers] are stressed especially because of thinking hard and do not want to do this work so sometimes treat the care recipients badly or reject them”.(CHW during an FGD session)

These results correspond with the assertion of Pharaoh and Schonteich (2003) that the presence of an HIV positive member may strain the mental and physical well being of the household member caring for an HIV-positive spouse, child or relative.

3.4. Stigma as a Challenge

Stigma has been singled out as one of the major bottleneck in the management of HIV and AIDS. The study results show that the caregivers still bear the brunt of stigmatization. And this stigma was not only because of the disease but also due to cultural expectations based on ascribed gender roles. This is as illustrated by the following response.

“Most of my friends and people stigmatize me because of my mom (mother). They think it’s wrong for me to take care of her hence they socially stigmatize me.” (Single male FCG)

Other challenges experienced include: limited resources for care provision, including the ability to buy medicine and supplies and the care recipient in some instance being uncooperative even when resources were available. In addition, even with the introduction of Free primary education (FPE) in Kenya some FCGs noted that meeting the costs for educating their children was greatly compromised especially when they had to cater for emergency medical costs of the PLWHA.

3.5. Coping Strategies

FCGs are faced with numerous challenges in taking care of PLWHA as shown in Figure 3. In order to adapt to these challenges, a number of coping strategies were adopted. A hundred and sixty five (93.2%) caregivers have adopted some strategies to cope with the challenges/challenges of care giving. The coping strategies used by FCGs as individuals include; increasing their resource base through getting loans/borrowing (50.3%), positive living (36.2%), prayers (36.7%), CHWs (24.6%) and improving knowledge of disease (13.6%).

Borrowing took the form of ‘soft’ loans, foodstuffs and requesting for nonmaterial assistance from friends and neighbours. This is consistent with the findings of UNAIDS (1999) that indicated that the major coping strategies adopted by households to cope with the HIV epidemic includes strategies to improve food security, those aimed at raising and supplementing income to maintain household expenditure patterns and those directed at alleviating the loss of labour.

Positive living involved accepting the care recipient and illness as well as taking a positive outlook of life and the care giving work even in times of adversity. Prayers were used to seek for divine intervention so that they can be able to do their work well. It was also used as a strategy to ease their minds of the challenges they were encountering. CHWs were usually called upon to train them, assist the FCGs in care giving roles such as daily living tasks, provision of medicine especially through referrals as well as psychosocial support. The FCGs sort to improve their knowledge of disease through the mass media, talking to friends and CHWs or consulting medical specialists.

In the context of the numerous challenges they were facing, over two thirds (69.5%) of the respondents felt that they were coping well as caregivers while the rest thought they were not coping well. This is unlike the finding of the study by Simpson (2006) whereby 41 per cent of caregivers felt they were not coping with the stressors of care giving. Generally, the overall coping strategies employed were mainly to ensure economic endurance and/or survival, psycho-social wellbeing and spiritual support.

From the results challenges included financial difficulties, provision of food, stress, stigma and isolation, inadequate medicine and supplies, difficult care recipient, and strain on education. These challenges were largely associated with the increased resource requirements in the family to meet the additional and special needs of the PLWHA.

In some instances, the caregivers were compelled to resort to loans and borrowing (especially from informal sources), prayers, positive living, seeking advice from CHWs, and seeking more information on HIV/AIDS to cope with the challenges faced. These strategies differentially affected the respective families with some reporting disturbances in their livelihoods for instance as a result of the huge interest rates paid for loans taken from informal sources and time taken to seek for external support from CHWs and seeking for more information.

4. Conclusion and Recommendations

FCGs faced a number of challenges including lack of adequate finances, food provision difficulties, stress and stigma. This therefore means that the FCGs may require targeted intervention strategies to counter the challenges. In addition, the coping strategies employed to ensure economic endurance and/or survival, psycho-social wellbeing and spiritual support were not adequate, with borrowing negatively affecting to adaptation levels. Consequently, there is a need for FCGs targeted interventions with specific focus on FCGs identified needs such as economic empowerment, provision of psychosocial support, supplies of basic needs and medication, and training on care giving.

Generally, sufficient as it seems, access to economic resources need to be complemented with strategies for management of stress, stigma elimination and training of FCGs prior to embarking on provision of care to PLWHA. The training to build FCGS capacity should be on a continuous basis. Strengthening of the support structures perhaps holds the key to the empowerment of the FCGs especially through a widened stakeholder involvement. These approaches may enhance their adaptation to care provision.

It is recommended that the Kenyan government should put in place strategies that will ensure equitable distribution of resources to all FCGs. This is mainly by economically empowering them with sustainable livelihoods.

Specific interventions by government and non-governmental agencies focusing on FCGs of PLWHA should pay attention to gender considerations with customized approaches or strategies for both males and females. This will require sensitization of the community members on gender differentials and care giving roles to PLWHA.

Financial support for FCGs by government and NGO’s through a community based revolving fund. This may require equipping the FCGs with skills for economic empowerment such as entrepreneurial skills, financial management, marketing and record keeping. Such skills will ensure that any IGAs the caregivers may start do not collapse after a short time due to their inability to manage them efficiently.

Figures

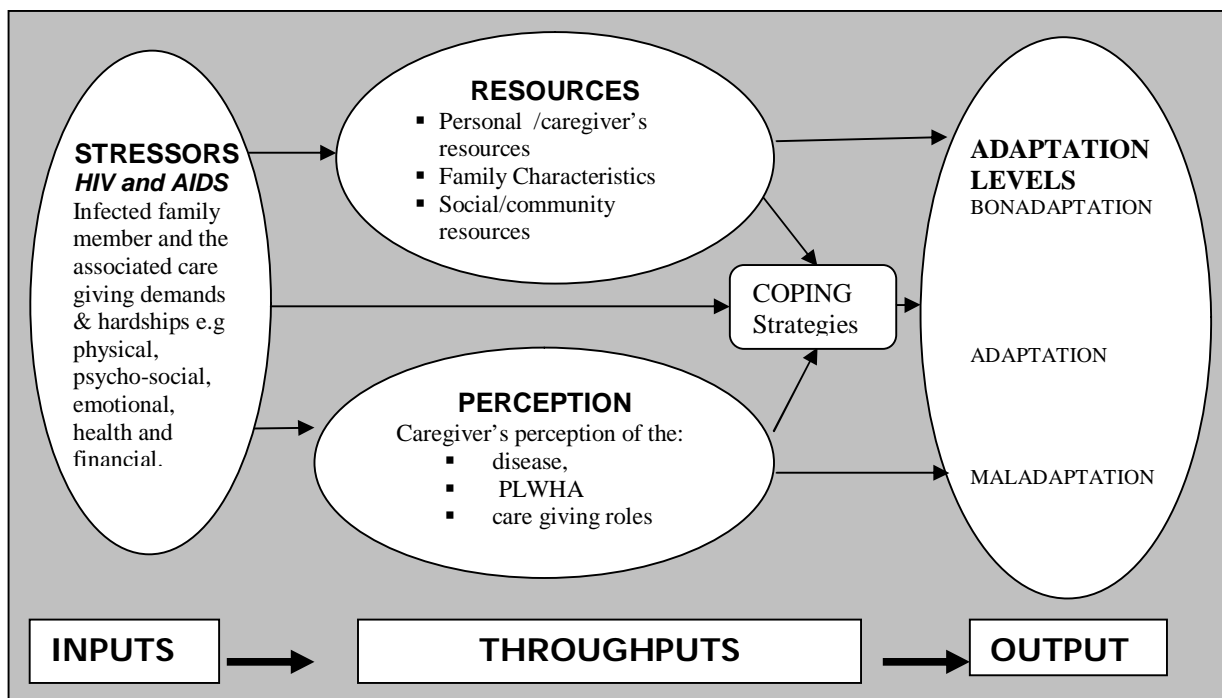


Figure 1: Conceptual Model

Source: Modified from McCubbin & Patterson, 1982

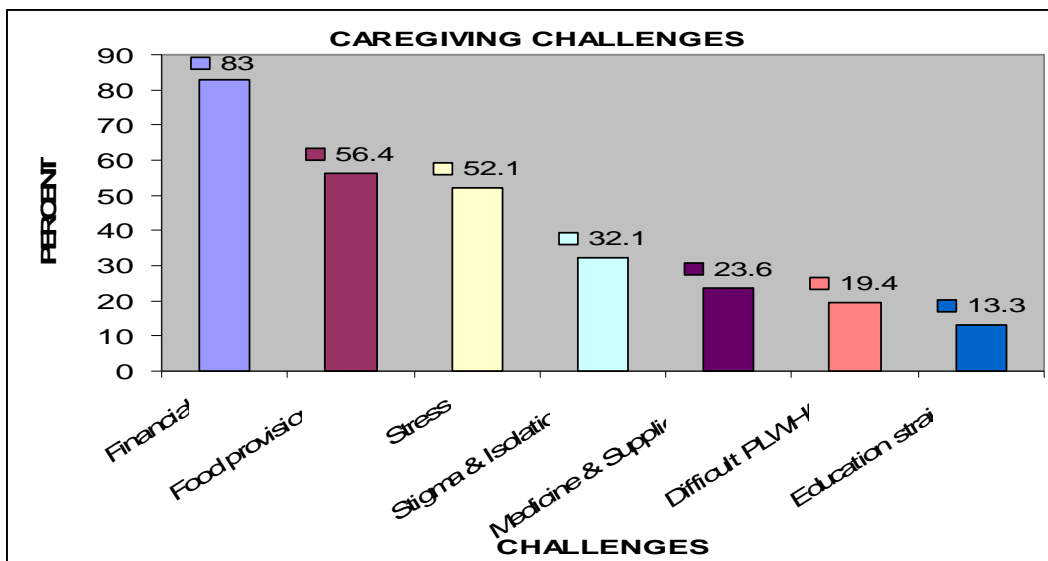


Figure 2: Challenges experienced by Family Caregivers of PLWHA

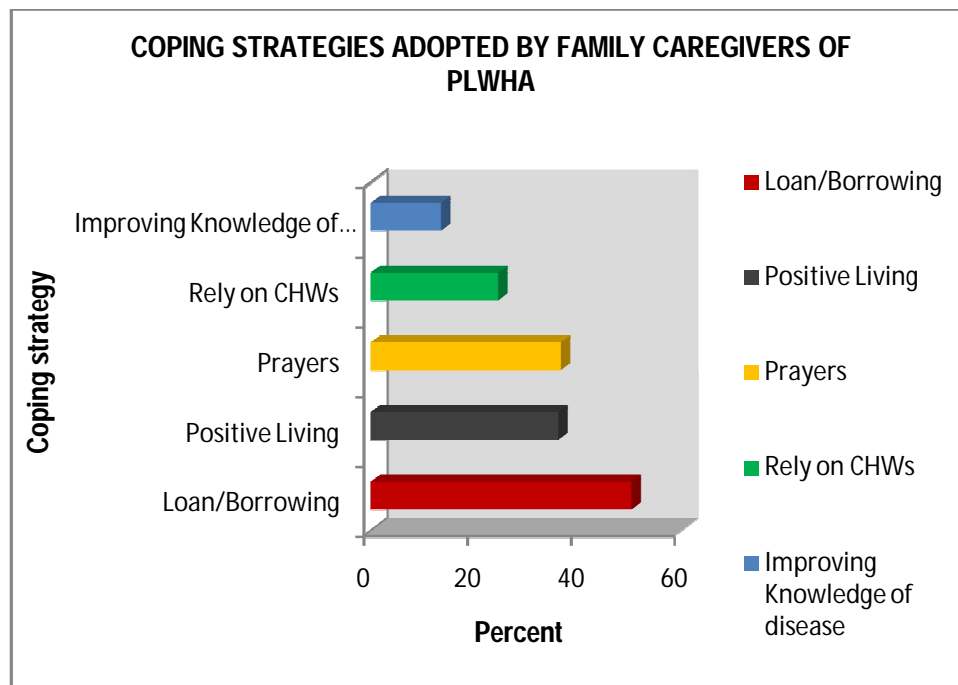


Figure 3: Coping strategies adopted by Family Caregivers of PLWHA

References

Akintola, O. (2006). Gendered Home-Based care in South Africa: more trouble for the troubled. *African Journal of AIDS Research*, 5(3):237-247

Barnett, T. & Whiteside, A. (2002). *AIDS in the Twenty-First century: Disease and Globalisation*. New York: Palgrave Macmillan.

Family Health International (2001). *Strategies for an Expanded and Comprehensive Response (ECR) to a National HIV/AIDS Epidemic*. In P. R. Lamptey, P. Zeitz, & C. Larivee, (Eds.), *A Handbook for Designing and Implementing HIV/AIDS Programs*. USA: FHI.

Hickey, A. (2001). What is government spending on HIV/AIDS? *AIDS Bulletin*, 15-17.

Jackson, H. (2002). *AIDS in Africa: Continent in crisis*. Harare: Zimbabwe SAfAIDS.

- Kenya Demographic and Health Survey [KDHS] (2003). Central Bureau of Statistics/ Ministry of Health/KERI/Centre for Disease Control/Measure DHS. Nairobi, Kenya: CBS.
- Kinyanjui, F. K. (2007). *Causes of Persistent Rural Poverty in Thika District of Kenya, c.1953-2000* (Unpublished PhD Thesis). Rhodes University.
- Leake, M. (2009). *HIV and AIDS care in the home*. Retrieved March 19, 2009 from <http://www.avert.org/aids-home-care.html>
- Limanonda, B. (2004). *HIV/AIDS Prevention, Treatment and Care: Regional situation and issues for consideration*. Retrieved from <http://www.unescap.org/esid/psis/population/workingpapers/HIV/AIDS.html>
- Lyons, M. (2004). Mobile Populations and HIV/AIDS in East Africa. E. Kalipeni, S. Craddock, J. R. Opongo and J. Ghosh (Eds.) (2004). *HIV and AIDS in Africa, Beyond Epidemiology*. Oxford: Blackwell Publishing Ltd.
- McClave, J. T., & Sincich, T. (2000). *Statistics* (8th ed.). New Jersey: Prentice Hall.
- McCubbin, H. I., & Patterson, J. M. (1982). Family adaptation to Crises. In H. I. McCubbin, A. E. Cauble, & J. M. Patterson (Eds.), *Family stress, Coping and Social Support*. Springfield, IL: Charles C. Thomas.
- Ministry of Health (2001). *AIDS in Kenya: Background, Projections, Impact, Interventions and Policy* (6th ed.). Nairobi: National AIDS and STD Council.
- Ministry of Health (2003). *Kenya Demographic and Health Survey, 2003*. Central Bureau of Statistics/ Ministry of Health/KERI/Centre for Disease Control/Measure DHS. CBS; Nairobi, Kenya.
- Ministry of Health (2005). *National health accounts 2001/02*. Nairobi: MoH.
- National AIDS and STI Control Programme/MoH (July, 2008). *Kenya AIDS Indicator Survey 2007: Preliminary Report*. Ministry of Health. Nairobi, Kenya.
- National AIDS and STI Control Programme/MoH (2005). *AIDS in Kenya*, 7th ed. Nairobi: NASCOP.
- National AIDS and STI Control Programme (2002). *Home Care Handbook : A reference manual for Home Based Care for people living with HIV/AIDS in Kenya*. Republic of Kenya. Government Printer: Nairobi.
- National AIDS Control Council (2005). *Kenya HIV/AIDS Data Booklet*. Nairobi: National AIDS Control Council.
- NACC/NASCOP (2007). *National HIV prevalence in Kenya, June 2007*. Nairobi: The National AIDS Control Council and National AIDS and STD Control Programme.
- Raveis, V. H. & Siegel, K. (1991). The impact of care giving on informal or familial caregivers. *AIDS Care*, Vol. 5 pp.39-43
- Republic of Kenya (1994). *Kiambu District Development Plan 1994-1996*. Nairobi: Government printer.
- Republic of Kenya (2001). *Thika District Poverty Reduction Strategy Paper-2001-2004*. Nairobi: Government Printers.
- Reuben, G. & Jonathan, M. (2001). *HIV, Health and your Community: A guide for Action*. USA: The Hesperian Foundation.
- Robson, C. (2004). *Real World Research: A Resource for Social Scientists and Practitioner-Researchers*. 2nd Ed. USA: Blackwell Publishing.
- Shebi, M. (2006). *The Experiences and Coping Strategies of HIV/AIDS Primary Caregivers within two disadvantaged communities in the Western Cape Metropole*. Unpublished PhD Thesis, Department of Psychology, Faculty of Community and Health Sciences, at the University of the Western Cape.
- Simpson, S. (2006). *A technical report Exploring whether Caregivers of People Living with HIV/AIDS receive sufficient Psycho-Social support. A south African Descriptive study at Community Care Project*. An assignment presented in partial fulfillment of the requirements for the degree of Master of Philosophy (HIV/AIDS management) at the University of Stellenbosch.
- UNAIDS (2004). *Report on the global AIDS epidemic July 2004*. Joint United Nations Programme on HIV/AIDS, UNAIDS, Geneva.
- UNAIDS (2008). *Report on the global AIDS epidemic, July 2008*. Joint United Nations Programme on HIV/AIDS, UNAIDS: Geneva.
- Uys, L. R. (2003). A model for home-based care. In L. R. Uys, & S. Cameron (Eds.). *Home-based HIV/AIDS care*. Cape Town: Oxford University Press.