



OVERCOMING HIV/AIDS DISCRIMINATION: THE ROLE OF COMMUNITY-BASED CARE IN KENYA

Author

Paul M. Ombati 

Email: revombati@yahoo.com

Egerton University, Kenya.

Cite this article in APA

Ombati, P. M. (2022). Overcoming HIV/AIDS discrimination: The role of community-based care in Kenya. *Journal of guidance and counselling*, 1(1), 21-28. <https://doi.org/10.51317/jgc.v1i1.170>



A publication of Editon Consortium Publishing (online)

Article history

Received: 23.05.2022

Accepted: 25.06.2022

Published: 02.08.2022

Scan this QR to read the paper online



Copyright: ©2022 by the author(s). This article is an Open Access article distributed under the terms and conditions of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License (CC BY-NC-SA 4.0).



Abstract

The aim of the study was to assess the impact overcoming HIV/AIDS discrimination: The role of community-based care in 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 determine the reliability of the instrument. The questionnaires yielded a reliability coefficient of 0.7815. SPSS version 12.5 for windows) was used to analyse data. The chi-square test was used to determine the presence of any association between *Mwanyagetinge* Community-Based Care and social discrimination. The data generated by the study established that *Mwanyagetinge* Community based caregiver visits helped PLWHAS to overcome social prejudice. The recommendation put forward by the study is that the government should give incentives to the community, churches and NGOs to develop the programs meant to assist PLWHAS and prevent the further spread of HIV/AIDS. The plan can be achieved through legislation and policy formulation for the care and protection of PLWHAS.

Key terms: Community-based care, social discrimination, *Mwanyagetinge*, impact.

1.0 INTRODUCTION

Illness can be very grave, severe or mild. Dealing with a terminal disease is perhaps the most challenging task for a family, complicated by prolonged illness and decisions about life versus facilitating the dying process. AIDS was discovered in Africa in the 1980s as the most challenging and terrifying epidemic of humanity. Scholars like Jackson (2002) likened it to the 'black death' or the Bubonic plague of the Middle Ages experienced in Europe, where thousands of people died from the disease. However, it differs from the plague because, in the case of the Bubonic plague, people were ill and died rapidly, whereas AIDS death occurs years after infection. The Human Immune Deficiency Virus (HIV) causes AIDS.

Once an individual is infected with the deadly virus (HIV), the body's immune system is reduced hence exposing the infected person to opportunistic infectious diseases. Such diseases take advantage of the collapsed immune system to attack the body. Examples of these opportunistic diseases include tuberculosis, pneumonia, coughing, fever, skin sores, and diarrhoea. HIV/AIDS is a silent epidemic spreading all over the world and rapidly posing a major threat to humanity. However, the life of an infected person can be prolonged through positive living, which implies counselling, provision of care, support and nutrition (Tuju, 1996). The cure or vaccine against this viral disease is yet to be found, but antiretrovirals (ARVS) slow down the replication of HIV to such an extent that the viral load in the blood is reduced to undetectable levels (UNAIDS, 2008). The World Health Organisation (2006) conducted a study and found that a combination of therapy with three drugs reduces the risk of death by 85per cent and declines the trends in incidences of opportunistic diseases. The rate of death of persons living with HIV/AIDS (PLWHAS) has been reduced in developed countries where ARVS are readily available. However, the case does not apply to 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). The transmission in expectant mothers in developing countries can be reduced by ART to 50per cent.

People infected by 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 an 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 dysfunction in 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 (NAS COP, 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. The study focused on determining the impact of Mwanyagetinge community-based care in helping PLWHAS overcome social discrimination in Kisii municipality.

2.0 LITERATURE REVIEW

A significant area where HIV/AIDS affects the operations of Kisii Municipality results from the silence and stigma that currently attend the disease. Kisii Municipality usually shares society's resistance to accepting the disease as a reality. Denial about HIV/AIDS affects not only individuals but also communities and the entire nation as well. One of the ways of combating denial is to give AIDS a 'human face. UNAIDS (2007) reports that once PLWHAS are stigmatised, they get a great psychological burden which affects them, preventing many others from admitting that they are HIV positive hence promoting denial mainly because of the shame that surrounds the disease. The infected are discouraged from disclosing their status to their partner for fear of desertion. PLWHAS tend to distance themselves from others in society because they have labelled them as promiscuous and deserve their fate. HIV/AIDS is usually related to irresponsibility, promiscuity and permissiveness and, for a long time, was seen as a disease of commercial sex workers and homosexuals (Conrad, 1986). Diagnosis of HIV/AIDS implies a death sentence to the victim. It is therefore feared as a disease with a fatal consequence because it is incurable and terminal (Nzioka, 1994). Therefore, a lack of understanding of HIV/AIDS disease and myths associated with its transmission continue to promote social discrimination and handicaps in caregiving in helping people already infected with the virus. Denial has greatly contributed to the spread of HIV/AIDS, though it is not different from other terminal illnesses like cancer.

His Excellency, the second President of the Republic of Kenya, Hon. Daniel Arap Moi, then in office, declared HIV/AIDS a national disaster in the year 1998; hence, for many years, the country has been in denial about the reality of this disease (Nzioka, 1994). This made the people's attitudes about the reality of HIV/AIDS change and increased acceptance of PLWHAS. Up to date, the social discrimination that PLWHAS go through has made it difficult to mention at funerals the cause of death, but repetition of phrases like, 'he died after a long illness without clarification of the nature of the illness. Individuals who are known to be seropositive and have confessed in public talked of discrimination, rebuke and abuse. Though the level of awareness is high, social discrimination is still manifested in the community.

Social discrimination is the greatest barrier to the prevention of HIV spread. This means that the quality of care provided is affected by the social meaning of the illness (Nzioka, 1994). AIDS carries so much fear that its social management is rendered extremely difficult. The patients fear condemnation, discrimination, ostracism and isolation (Conrad, 1986). UNAIDS (2004) updated global report indicates that only 10 per cent of PLWHAS knows their seropositive status. Others are unable to be open about their status because they fear they will face social discrimination. Society needs to realise that there is a need to appreciate that PLWHAS are the greatest resource in the fight against social discrimination, thus the need to involve them in response to the epidemic. Community-based care ensures treatment and prevention are accessible to all. However, the origin of HIV/AIDS social discrimination is deep-rooted in society. Disclosure of HIV status is an indication of self-acceptance and overcoming of social discrimination. It can either be partial, where PLWHAS only tell certain people their status or full disclosure, in which case, the individual reveals his/her status publicly.

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 determined through a pilot study. The questionnaires yielded a reliability coefficient of 0.7815. SPSS version 12.5 for windows 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 were any association between Mwanagetinge Community-Based Care and social discrimination; counselling services and sexual behaviour of PLWHAS; awareness and prevention of HIV/AIDS; Palliative Care Services and Mwanagetinge Community-Based Care Programme.

4.0 RESULTS AND DISCUSSION

Community-Based Care and Social Discrimination

The study investigated the impact of the Mwanagetinge Community based care programme in helping PLWHAS overcome social discrimination.

Frequency of Care Giver Visits

Respondents were asked about the frequency of visits they got from their community-based caregivers.

Table 1: Frequency of Community Based Care Giver Visits to PLWHAS

Care Giver Visits per Month	Frequency	Per cent
None	20	9.9
Once	30	14.9
Twice	51	25.2
More than twice	101	50
Total	202	100

Table 1 indicates that 50% of the PLWHAS were visited more than twice per month by their community-based caregivers. Those who were visited twice per month accounted for 25.2% of the total sample, and those visited once per month accounted for 14.9%. It was established that 9.9% of the respondents were not visited by their community-based caregivers.

Effects of Community Based Care Giver Visits

Respondents were required to state their views about the visits made by the community-based caregivers to their community and family.

Table 2: Effects of Community Care Giver Visits to the PLWHAS

	Frequency	Per cent (%)
Makes them isolate you	25	12.4
Motivates gossip about your status	31	15.3
Motivates them to show concern for you	146	72.3
Total	202	100

Table 2 shows that 72.3% of the respondents felt that community-based caregiver visits motivated their community and family to show concern for them. About 15.3% of the respondents were of the view that these visits motivated gossip about their status, and 12.4% of them felt that the visits made their neighbours isolate them. The data generated by the study, therefore, established that Mwanayagete Community based caregiver visits help PLWHAS to overcome social discrimination.

The Most Important Services Provided by Community Based Care Givers

Respondents were required to state, in their opinion, the most important service that their community-based caregivers provided them.

Table 3: The Most Important Services Provided by Community Based Care Givers

	Frequency	Per cent
Counselling for positive living	82	40.6
Provide food with high protein	20	9.9
Support group meeting	70	34.7
Medication	30	14.9
Total	202	100

As indicated in Table 3, the respondents felt that the most important service that their community-based caregivers provided them with was counselling for positive living, as indicated by 40.6% of the total respondents. Respondents who felt that support group meetings were the most important services their caregivers provided them with accounted for 34.7% of the sample, while 14.9% of the respondents felt that medication was the most important service. To 9.9% of the respondents, the provision of food with high protein was the most important service that their community-based caregivers had provided them.

Adequacy of Medication and Counselling Services

The research sought to establish the adequacy of the medication and counselling services as rated by respondents to assess how effective Mwanayagete Community-based care has helped PLWHAS overcome social discrimination. The respondents were therefore asked to rate how adequate the counselling and medication services were at the Mwanayagete centre.

Table 4: Adequacy of Counselling Services in Mwanayagete Centre

	Frequency	Per cent
Very poor	10	5.0
Just enough	79	39.3

Very good	112	55.7
Total	201	100

Table 4 shows that 55.7% of the respondents rated the provision of counselling services in the Mwanagetinge centre as very good. Those who felt that the service providers were just enough accounted for 39.3%, and those who rated it very poor were 5 per cent of the total respondents. Therefore, research findings indicate that counselling services provided by the Mwanagetinge Community-based caregivers were adequate. In a general discussion with the paramedics involved in the programme, the positive impact of drugs and palliative care education has been observed in the following ways:

- (i) The drug usage of many opportunistic infections has reduced by a great extent since infections have reduced significantly since the emphasis on hygiene as a preventive method and less use of drugs for curative purposes.
- (ii) The supplementary role of counselling and group therapy in medicine is encouraged to get psychological assistance at times.
- (iii) PLWHAS in Mwanagetinge Community-based care programmes are poor; therefore, there need to provide them with adequate drug education to empower them to decide if they are to start using antiretroviral therapy, which, considering their social and economic background, may not be sustainable.
- (iv) PLWHAS have been educated and encouraged to use traditional and locally available foods and herbs that are cheap. This is a sustainable way of health management that has been adapted in the following ways:
 - a) Oral re-hydration salt is used for the replacement of water in the body in the treatment of diarrhoea.
 - b) Pawpaw seeds are used for the treatment of amoeba and to stop diarrhoea.
 - c) Frangipani sap from a tree that treats herpes zoster, a clinical symptom of HIV/AIDS.

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. However, HIV/AIDS has been a challenge to palliative care provision offered by the Mwanagetinge community-based programme in the following ways identified during group discussions with the paramedics;

- i). The complex nature of the disease involves some patients remaining free of serious symptoms for a long period, other suffer episodes of acute illness. Patients' economic response is different, and this affects the planning and delivery of palliative care.
- ii). Stigmatisation and discrimination are still a big challenge in families, communities and even among health workers. The psychological burden involved may make the treatment less effective.
- iii). HIV/AIDS affects the whole family; any treatment will only be fully effective if the psychological, social and economic needs are addressed.

In-group discussions, the following comparison was made on community-based care with defects of hospital care, as presented in Table 5.

Table 5: Summary of the Strengths of Community-Based Care and Defects of Hospital-Based Care

Advantages of Community-Based Care		Defects of Hospital-Based Care	
(i)	PLWHAS enjoy counselling support by family and neighbour	(i)	Isolation and loneliness since no visitors
(ii)	They receive individual attention in care provision at home.	(ii)	The hospital's environment always sets an environment of bereavement and death on the way.
(iii)	Community offers pastoral care and hence holistic constantly.	(iii)	Stigmatisation by nurses and doctors with kind words and no sympathy.
(iv)	Cheaper to sustain	(iv)	Congestion and sharing beds
(v)	The diet is more patient, friendly and flexible	(v)	The unhygienic and untidy hospital environment
(vi)	Education on caregiving always and constant supervision sustain motivation for palliative care.	(vi)	TB infection is high because of congestion (a) Fixed diet not friendly to the sick (b) Seclusion to exclusive wards stigmatises the home

The remedy to defects of the hospital-based care is in a well-developed community-based programme tailored to give PLWHAS a dignified death. According to WHO (2003) reports that a comprehensive response to HIV/AIDS includes preventing new infections, preventing mother-to-child transmission, prophylaxis and treatment of opportunistic infection, dignified end of life, and critical environmental therapy is needed to ardently tackle the epidemic. Mwanayagete based-care programme is ideal in providing such a comprehensive approach though not without its own limitation.

Effect of the Services Provided Through Care Giver Visits

Respondents were also required to indicate whether the services provided through visits by the Mwanayagete Community-Based caregivers had positively improved their social relations. From data collected in the research, 65% of the respondents indicated that it had. From the research findings, we, therefore, draw the conclusion that visits by Mwanayagete Community based care teams have positively improved how the community and family treat the PLWHAS.

5.0 CONCLUSIONS AND RECOMMENDATIONS

Conclusion: The data generated by the study established that Mwanayagete Community-based caregiver visits helped PLWHAS to overcome social discrimination.

Recommendation: The government should give incentives to communities, churches and NGOs to develop the programs meant to assist PLWHAS and prevent the further spread of HIV/AIDS. This can be done through legislation and policy formulation for the care and protection of PLWHAS.

6.0 REFERENCES

1. Conrad, P. (1986). The social meaning of AIDS. *Journal of Social Policy* 17(1) 51-56. Cox Erica (2001). *Psychology for a Level*. Longman publishers.

Journal of Guidance and Counselling

2. Jackson, H. (2002). *AIDS Africa-Continent in Crisis*. Published by Sat AIDS.
3. NASCOP, M. (2008). National guidelines for HIV testing and counselling in Kenya. *National AIDS and STI Control Programme (NASCOP), Ministry of Health (MOH-Kenya)*.
4. Nzioka, C.B.K. (1994). *The social Construction and Management of HIV and AIDS among Low-income Patients in Nairobi*. Goldsmiths College.
5. Tuju, R. (1996). *AIDS: Understanding the Challenge*. ACE Commucalist Ltd.
6. UNAIDS (2004). 2004 Report on the Global AIDS Epidemic. UNAIDS.
7. UNAIDS, (2002). *Epidemiological Fact Sheet*. 2002 Update Kenya. UNAIDS.
8. UNAIDS, (2007). *Report on Global HIV/AIDS Epidemic*. 1st Global Report. UNAIDS.
9. UNAIDS, (2008). *Report on the Global HIV/AIDS Epidemic*: 4th Global Report. UNAIDS.
10. WHO. (2003). Treating 3 million by 2005: Making it happen: The WHO strategy. *Book Treating 3 million by 2005: Making it happen: The WHO strategy*, 40-53.
11. World Health Organization. (2006). AIDS Epidemic Update. UNAIDS. *World Health Organization*, 190.