

## PALLIATIVE CARE ACCEPTABILITY AMONG PEOPLE LIVING WITH HIV/AIDS IN KISII COUNTY OF KENYA

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### Abstract

This study investigated the palliative care acceptability among people living with HIV/AIDS in Kisii County of Kenya. The study used a case study design. The target population was 300,000 people affected and infected by HIV and AIDS epidemic within Kisii Municipality. From an accessible population of 500 people, a sample size of 239 was purposively selected, out of which 128 PLWHAS were support group members, whereas 74 were not, and 25 were family caregivers. Data were collected using questionnaires. A pilot study was done to check on reliable the instruments are. The questionnaires yielded a reliability coefficient of 0.7815. SPSS programme was used to analyse data. The t-tests were employed to establish any differences between support group attendances, gender and stress levels of PLWHAS. On the other hand, the Chi-square test was employed to establish any association between Mwanagetenge Community-Based Care and counselling services and the sexual behaviour of PLWHAS. It was concluded that Most PLWHAS 55.4% reported that family caregivers' attitudes towards them had positively improved due to home visits by skilled programme caregivers. This study recommends sustaining positive behaviour and prolonging the lives of PLWHAS; support group therapy could be encouraged in churches and schools to avoid isolation and loneliness. A suggestion for further research was that a study is done to determine the preparedness and effectiveness of counsellors in helping the PLWHAS in community-based programmes.

**Key terms:** Palliative care, community-based care, attitude, balanced diet.

## 1.0 INTRODUCTION

HIV/AIDS is a silent epidemic spreading worldwide and rapidly posing a major threat to humanity. However, an infected person's life can be prolonged through positive living, which implies counselling, care provision, support and nutrition (Tuju, 1996). The cure or vaccine against this viral disease is yet to be found, but antiretrovirals (ARVS) slow down HIV replication to the point that the viral load in the blood is reduced to undetectable levels (UNAIDS, 2008). UNAIDS (2006) conducted a study and found that combining therapy with three drugs reduces the risk of death by 85per cent and declines the trends in incidences of opportunistic diseases. The death rate of persons living with HIV/AIDS (PLWHAS) has been reduced in developed countries where ARVS are readily available. However, the case is different in developing countries. The situation in developing countries is the pressing need to provide treatment essential to alleviate suffering and mitigate the devastating effect of HIV/AIDS (UNAIDS, 2007). In addition, the transmission in expectant mothers in developing countries can be reduced by ART to 50per cent.

An increase in the child's health, survival and decreased infection among orphans can be reduced by visiting the VCT, using ARVs and replacing feeding for the baby (UNAIDS, 2007). An updated survey conducted by World Health Organisation (UNDP HIV/AIDS, 2008) indicated that 1.2 million Kenyans live with the disease, of which 720,000 are women, and about 650 000 are orphaned. When a woman falls sick, a younger or older woman comes in to care for them and take responsibility for the children. On the other hand, when a man becomes ill, the wife provides care and takes on additional duties to support the family. Community-based care for the infected reduces the burden on women in Sub-Saharan Africa, who carry 90per cent of the burden of caring for the sick (UNAIDS, 2002). Over a million people out of a total population of 30 million are infected with HIV/AIDS, and about 700 Kenyans succumb to the disease daily (UNAIDS, 2008). Research by the National AIDS Control Council (2000) states that about 1.5 million people in Kenya have died since the 1980s. As a result of this, about one million orphaned children in Kenya have been affected. In addition, Potential, productive knowledgeable persons have succumbed to the disease, which has greatly affected the national achievements gained in social, political, cultural and economic spheres.

Mwanyagetinge community-based care is found in the western part of Kenya, Nyanza Province, Kisii District. The community has many people infected with HIV/AIDS. Mwanagetinge community-based care uses the palliative care model and embraces medical and nursing care and the wider needs of individual families and communities. As HIV/AIDS epidemic expands, caring for patients with HIV-related diseases is increasingly taking place in the community and at home. The reason is; economic implications since the disease suck all family resources; hence they cannot pay for a long time stay in hospital. Jackson (2002) defines community-based care as a holistic concept that would incorporate the full needs of patients and address those of family carers and orphaned children.

The PLWHAS is being recognised as an important instrument for preventing the further spread of the disease and recognising that they, too, ought to die with dignity. Another unique aspect of HIV/AIDS is the secrecy, stigma, and isolation that accompany it. Despite improvements in understanding of HIV/AIDS, those who are infected continue to face possible fear, rejection and prejudice if and when their diagnosis become known. It is only friends and community members who are not told of an individual's illness. Infected adults may impact communication patterns, attitudes toward HIV infection and willingness to access social and psychological support systems. In Kisii Municipality, various organisations and churches have set up community-based care programmes since the focus is now changing from prevention to caring for PLWHAS. They have already overstretched the health and family resources to the limit. This research will focus on the impact of community-based care on social discrimination and stress levels of assisting people living with HIV/AIDS in Kisii Municipality.

People who are infected with HIV/AIDS are discriminated against in society. They are labelled by society as immoral and deserving of their predicament. They undergo self-blame, humiliation and social discrimination, which greatly affect their stress levels, and affect them psychologically. Many hospital wards are congested and unaffordable to many poor PLWHAS. HIV/AIDS is a terminal illness that compromises the immunity of the infected person and requires a long period of management of opportunistic infections, which is either done in the community, at home or in the hospital. Irrational thinking results in inappropriate emotions and ineffective behaviours resulting in dysfunctional families. People with HIV often suffer severe bouts of depression and, later in the illness, can experience many cognitive problems due to the viruses in the brain. This can not only lead to feelings of being scatter-brained but can also cause a significant amount of anxiety as the cognitive becomes more noticeable. According to HIV/AIDS strategic plan 2003 – 2007, Kisii municipality showed a stable but high prevalence of HIV/AIDS; hence about one person in every five is infected or affected by the disease. Community-based care approach has emerged as a holistic and collaborative effort by the hospital, the family and the home of the patients to enhance the quality of life of PLWHAS. This approach involves those infected and affected by HIV/AIDS and encompasses social support, counselling and nursing care (NASCO, 2008). The PLWHAS are encouraged to learn and discuss HIV/AIDS openly, dispel myths about its transmission, and reduce stigma and bullied stress levels of clients by mobilising the family and community.

## 2.0 LITERATURE REVIEW

Palliative care for PLWHAS is essential, and since the immune system is compromised, there will always be the management of opportunistic infections. Tuju (1996) points out that two alternatives that are open to an individual who tests positive for HIV are: either alienate yourself from the rest of the world or come to terms with the disease and live positively. The following are some of the elements of positive living for those infected: support group, avoiding smoking, change in sexual behaviour and eating a balanced diet. According to UNAID (1999), ART has been effective in prolonging the lives of those who can afford it and who have access to good health services. Breastfeeding mothers who are HIV positive should be discouraged from breastfeeding their children to prevent transmission.

House, Robbins and Metzner (1982) found out that support groups could be a very useful resource for people with long-term illness or poverty. One way of handling stress related to HIV/AIDS sickness is to draw on social support. Those infected with the HIV/AIDS virus need support groups to share, encourage each other and develop spiritual and economic projects together. Their lives can be prolonged by the realisation that there are many people suffering from a similar problem.

### 3.0 METHODS

The study used a case study design. The target population was 300,000 people who were affected and infected by HIV and AIDS epidemic within Kisii Municipality. From an accessible population of 500 people, a sample size of 239 was purposively selected, out of which 128 PLWHAS were support group members, whereas 74 were not, and 25 were family caregivers. Data were collected using questionnaires. The reliability of the instruments was checked. The questionnaires yielded a reliability coefficient of 0.7815. SPSS was used to analyse data. The t-tests were employed to establish whether there were any differences between support group attendances, gender and stress levels of PLWHAS. On the other hand, the Chi-square test was employed to establish whether there was any association between Mwanayagete Community-Based Care and counselling services and the sexual behaviour of PLWHAS.

### 4.0 RESULTS AND DISCUSSION

#### Palliative Care

##### 1) Distribution of ARVs by Community Based Care Givers

The survey established that only 55.4% of the PLWHAS claimed to have been receiving ARVs from community-based caregivers. This means that 44.6% have never used antiretroviral therapy. This could be attributed to a lack of resources since the programme cannot afford such requirements as; safe storage, regular monitoring of persons' immune systems and enough food. On the other hand, it is recommendable to note that, Mwanayagete community-based care programme is doing a good job. This is indicated by the 55.4% of the PLWHAS who are in antiretroviral therapy. The comprehensive approach demands that during treatment, adequate information on the drugs to be taken, their effects as well as their limitations are provided since HIV/AIDS doesn't have a cure as yet.

**Table 1: Distribution of PLWHAS Who Received ARVs from the Caregivers**

Do you get ARVs from community-based caregivers?	Frequency	Per cent
Yes	112	55.4
No	90	44.6
<b>Total</b>	<b>202</b>	<b>100</b>

##### 2) Adequacy of Social and Professional Support

The research established that 50% of the PLWHAS had been visited more than twice each month, 25.2% twice, 14.9% only once and 9.9% had never been visited. These findings are presented in table 2; from the

findings, it is clear that the PLWHAS are convinced that the program caregivers are doing a good job. As already mentioned above, on average, every homestead with a victim is visited twice a month, which provides an opportunity for contact and interaction between family caregiver, patient and programme caregiver. Services provided include counselling, nursing skills education and medical care. The majority of the PLWHAS who is bedridden after the medication has come up and later identified with the support group where they share testimonies of their lives.

**Table 2: Frequency of Visitation by Care Giver Teams per Month**

Frequency of visitation by caregiver teams per month	Frequency	Per cent
Zero	20	9.9
Once	30	14.9
Twice	51	25.2
More than twice	101	50.0
<b>Total</b>	<b>202</b>	<b>100</b>

Respondents were also required to rate the adequacy of medication and counselling services at the Mwanagetinge Centre. It was established that 55.4% rated the provision of these services as very good, 39.1% rated it just enough, and 5% thought it was very poor. About 0.5% of the respondents did not respond to this item in the questionnaire. Data are indicated in Table 3.

**Table 3: The Adequacy of Medication and Counselling Services**

Adequacy	Frequency	Per cent
Very poor	10	5.0
Just enough	79	39.1
Very good	112	55.4
Non-Respondents	1	0.5
<b>Total</b>	<b>202</b>	<b>100</b>

A majority of PLWHAS (55.4%) reported that family caregivers' attitudes towards them had positively improved due to home visits by skilled programme caregivers. Mwanagetinge community-based care programme is making a positive impact in reducing social discrimination by encouraging regular attendance to support groups. Empowerment during such meetings motivated PLWHAS to overcome social discrimination so that they could play their role in the prevention of this disease. Community visits by the caregivers help to break isolation tendencies from family members and make them feel that they are dignified human beings. The visits break down isolation and discrimination by family members concerned with the care of the sick person. They have a modelling effect as they see what is expected of them on the caregiving task. Such visitation also provides an opportunity to clarify misconceptions about HIV that many times hinder care and support by the family members. This is in agreement with Beck

(1976), who believes that offering guidance, visitation and support for PLWHAS will greatly reduce the stigma which is associated with people living with HIV/AIDS. It is important to emphasise that friends and family clearly want desperately to be helpful and supportive to their loved ones with AIDS, but often they simply don't know how.

### 3) Education of Limits and Outcomes of the Treatment

In palliative care, it is important to educate the beneficiaries on the limits and outcomes of the treatment they receive. This is one of the variables that the research sought to establish in terms of its adequacy. The data is presented in table 4.

**Table 4: Education on Limits and Outcome of Treatments**

	<b>Frequency</b>	<b>Per cent</b>
Always	79	39.1
Sometimes	93	46.0
Never	30	14.9
<b>Total</b>	<b>202</b>	<b>100</b>

Table 4 indicates that 39.1% of the respondents were always educated on the limits and outcomes of the treatment they received, while 46% were given this information sometimes. About 14.9% were never educated on the limits and outcomes of the treatment that the community-based caregivers provided to them. The comprehensive approach demands that during treatment, adequate information on the drugs to be taken, their effects as well as their limitations are provided since HIV/AIDS doesn't have a cure as yet.

## 5.0 CONCLUSION AND RECOMMENDATIONS

**Conclusion:** A majority of PLWHAS 55.4% reported that family caregivers' attitudes towards them had positively improved due to home visits by skilled programme caregivers.

**Recommendations:** It was established that palliative care education among men and women living with HIV/AIDS in the Mwanagetenge community-based care programme was adequate. Community-based palliative care education for HIV/AIDS persons and other terminal illnesses ought to be promoted in every sector. This will provide systematic desensitisation in the removal of stigma associated with such diseases and consequently bring up future stigma-free generations and lessen the burden on health facilities. The government should fund community-based care programmes in the country to minister to the PLWHAS.

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