Quality of Life of Women living with HIV and AIDS in Korogocho Slums, Nairobi, Kenya

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SUMMARY

Background: **Since HIV/AIDS was reported in Kenya the country has been and continues to be impacted negatively in all sectors. Despite Government's intervention initiatives to mitigate the impact, patients continue to succumb to this condition. The main objective of this study was to assess the factors that affect on the Quality of Life among HIV and AIDS positive women in Korogocho Slums.**

Methods: **This study employed an exploratory design. Quality of Life was evaluated using several items which employed a Likert-type five-point scale. These items were distributed in four domains: Physical health and level of independence; Psychological well-being; Social relationships and environment. The domain scores scaled in a positive direction – higher scores denoted higher quality of life and vice versa. Structured interviews were used to collect quantitative data while in-depth interviews were used to collect qualitative information.**

Results: **A total of 83 female patients were interviewed in this study. Only 31% reported that they were restricted by physical pain to go about their business. As high as 70% of the respondents reported that they did not get enough support from relatives and friends. Eighty percent reported that they were not satisfied with their sex life and 37% reported that the environment they lived in was unhealthy. This study reported a low quality of life of 53% among the respondents.**

Recommendations: **Clinicians and health practitioners in their interaction with women with HIV and AIDS to consider involving them in their health decision making since they are the owners of their bodies who continuously listen to the manifestation of the condition in order to improve health care outcomes.**

Key Words: Health Related Quality of Life; HIV and Aids

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Background

Since the discovery of HIV and AIDS in Kenya in 1984, the country has been and continues to be affected by the disease both negatively and positively. In its efforts to mitigate the effects of the disease, the Government of Kenya (GoK) established National Aids Control Council (NACC), a body that was mandated to come up with diverse and immediate programmes to mitigate the epidemic. Although this has been done, patients continue to succumb to the condition. This research examined the aspect of quality of life of the affected persons and how this may determine health care outcomes.

The World Health Organization (WHO) defines health as a State of complete physical, mental and social well being and not merely the absence of disease [WHO 1948]. It follows that the measurement of health and the effects of healthcare must include not only an indication of changes in the frequency and severity of diseases but also an estimation of well being. This can be assessed by measuring the improvement in the quality of life related to health care.

The WHO quality of Life user manual defines quality of life as an individual's perception in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL 1998). It is a concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationships to important features of their environment. Friedland noted that several researchers have defined quality of life as a fighting spirit associated with longer survival time for individuals (Friedland et al 1996). Taking in to consideration of the above definitions QoL then relates to adequacy of material circumstances and to personal feelings about these circumstances. Additionally, McDowell conjures that QoL includes overall subjective feelings of well being that are closely related to morale, happiness and satisfaction (McDowell 1987).

Problem statement: The manifestation of HIV and AIDS is complex. HIV infected individuals suffer from the chronic symptoms of virus induced immunodeficiency and varied psychological manifestations. Determining the impact of HIV and AIDS on the quality of life in HIV and AIDS patients can be important for estimating the burden of the disease. It could also be a road map to improve understanding of the factors that contribute to health-related quality of Life among HIV and AIDS patients. This can help in identifying targets for improving the same. In addition determining the quality of life among HIV and AIDS patients can improve the doctor-patient relationship and in understanding healthcare outcomes in healthcare management.

Objective: The study assessed the factors that affected the Quality of Life in HIV and AIDS women in Korogocho slums, Kenya using the World Health Organization measuring guideline for quality of Life among patients.

The study was conducted in Korogocho slums in Kariobangi South in Kasarani Division, Nairobi Province. Korogocho has 14,665 households with 24,257 male and 19, 545 female and is a slum settlement. It is part of the larger Mathare slums. Mathare slum is the second largest dwelling in Kenya. Korogocho has 7 villages: Grogon, Githaturu, Ngunyumu, Highridge, Ngomongo, Kisumu Ndogo/Nyayo and Korogocho. The area is served by one government health centre, five faith-based health facilities, many individual clinics, a number of chemists, herbalists, and prayer men/churches. HIV and AIDS is seen to be more prevalent in slum dwellings than in the up market settlements due to risk behaviours associated with poverty and sometimes illiteracy. This site was purposively chosen among the many slums in Nairobi province.

Study Population: The study subjects were females infected with HIV and AIDS. The sample size was 83 female patients aged between 18-55 years. Women are the burden bearers in society which translates heavily on their many aspects of life including QoL (UNAIDS 2004).

Methodology: This study was an exploratory one which utilized both quantitative and qualitative methods of data collection. Quality of Life was evaluated using 26 items. Each item used a Likert-type five-point scale. Other data collected included basic demographic information (age, education level, marital status and area of residence). These items were distributed in to four categories that included Physical health and level of independence (seven items assessed areas such as presence of pain and discomfort; energy and fatigue, mobility; sleep and rest; activities of daily living: perceived working capacity); Psychological well being (eight items assessed areas such as affect, both positive and negative self concept, higher cognitive functions; and body image; Social relationships (three items assessed areas such as social contacts, family support and ability to look after family; sexual activity and environment (eight items assessing areas such as freedom, quality of home environment; physical safety and security and financial status; involvement in recreational activity; health and social care: quality and accessibility). The domain on environment was also considered because it plays a major role in determining health status, mediating disease pathogenesis and limiting or facilitating access to health care. The domain scores scaled in a positive direction – higher scores denoted higher quality of life.

Sampling procedure: The research targeted women who were HIV positive and therefore purposive sampling and snow balling was used.

Data collection: The study employed two methods of data collection, structured interviews and group discussions. A structured questionnaire was used to collect quantitative data. The questionnaires were administered by field assistants. Several dimensions of the questions were put into consideration to cover issues that determined HRQOL as mentioned above. Since the research was carried out on human subjects who were living positively, ethical consideration was adhered to. The subjects therefore were given the opportunity to consent to the study by signing consent forms after the purpose of the study was explained to them. They were also assured of confidentiality of their records. Two FGDs of 10 people each were administered. They were sourced through snowballing and those who were willing to participate. The Principal Investigator moderated the interview. A guide was developed and used to provide direction for the group discussion. This ensured that all related issues were covered in the study. An Assistant was trained on taking field notes. FGDs were tape-recorded to ensure that all information was recorded and therefore compared with the written notes for accuracy. Permission to record their voices was sought. Key informant interviews were included in the study. It targeted social workers (HIV positive as well and counselors), leaders of support groups, the area chief and church leaders. A guide was developed to guide the direction of the interview. Responses were sorted out in themes and transcribed.

Data Management, Storage, and Analysis: Notes on responses were taken, sorted out into themes and transcribed. Tape recorded data was stored safely under lock and key. Data was then transcribed. Quantitative data was analyzed using Excel.

Results and discussions: This was an exploratory study that targeted HIV positive women. The demographic variables included their age, level of education and marital status. It was noted that academically 69% of the respondents attained only primary level of education. This is a huge number going by the disadvantages of low education levels in Kenya. In itself, this may contribute a lot on the prevalence of HIV and AIDS in slum areas due to lack of enough information to make major decisions or informed choices. On marital status 7% were cohabiting, 15% were married, 43% were widowed and 35% were single. This factor poses a lot of challenges both economically and socially especially among the widowed and the singles. Stigmatization due to HIV negates social network capital in any community. Sustaining intimate relationships becomes near impossible because of the burden of the condition and its associated risks and perceptions. On one level feeding of families in resource challenged societies creates complexity among people living with HIV and AIDS. It becomes easier for women to look for other sources of income through areas like sex bartering thereby increasing the chances of re-infections. These factors pose a lot of challenges to caregivers both at micro and macro levels.

The average age of respondents was 33 years of age. These were young women with many aspirations and hopes of life but already burdened with HIV/AIDS complications. The same group was disadvantaged due to the fact that they also belonged to the majority group with primary education. Due to this they could be limited in choice making on many issues for lack of appropriate knowledge. Being mothers, they were the caregivers in all spheres of life. The fact that they could wish to engage in fulfilling relationships but hampered with stigmatization could make them engage in risk behaviours that continued to reduce their life cycle. These factors could actually lower their QOL perceptions.

Extent of physical Pain

Apparently only 31% reported that they were hampered by physical pain to go about their business. This is probably due to the fact that HIV and AIDS is not a disease but a condition. Pain only sets in when opportunistic diseases like malaria or TB manifests.

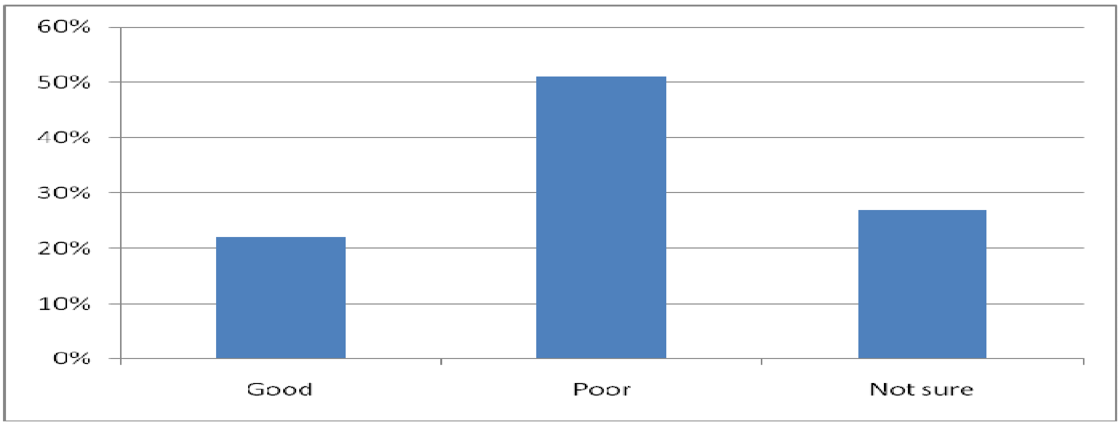
Table 1: Distribution of respondents according to the extent to which the physical pain prevented them from doing what they needed

Response	N	Percentage
Not at all	6	7.3
A little	37	45.1
Moderately	13	15.9
Mostly	17	20.0
Completely	9	11.0
TOTAL	**83**	**100.0**

Capacity to work or get around

On the element of capacity to work, 70% reported they were unable to work or carry on with their normal daily activities most of the time. This result seems to agree with Bertero in his study on leukemia patients (Bertero et al 1993). Fifty one percent reported that they were not able to comfortably get around most of the time. Montazeri also alluded to the importance of respondents' ability to comfortably do what they needed to do as highly ranking in his studies (Montazeri 1993). This again depends on many factors e.g. if one is sick, emotionally stressed or physically weak. The manifestations of HIV and AIDS are varied sometimes due to the opportunistic infections that affect the patients negatively thus limiting their functionality options especially if nutrition is poor.

Figure 1: Percentage distribution of how well respondents reported that they were able to move around



The factor of enjoyment of life

On enjoyment of life 31.5% reported that they enjoyed life. The aspect of life enjoyment is individually centered; it could also be linked to the environment, the circumstance and the condition of the body system. Factors that may lead to negative life enjoyment in PLWHA include; persistent opportunistic infections, stigma associated with the condition and limited strength to perform various tasks.

Table 2: Distribution according to degree of enjoyment of life

Response	N	Percentage
Not at all	6	8.2
A little	20	27.4
Moderately	24	32.9
Mostly	10	13.7
Completely	13	17.8
TOTAL	**83**	**100.0**

Satisfaction with Sex Life

Eighty per cent reported that they were not satisfied with their sex life. It should be noted that a large percentage of respondents involved in this study were the widowed and the singles. This could create challenges to get sex satisfaction because of lack of permanent relationships as a result of their condition. As found out from the qualitative studies relationships did not last on realization that the women were positive. It was also revealed that women engaged in unprotected commercial sex because it paid higher than the protected sex. It was reported from the qualitative studies that most male partners did not disclose their HIV status and they demanded unprotected sex. This can lead to re-infections most of the time. Some of the women engaged in alcoholism because they believed that alcohol made them forget their problems. This was dangerous because then they became vulnerable to circumstances surrounding them. Commercial sex was highly practiced to supplement their income but it came with fears and concerns.

> *"My husband died and left* me *with HIV and 7 children. I struggle to feed them. Sometimes I am forced to leave them in the house alone as I go to look for sex business at night. But now I discovered that my girl of 15 years is pregnant and I feel so sad because I do not know whether she is positive. I am depressed about this".*

Table 3: Distribution of respondents' satisfaction with sex life

Response	**N**	**Percentage**
Very dissatisfied	44	54.3
Dissatisfied	21	25.9
Neither nor dissatisfied	10	12.3
Satisfied	1	1.2
Very satisfied	5	6.2
TOTAL	**81**	**100.0**

Satisfaction with Personal Relationships

On Satisfaction with personal relationships, 67% reported that they were dissatisfied. This result seems to agree with findings of Bowling who noted that support from friends ranked highly to chronically ill patients (Bowling 1991). Generally people fear rejection at all levels. HIV has stigma, both self perceived or real profoundly attached to it. Body appearance was another factor, yet the risk involved was another aspect. In the qualitative interviews it was noted that in intimate relationships, women did not disclose their status because when they did, the male partners discontinued the relationship. It was also noted that group therapies played a distinctive role.

> *"I get inspired when I meet with other people living with HIV."*

Table 4: Distribution of respondents' satisfaction with personal relationships

Response	N	Percentage
Very dissatisfied	26	31.7
Dissatisfied	29	35.4
Neither nor dissatisfied	18	22.0
Satisfied	4	4.9
Very satisfied	5	6.1
TOTAL	**82**	**100.0**

Satisfaction with Support from Friends

As high as 70% of the respondents reported that they did not get enough support from friends. In his studies, Bowling also noted that support from social networks was important (Bowling 1991). Gilligan noted that women's identity and sense of integrity was entwined with their ability to be involved in caring responsibilities and relationships with others (Gilligan 1982). There was an element of lack of family support. It was noted that most mothers were single. They reiterated that they did not get enough support from their families due to their condition.

Most of them felt lonely as they did not get enough support from their friends and families. Falling in love inspired them although the relationships did not last. They gave this as the reason to why they did not wish to state their status because the men abandoned them on revelation of their status. Well, friends can only support you up to a certain point. The burden of supporting an HIV person may also be perceived as a continuum hence no beginning or no ending points. By nature human beings are not as ready to carry burdens forever and therefore support may be available only occasionally.

Table5: Distribution of respondents' satisfaction with support from friends

Response	N	Percentage
Very dissatisfied	34	42.5
Dissatisfied	22	27.5
Neither nor dissatisfied	15	18.8
Satisfied	7	8.8
Very satisfied	2	2.5
TOTAL	**80**	**100.0**

Effects of Environment on the Quality of Life

About 37% reported that the environment they lived in was unhealthy. Burbank in his studies also mentioned suitability of the home as an important component of the quality of life (Burbank 1992). In the case of this study, this could be explained due to the fact that in slum setting, there is lack of clean water, no sewerage system and maintenance of garbage disposal. In adequate housing facilities also leads to large families putting up in single rooms. The above factors make the environment not conducive enough for human habitation. On the other hand people tend to get used to these conditions after putting up in such places for a while and so do not attribute much attention as to whether the environment was healthy or not.

Plights of women living with HIV and AIDS, their aspirations and hopes

The issues and fears that women with HIV and AIDS faced were varied. There were incredible revelations from the participants that outlaid their fears, aspirations and hopes. The most fear that positive mothers had was that of leaving orphans behind when they eventually died. Another aspect that was noted was the non-adherence to medication. Asked why they felt they could not complete the medication, they said the tablets were big in size and therefore uncomfortable to swallow.

> *"I know that even if I take drugs I will eventually die anyway and this frightens me" said* one participant. *"When I feel a little better I do not take medicine and sometimes we share drugs especially if one of us is too ill to visit a health facility"*,

There were those women who were in the category of ages 18-24 and who were HIV positive.

> *"I got infected as a child through mother to child transmission. Am still a virgin but I wish to get married and have my own children and live a normal life like everybody else. I still do not know how to deal with the fact that am a virgin yet am HIV positive".*

Yet another aspect noted was that mothers were still delivering at home for fear of finding out their status. The participants also outlined their concern towards most Non-governmental organizations and support groups that carry out research.

> *"Most of them have been carrying out research using us as guinea pigs and yet we do not see or benefit from these researches. In fact we are tired of people using our condition to collect data. Some go as far as exposing our status",*

Conclusion

On this AIDS front, HIV and AIDS programmes must be a continuous process. The policy makers must expand and intensify HIV prevention measures, because knowledge has shown that prevention works. This should be done at two levels, at the level of the individual to increase knowledge and skills and encourage safe personal behaviour, and at the level of society, its institutions and attitudes, to create an environment supportive of safe behaviour. Furthermore, the prevention campaigns must give higher priority to the most vulnerable groups. They must actively involve their target populations to ensure they are relevant. HIV programming must strive for equity so that women all over Kenya and from all walks of life are able to benefit from the advances in science and technology that only a tiny minority enjoys at present.

Recommendations

The Government's intervention programs aim at improving the QoL of people affected by HIV/AIDS. However this research reported a low quality of life of 53% among the respondents. It is recommended that specific HIV and AIDS programmes should be tailored towards vulnerable groups so as to enhance their quality of life. Clinicians and health practitioners in their interaction with women with HIV and AIDS to consider involving them in decision making since they are the owners of their bodies who continuously listen to the manifestation of the condition in order to improve health care outcomes.

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