

Care support and quality of life outcomes among persons living with HIV in the HAART era: Findings from southwest Nigeria

Adebola A **Adedimeji**¹ Oluwole **Odutolu**²

¹Department of Population and International Health, Harvard School of Public Health, Boston, MA USA

²Harvard AIDS Prevention Initiative in Nigeria (APIN), Abuja, Nigeria

Corresponding author:

Adebola A. Adedimeji

Harvard School of Public Health

665 Huntington Avenue,

Building I, 12th Floor

Boston, MA 02115

Tel: 617-432-1700

Email: aadedime@hsph.harvard.edu

Abstract

HIV/AIDS is a major public health problem in many developing countries where it has contributed to undermining the health infrastructure and lowered life expectancy among those infected. Although no cure exists for AIDS, significant advances in therapies have transformed AIDS into a manageable chronic condition and improve well being of those infected in developed countries. However, in developing countries, such transformations are yet to occur due to socio-economic, structural and environmental factors. This paper addresses the issue of how care and social support contribute to improving quality of life of People living with HIV/AIDS (PHA) in view of serious difficulties confronting them and the inadequate access to therapies.

Fifty persons living with HIV/AIDS, 8 health personnel and 32 persons who provide care for PHA were involved in the study. Qualitative data were obtained through participatory methodologies such as interviews and discussion sessions in Ibadan and Ilesa, both in Southwest Nigeria. Analysis of data used the grounded theory (GT) approach. Themes that emerged, including personal/health concerns, family/children's needs, financial pressures, stigma, access to drugs/health services, and availability of care and social support, were considered by PHA as crucial determinants of their health and well-being. The activities of the support groups, however, appear to cushion the negative effects of these. The authors recommend that HIV/AIDS programmes should address issues that affect the quality of life of PHA given the socio-economic and structural constraints to care, particularly in resource-poor settings while governments need to provide a policy environment that strengthen support groups promoting the interests of PHA.

Key Words: Health-related Quality of life; Care support; People living with HIV/AIDS; Southwest Nigeria.

Background

Human immunodeficiency virus (HIV) infection and Acquired Immune Deficiency Syndrome (AIDS) constitute the greatest health challenge for mankind in the 21st century. In Nigeria, the epidemic already poses a massive public health burden with figures from sentinel surveys conducted between 1991 and 2001 (Federal Office of Statistics, Sentinel Survey Data, 2001) showing a consistent rise in prevalence rates, morbidity and mortality. While the search for a vaccine goes on, hopes for reducing related mortality and morbidity depend on the availability and accessibility of antiretroviral therapies (ARVs) that can delay disease progression and increase life expectancy (Deeks, Smith, Holodniy, Kahn, 1997; Saag & Schooley, 1998).

In many high income countries where antiretroviral therapies are available and accessible, they have helped in maximising well being and improve quality of life (QoL) for large numbers of people living with HIV/AIDS (PHA), thus transforming AIDS from a fatal disease to a manageable, chronic illness. Such transformations have however not been achieved in poorer parts of the world, particularly in sub-Saharan Africa where the epidemic is most severe, due in part to limited or complete lack of access to ARV. The World Health Organisation (WHO) estimates that only 8% of the 6 million persons who need ARV have access to them due to social, economic and structural obstacles. These obstacles are currently being addressed via the “Treat 3 million by 2005” (3 by 5)” global initiative of the WHO (World Health Organization, 2003). In line with this initiative, the Nigerian government embarked on a pilot programme to provide ARV to those who need it and to expand access in the near future.

The advantages inherent in providing universal access to ARV could be offset by potentially negative challenges in the lives of PHA. For example, the absence of care and social support, critical to ensuring adherence to ARV and reinforce prevention efforts, may jeopardize the modest gains achieved in resource poor settings and compromise well being. This is particularly important because the psychosocial and economic challenges confronting people living with HIV/AIDS (Schonnesson, 2002) anxieties and uncertainties regarding the side effects of medications, societal oppression, stigma and discrimination (Letamo, 2003; Paxton, 2002) may stimulate feelings of loneliness, abandonment and isolation. It is therefore important to consider maximising QoL when prolonging survival (Sanders & Burgoyne, 2002).

Infection with HIV is known to significantly affect health status and health related quality of life (HRQoL) (Bastardo & Kimberlain, 2000). Available evidence suggests that social support can attenuate this effect on well being and health outcomes (Stansfeld, Bosma, Hemingway & Marmot, 1995; Woloshin, Schwartz, Tosteson, Chang, Wright, Plohman & Fisher, 1997). Studies of HRQoL among HIV infected persons in developed countries (Sowel, Seals, Moneyham, Demi, Cohen & Brake, 1997; Burgoyne & Renwick, 2004) documented a positive relationship between social support and health outcomes. However, few studies (Bastardo & Kimberlain, 2000) have examined how care and social support have affected quality of life among HIV positive people in developing countries, especially in sub-Saharan Africa where the impact of the epidemic has been most dramatic. Understanding the role of care and social support and its relationship to HRQoL is important for several reasons; first is the HIV related stigma and discrimination, which make access to care and social support more difficult for victims. Second, HIV infected persons in Africa face restricted access to ARVs due to several socio-economic, structural and other constraints. Third is the ambivalent attitudes and behaviours from family members, caregivers and friends (Castro, Orozco, Aggleton, Eroza & Hernandez, 1998) and finally, the significant challenges that the number of infected persons pose to the fragile socio-economic, cultural and health institutions. Such knowledge will aid understanding of the impact of the infection on the overall well being and coping mechanisms among PHA.

The rising prevalence rates in resource poor settings where most individuals do not have access to medical care also makes the study of factors outside of clinical environment that impact on quality of life more important. In addition, while the effectiveness and cost of different medication regimes in reducing the impact of HIV/AIDS has received sufficient attention in medical literature (Creese, Floyd & Guinness, 2002), the need for supportive interventions has not been well researched (Magnus, Schmidt, Brown & Kissinger, 2002). Thus, as O’Keefe and Wood (1996) argued, ‘it is important to be able to identify areas where intervention can improve function and keep PHA independent for as long as possible’ (p.32) . Such research will provide a basis for addressing behaviours that cannot be easily investigated within clinical settings.

In this paper, QoL is operationalized to take cognisance of the totality of an individual's well being and the subjective reality of their conditions rather than on the clinicians (or researchers) perception based on a number of indicators. This approach is adopted recognising that QoL refers to a broader concept of health. It is within this scope that the impact of care and social support in contributing to QoL among people infected with HIV was investigated.

Given the foregoing, this paper highlights findings from a study that examined the influence of care and social support on QoL outcomes amongst PHA. It appraised the extent to which social, economic, psychological, health-resource and environmental factors contribute to improve QoL of PHA. Based on the assumption that individuals who have access to care, social support and ARV therapy will experience better quality of life than those who do not, it documents how these factors impact on the livelihood, coping mechanisms and QoL of persons living with HIV in southwest Nigeria.

Methodology

Study Design

This is an exploratory study that obtained data through a participatory methodology; an interactive process designed to investigate perceptions, knowledge and practices about specific issues using both verbal and non-verbal techniques.

Study sites

Ibadan and Ilesha in southwest Nigeria were the study sites. Several factors influenced their selection: the prevalence of AIDS, availability of health facilities where PHA seeks care and availability of support groups. The difficulty with recruiting participants on an individual basis required the involvement of health personnel and support groups who facilitated access to potential study participants. In each study location, one support group was identified after taking into consideration the size of membership, length of existence and previous/current activities. These self-help associations have the aim of supporting and meeting members' needs, which include emotional, financial and material support, skill acquisition, access to ARVs and advocacy activities. Both associations, with a combined membership of 350 persons from low socio-economic background, are part of the Network of People Living with HIV/AIDS in Nigeria (NEPWHAN) whose affairs, like those of the support groups, is coordinated by a body of elected officers. Funding for these groups comes mainly from donations and contributions from membership dues which are used to meet members' needs.

Subjects

Subjects were a sample of PHA aged 18 years and above. Selection was done in stages after extensive deliberations and agreement with health personnel and officials of support groups regarding access, confidentiality, purpose of the study and logistics for data collection. The first stage involved contact with officials of selected health facilities and support groups to create awareness and seek approval for their participation in the research.

Stage two involved selection of 50 persons (25 from each study location), using simple random sampling techniques, from a list of registered members obtained from the support groups. Registered members are PHA who participate regularly in the associations' activities and have a series of obligations and benefits. Respondents were included in the sample after they had given informed consent following the investigators' invitation to participate in the study.

Stage three of the selection process involved the selection of caregivers and health personnel identified by selected PHA respondents. In selecting caregivers, each PHA was required to identify someone s/he considered as playing a key role in providing them with care support since they were confirmed positive. Those identified represented a range of biological and non-biological relationships: parents, children, siblings, extended family, and members of religious groups. Of the 50 persons identified in this category, 32 persons consented to participate in focus group discussions, while 8 health personnel granted in-depth interviews.

Instruments

Based on the issues identified in the literature review, an interview guide, containing issues identified from literature as being important to PHA quality of life was developed and used for individual interviews with PHA. This guide was continuously revised and updated to incorporate emerging issues as the interviews proceeded from one PHA to another in line with the grounded theory approach. In addition, a demographic questionnaire, flow charts and pair wise rankings were also used among PHA. Discussion guides were developed for focus group sessions with care providers and in-depth interviews with health providers. The guides were similar and elicited information concerning participants QoL, general health status, care and social support, stigma, coping styles and access to drugs and treatment.

Individual Interviews

Interviews and discussion sessions were conducted in Yoruba language over a three-week period. These were recorded on audio- tapes after permission was obtained from participants. IDIs lasting between 60 and 90 minutes were held with PHA respondents. These were held in various locations; homes, health facility, support group offices, workplaces, etc, depending on what was acceptable and convenient for the respondent. The investigators, working with 2 research assistants conducted all the individual interviews with each PHA. In all cases, no third parties were present during interactions with respondents to create an atmosphere in which respondents felt free to discuss issues raised and fully express themselves without inhibitions. Interviews were also held with 8 health personnel who consented to participate in the study. Interviews with health personnel were held in the health facilities where they work.

Focus Group Session with Caregivers

A total of thirty-two respondents participated in the 4 Focus group sessions held with caregivers already identified by the PHA. Each caregiver was invited to participate in the study after similar procedure to obtain informed consent was applied. The discussion guide elicited information about general perceptions, reactions and acceptance of PHA within the community. Given the nature of participant selection, it was not entirely possible to strictly apply rules of homogeneity in allocating individuals to discussion groups. However, discussion groups were separated on the basis of gender

Ethical approval

The Ethics Committee of the London School of Hygiene and Tropical Medicine granted ethical approval for the study. Respondents were asked whether they were willing to participate in the study after they were fully briefed about the purpose and objectives of the study by the investigators. Those who consented were required to complete and sign an approved written consent form and a demographic information sheet prior to interviews and discussion sessions. Respondents were informed of their right of withdrawal at anytime during the interview if they felt compelled to do so. No refusal was recorded at this stage.

Data Analysis

The study used the grounded theory (GT) approach (Glaser & Strauss, 1965), which revolves around the concept that emerging theory is grounded in the information gathered directly from a target group of individuals, and places emphasis upon individual's account of their experience (Pidgeon, 1996). GT involves an iteration process in which data collected from one interview is analysed before conducting the next interview, thus making it possible to introduce issues for discussion into the next interview from the information obtained from earlier interviews. In this way, each individual interviews and discussion session was analysed before the next one was conducted.

Each interview was transcribed and translated verbatim and transcripts were reviewed for accuracy by re-listening to tapes and checking for anomalies. Each transcript was closely inspected to generate several themes that were further explored in subsequent interviews. An indexing system of themes was generated with cross-references between themes and specific interviews and points in the text where the theme emerged. The aim of this process was to arrive at a range of indicators, which reflected the impact of care and support on HRQoL. The whole process was iterative, starting with transcription of the interviews, highlighting pointers on the interview transcripts, making notes, linking themes together, further integration of categories and defining the core themes. This process was repeated until no further themes emerged and a saturation point was reached. A validity check on this process was conducted, which

involved the transcript being read by 3 persons who did not participate in the interview and there was complete agreement on the themes, which emerged.

Six themes emerged from the data. These include personal/health concerns, family/children's needs, financial pressures, stigma, access to drugs, treatment/health services, and availability of care/social support. These issues impact significantly on the QoL of PHA and the findings are presented to highlight these issues.

Study Limitations

Infection with HIV/AIDS is a highly stigmatized condition in the study setting, therefore many PLWHA are unwilling to disclose information about their condition or they may deny the condition when asked if they are positive even in the health facilities where they receive treatment. This makes it difficult to identify and interview potential participants. To overcome this problem, participants for the study were recruited via support groups. This is a limitation of the study since only participants who were already linked with a support group identified in the study sites were included in the study.

Results

Demographic characteristics

Table 1 presents participants' demographic and health characteristics. More females (70%) participated in the study. Respondents' age ranges from 18 to 56 years with those aged between 31-35 years in the majority. Forty-eight percent reported being self-employed and 32% were unemployed. Although, less than half (46%) were married, one in four reported having biological children. Living arrangements showed more than half live in rural areas mostly with parents.

Two-thirds of respondents were Yoruba, the dominant ethnic group in southwest Nigeria. Educationally, 55% had secondary school or lower. Accurate information on income could not be obtained but most reported an equivalent income of less than \$1 a day. Regarding health status, reported length of HIV diagnosis range from 8 months to 6 years with 45% reporting at least 2 years. Although, seventy-five percent of respondents are in stages 2 and 3 of the classification by WHO, few (36%) had commenced ARV treatment.

Ranking of factors determining QoL

The PHA were able to identify and rank issues that they consider most important in terms of improving their QoL using the flow charts and pair wise rankings. In doing this, a list was generated, based on the themes that emerged from the various interviews and the PHA had the opportunity of adding other issues which were not highlighted in the interviews. Through this process, a list was developed and on a scale of 1 (least important) to 10 (most important) participants ranked issues they considered important in improving their QoL. The issue rated highest was availability of care and social support from family members and close friends (93%). Other highly rated concerns include: financial pressures (89%) stigma and discrimination (87%) health concerns and counselling (85%), access to drugs and treatment (83%), use of ARVs (65%) and family and children's needs (80%).

Emerging Themes

The following section presents relevant information from the qualitative data that buttress the ranking presented above.

Health concerns and the impact of counselling

Participants' experiences and reactions reflect the difficulties in coming to terms with testing positive for HIV. Reported reactions when respondents first heard about their positive status include denial, surprise, despair, confusion, anger and suicidal thoughts. However the availability of pre and post-test counselling considerably influenced how some adjusted to this period. A woman in her late 30's said:

'I was convinced the Doctor made a mistake. I've never messed around. I just couldn't believe it was true when he told me I was positive, ...I wanted to go mad, but the Nurse told me that my late husband could have unknowingly infected me and it occurred to me that he died after a prolonged illness which nobody could explain.'

Some expressed a deep sense of sorrow and hopelessness regarding the future particularly in view of the constant interaction with the medical system. This interaction reminds them of their positive status. One of those in this category said:

'...Outwardly you look good; many people don't know you are positive. When you are in the midst of people and you ought to be happy, constant medication and visits to the hospital makes you feel sad and abnormal. You worry about people knowing your status when they see you here [hospital] because they know this is a hospital for HIV people'.

Despite these negative experiences, others accept the situation with optimism, especially with continuous counselling from health workers. Even among those who have developed full blown AIDS, they expressed optimism about their health as a result of the continuous counselling to which they were exposed. Some participants reported that the counselling they received made them cope better with the challenges that daily confront them in their efforts to remain healthy and active. One of the participants reported that:

Family commitments and children's needs

Family commitments and children's need was also identified as an important issue with potential for quality of life of PHA. Participants who have children and family commitments were concerned about what will happen when they die. Thoughts like this leads to mental stress that worsens their condition. As a single mother reported:

'My greatest concern is for my two children. It is difficult to meet the needs of the children how much less yourself. Their situation has worsened since my illness started and their father abandoned us. 'We were told to eat well, but I don't even have the money to buy the necessities. I often deny myself food so that my children can eat and this worsens my condition. I cannot work as hard as before to be able to meet their needs, but I have no choice if I don't want them to suffer, I need to be strong for them [children]'.

Others were worried about how their HIV status will affect their children once people in the community know that they are HIV positive. Others were concerned about children taking on adult responsibilities when they are not ready for it because of their condition. Despite these concerns, children's welfare strengthened the resolve to stay healthy as long as possible. Among participants who had no children, concerns about family welfare were similar, particularly where the infected person was the breadwinner or a major financier of the family before the onset of illness. One participant reported:

'I am the first child of my aged parents and I have several younger ones who depend on me. I hate to see that I can no longer cater for them due to this illness. My parent's condition has changed and I can only blame myself for allowing this to happen'.

Financial concerns

Finance was a problem for all the participants. It was an issue that recurred throughout interviews and discussion sessions. Even though accurate estimates could not be obtained, those who have a source of income reported the equivalent of less than \$1 a day. Financial difficulties affected several aspects of life of PHA, including access to food and drugs. It is especially acute due to the cost of ARVs (between N1500 [\$11.5] to N3000 [\$23] per month)' in addition to the cost of travel. For example, a PHA who has commenced ARV treatment spends between N2500 [\$19] and N5,000 [\$38] every month to buy the drugs in Lagos or Ibadan. Those living in rural areas spend more on transport and accommodation than those living in cities.

The situation is critical for those without a regular income and even more severe among those with irregular incomes. Those who are self employed reported the considerable impact inadequate financial resources has on their ability to cope, particularly in terms of meeting the basic necessities that will keep them stable. The deteriorating health also affected their ability to generate/earn an income because they were no longer able to work or devote time to manage their business. Those in paid employment were concerned about losing their present source of income. As one middle-aged man said:

'Nobody in my office knows my problem, but I keep taking time off every month to see the doctor or travel for ARV. In fact, it has become too frequent that I am worried I may lose my job and I cannot afford that now, otherwise it will hasten the deterioration of my health'.

Inadequate financial resource is severe among respondents with irregular incomes, with unstable employment, with low level of education, who are women, and lack support from immediate family members mostly because they have been abandoned. The severity of the problem compelled the support groups to render financial assistance to those in dire need. The opportunity to secure financial assistance is, perhaps, the most important reason for the large membership of support groups. One participant reported that:

'Without this association [support group] where would many of us be now? I am sure half of the people here would have died since they cannot afford meeting their basic needs how much less the cost of travelling to buy drugs? The financial assistance coming from this organisation has gone a long way in helping many of us stay alive'.

Caring for PHA during bouts of opportunistic infections involves considerable financial resources. Family members who participated in discussion groups agreed that many have had to sell personal property in order to care for the PHA. Similarly, the lack of financial resources to meet basic needs of PHA was reported as the most challenging issue confronting the support groups. This fact was alluded to by the response of one of the officers of the support group who corroborated what the PHA said when he noted:

'Meeting financial needs is the most challenging aspect of our work. Most members do not have a source of income, but we have to ensure they have access to the only lifeline [ARV] by proving it free to those least able to afford it while those who can are listed on the revolving loan scheme. We are desperately in need of help regarding this...'

Experiences of Stigma

Experiences of actual or perceived stigma compromise the quality of life lived by most PHA and these contribute to the unwillingness to disclose information about their status. In most cases, PHA only disclose information about their status only to support group members or trusted relatives in anticipation of and/or return for care and support. For this reason, PHA often undertake treatment and counselling activities related to their HIV status with utmost secrecy for fear of what would happen if people around them find out about their status. To hide their status, many PHA are forced to seek services or join support groups far from their local communities. Thus, it is common to find PHA from Ilesha go to Ibadan or those in Ibadan go to Lagos to procure drugs and other services. In the same connection, we found that only two-thirds of PHA who have been diagnosed for up to 2 years disclosed information about their status to a family member, some doing so immediately and others waiting for between 6 months to several years. These stigmatising experiences were linked to persons in the community and institutions involved in service delivery, including hospitals and health personnel. Some participants reported that:

'Even nurses and doctors who are supposed to know better treat us as if we are untouchables...they are always wearing gloves and washing their hands even when they have to give you drugs; always stealing a look at you, not straight in the eye'. The consciousness that you are a potential source of infection is always there and it resonates in the way people deal with you. Sometimes the way you are treated speaks volumes about the nature of your problem'.

'I was admitted in a maternity ward to have my baby. At first, the nurses and everybody was nice and treated me well. After the birth of my baby, they suddenly began to treat me differently and I got a lot of attention more than other women. Whenever anyone attends to me, they do strange things I don't understand. It was much later that my husband and the doctor told me I am HIV positive. I can never forget that experience...it was very embarrassing'.

The consequence of stigma on the health of PHA has been a major focus of campaign activities from support groups. As some of the officers pointed out, stigma-reduction activities have focused on awareness creation by getting well known PHA in the country to share their experiences. From the responses, these efforts have improved the perception and treatment of PHA in the community.

Access to drugs, treatment and health services

There are a number of ongoing projects that aim to increase access to ARVs for PHA in Nigeria. In spite of these programs, it is apparent that few PHA have access to drugs, the major reason being financial. Among participants who had commenced ARV therapy, there was agreement that access to ARV contributed immensely to improving health by preventing opportunistic infections. However, the importance of ARVs was overshadowed by issues relating to cost.

The importance of cost as a barrier to ARVs was extensively discussed by PHA and during discussions with care providers. An emerging consensus is that while availability of ARVs is important, access to it is most crucial. Those currently on antiretroviral reportedly pay between N1500 to N3000 (\$10-\$20) every month to access drugs. This cost includes travel, accommodation and feeding for 1 or 2 nights (depending on location) spent outside place of residence when travelling to Lagos or Ibadan to purchase drugs. Participants also spoke about the efforts of the support groups in ensuring access to drugs. When asked about how those with no source of income buy drugs, a support group worker said:

'It is difficult...many of them depend solely on this group for access to drugs. For this reason we set up a scheme in which drugs for those with most need are purchased from donations. In other cases, we use a revolving loan scheme to allow members have access to drugs'.

Aside affordability, availability of drugs was another issue. As reported in a group discussion:

'Sometimes, you have the money, but the drugs are not available... out of stock. Earlier this year [2004] we were forced to use expired and/or fake drugs because the government designated centres ran out of stock and there were concerns about developing resistance'.

Concerns were also raised regarding access to treatment and health services. One hospital worker said:

'Quite a lot of people are getting this condition [HIV], but the facilities are not there to treat them. Sometimes, we are short of doctors/nurses to attend to them especially when they are in a crisis. Many of them have died because of this. Again, the facilities are supposed to be free, but they have to pay for almost everything... from registration to being tested for a CD4 count due to under funding from the ministry'.

Care support

Concerns relating to care support were extensively discussed and were particularly heightened among those who are asymptomatic. As reported earlier, the desire for care support considerably influence the willingness to disclose information about one's status. Where support is not expected, information is withheld. Some of the responses obtained to questions regarding care support buttress this point. A young woman said:

'I've gained a lot by telling close relatives and trusted friends who have supported me since they know I hadn't lived a rough life. They also know how to relate to me better'. 'If I did not tell my mother who would have been taking care of me now? Every time she comes here with me, especially at the initial stage when my health deteriorated seriously. I couldn't walk or do anything by myself; it was my mother who was there for me'.

The provision of care support is largely influenced by the prevailing cultural norms among the Yoruba of providing care for those who are ill. In the case of HIV/AIDS and given the ignorance and stigma that surround the diseases, such care is provided only by close relatives of PHA who consider it an obligation to take care of their own. One mother said:

'No body wants to touch her...even the hospital staff. So if I don't do it, then who will do it? She is my daughter; I don't want her to die. I've been told with proper care, she can live long and I have seen a lot of changes since she was placed on medication'.

In spite of this obligation, some care providers complained of being overwhelmed by the demands of caring for PHA. The wife of a PHA said:

'Since this terrible disease started, there has not been rest for anyone of us. I had to leave my job, moved to the village and the business I started here has lacked attention. Both the children and I take turns caring for him. My joy however is that without us standing by him, he would have died long ago'.

It is noteworthy that such level of care is not universal for all PHA. Some reported being isolated and rejected by the community and family members. One participant acknowledged:

'Being infected with AIDS is synonymous with death; nobody wants to associate with you, people device all sorts of excuses to stay away'. Being rejected and despised makes you feel really sad and depressed; when death stares you in the face and you have people supporting and encouraging you it makes you happier and hopeful'. This is an important thing that is lacking in my situation.'

These negative and stigmatizing attitudes compel many PHA and their families to deny their status in order to avoid social exclusion from neighbours and the community. The low level of social acceptance, stigma and isolation by family and community members results from ignorance and fear of being infected. Other social concerns mentioned relate to the attitude of the government, given the perception that government is not doing enough about solving the problem of HIV/AIDS. For instance, participants expressed concerns about lack of comprehensive health care and welfare policies to ensure PHA have an acceptable QoL, government's neglect and being left at the mercy of so-called non-governmental organisations that profit from HIV/AIDS programmes.

Discussion

Epidemiological studies highlighted the importance of social support in attenuating the effects of stressful events and reducing the incidence of disease (Broadhead, Kaplan & James, 1983). Social support is generally defined in terms of the availability of people whom the individual trusts, who can be relied on and who makes a person feel valued and cared for (McDonald & Newell, 1996). Weiss (1974) perceived social support as performing both instrumental and expressive functions for the individual; providing social integration, nurturance, alliance and guidance, and fostering feelings of worth and intimacy. Sherbourne and Stewart (1991) distinguished five categories of support: (a) providing emotional support, love and empathy, (b) providing instrumental or tangible support, (c) providing information, guidance or feedback on behaviour, (d) offering appraisal support which helps the person to evaluate him/herself and (e) giving companionship in leisure and recreational activities. The importance of the themes reported in this paper is in the way they connect to and buttress the categories of support identified in previous studies.

The study findings confirm earlier studies that psychosocial factors and social support influence health outcomes of HIV infected individuals (Berkman & Syme, 1990; Stanfeld, Bosma, Hemingway, et.al. 1998). There is evidence that social support affects health outcomes either through its effects on the function of the immune system (Antoni, Schneiderman, Fletcher, Goldstein, Ironson & Laperriere, 1990) or through its effects on self-care activities and other illness behaviours (Lutgendorf, Antoni, Schneiderman & Fletcher, 1994). Obtaining social support may however be problematic for some persons because of AIDS-related stigma. The findings about psychosocial effects of testing positive for HIV are important considering that psychological and existential issues impact heavily on QoL of PHA. Constant worry, stress and anxiety contribute to poor QoL, but these could also become catalysts for adopting health enhancing behaviour as demonstrated by some participants. Similarly, continued stigma and social isolation still pose considerable barriers to disclosure of HIV status. It has implications for access to treatment facilities (Carr & Gramling, 2004), compliance with medications (Crosby, Holtgrave, Bryant & Frew, 2004) and generally hinders prevention efforts directed at HIV/AIDS. Contrastingly, expectations of economic and social benefits considerably influenced individual's willingness to disclose HIV status.

Availability of ARV therapy is associated with improvements in physical health. Although, few PHA currently have access to ARVs, a lot of gaps regarding accessibility and availability need to be plugged. The major problems are related to the cost of accessing ARVs and the logistics of distribution. Presently, ARVs are available in few government-designated centres throughout the country, far from where most PHA lives, thus accessing ARVs puts a strain on the resources and health of PHA, their families and support workers. Secondly, those who are on ARV are also expected to carry out a number of significant laboratory test- (such as CD4 count, viral load, screening for TB) to monitor their response to the drugs and exclude TB co-infection. The cost of such tests ranges between 20,000 and 25,000 Naira. Few PHA can afford such cost, leading to more anxiety. In a country where 70% of people live below the poverty line (World Bank, 2001), policy interventions are needed to redress this situation. This problem is severe among those who lack a stable job, are women, live in rural area, had low education and are not supported by immediate family and these may experience poorer QoL. These difficulties have also given rise to a thriving black market where ARVs (which are often fake and/or expired) are sold to those needing them with implications for poor outcomes such as drug abuse, and development of resistance.

An important finding of this study relates to the impact of psychosocial counselling as an important determinant of QoL. There are a host of socio-economic, psychological and cultural concerns about living with HIV, though these vary slightly among those who have full blown AIDS and those who are still asymptomatic. The findings however highlight the importance of psychosocial counselling for all categories of PHA to improve QoL. Counselling enables PHA to cope better with the disease, leading to a sense of fulfilment, satisfaction and hope. It also encourages open disclosure about disease status, thus leading to reduction in stigma and discrimination experienced by PHA. The role of the government in improving the situation particularly in terms of education and policy intervention cannot be overemphasized.

Conclusions

This study demonstrates that provision of ARV is important but not sufficient to guarantee improvements in the quality of life of people infected with AIDS. Any effort towards mitigating the impact of the epidemic, particularly in resource-constrained settings like Nigeria, needs to focus on improving the quality of life of PHA. To do this would require a holistic approach that incorporates the continuum of prevention (of opportunistic infections), treatment (of chronic conditions) and care (provision of economic and social support). Current approaches and policies need to be re-evaluated, refocused and redesigned to achieve this.

This study has highlighted the need to bring ARVs closer to the places where PHA live, mostly in the rural areas, in order to eliminate some of the issues that compromise quality of life. As a matter of urgency, government agencies and civil society groups undertaking AIDS-related activities may need to explore reviving the primary health care structure and train a core of personnel that can deliver ARVs at the primary health care level. As an immediate measure, it is worthwhile to explore strategies for effective distribution of ARVs through utilizing existing private health care facilities. For this to be effective, PHA in each locality should be encouraged to form support groups and register their members with appropriate authorities who work out strategies with identified private facilities to distribute subsidized ARVs. It would be important to train the personnel at these facilities and to equip them with the resources needed. Such a strategy will eliminate the problems of access to drugs, facilitate the attainment of the 3 by 5 target for the country as a whole. This modality for doing this should be worked out with input from PHA themselves bearing in mind the principle of greater involvement of people living with HIV/AIDS (GIPA). Furthermore, such approach will encourage community involvement in AIDS prevention, treatment and care activities, particularly in strengthening and consolidating ongoing stigma reduction efforts, within a programme and policy framework, that discourage stigmatising attitudes towards PHA. Following valuable lessons from the Uganda Memory Project (Nabwire, 2000), and other examples across Africa, PHA should be encouraged to disclose their status to family members in order to address issues around stigma and facilitating enrolment on the ARV programme.

Uniting PHA to give them voice and social inclusion may be important factors in ensuring better QoL. Support groups are important in providing care and supporting PHA, thus contributing to improvements in QoL. For this reason, support groups should be better organized to make them effective in assisting PHA. The financial and structural/environmental constraints confronting support groups demand that governments, non-governmental organisations and philanthropic individuals collaborate to address these. These constraints compel imposition of stringent conditions of membership for PHA who seeks to benefit from group support. It may be worthwhile therefore, to explore means through which PHA, particularly those in advanced stages of AIDS can continue to benefit from group support even when they are not able to fulfil these requirements. The message therefore is to strengthen and '*support*' the support groups by encouraging their formation at community levels as well as registration and participation of all PHA in groups' activities. Strong and vibrant support associations will also provide avenues through which scarce resources (such as funds from the Global Fund, World Bank or PEPFAR) devoted to addressing HIV/AIDS programs can be equitably allocated to PHA who are most in need. The success of Uganda in attaining the target of 3 by 5 is based on government recognition of active support groups that encourage people to speak openly about their HIV status; an effective strategy in combating stigma and discrimination.

References

- Antoni MH, Schneiderman N, Fletcher MA, Goldstein DA, Ironson G, Laperriere A. (1990): **Psychoneuroimmunology and HIV**. *Journal of Consultant Clinical Psychology*; 58:38-49
- Bastardo YM, Kimberlain CL. (2000): **Relationship between quality of life, social support and disease-related factors in HIV-infected persons in Venezuela**. *AIDS Care*, Oct; 12(5): 673-84
- Berkman LF, Syme S. (1990): **Social networks, host resistance and morality: a nine-year follow up study of alameda county residents**. *American Journal of Epidemiology*, 109:186-204
- Broadhead WE, Kaplan BH, James SA. (1983): **The epidemiologic evidence for a relationship between social support and health**. *Am J. Epidemiology*, 117:521-537
- Burgoyne, R. Renwick R. (2004): **Social Support and quality of life over time among adults living with HIV in the HAART era**. *Social Science and Medicine*, Apr; 58(7):1353-66
- Carr RL, Gramling LF. (2004): **Stigma: A Health Barrier for Women with HIV/AIDS**. *J Assoc Nurses AIDS Care*, Sep-Oct; 15(5):30-9.
- Castro R, Orozco E, Aggleton P, Eroza E, Hernandez JJ. (1998): **Family responses to HIV/AIDS in Mexico**. *Social Science and Medicine*, Nov, 47(10):1473-84
- Crosby RA, Holtgrave DR, Bryant L, Frew PM. (2004): **Factors associated with the acceptance of an AIDS vaccine: an exploratory study**. *Prev Med*. Oct;39(4):804-8.
- Creese A, Floyd K, Guinness L. (2002): **Cost effectiveness of HIV/AIDS interventions in Africa: a systematic review of evidence**. *The Lancet*, 359(9318): 1635-43
- Deeks SG, Smith M, Holodniy M, Kahn JO. (1997): **HIV-1 Protease Inhibitors. A review for clinicians**. *JAMA*, 277:145-153
- Federal Office of Statistics/Ministry of Health/NASCAP (2001): **HIV/AIDS Sentinel survey data, 2001**
- Glaser BJ, Strauss AL (1965): **Awareness of Dying**. Chicago, Illinois, Aldine
- Letamo G. (2003): **Prevalence of and factors associated with, HIV/AIDS related stigma and discriminatory attitudes in Botswana**. *Journal of Health, Population and Nutrition*, 21(4): 347-57
- Lutgendorf S, Antoni MH, Schneiderman N, Fletcher MA. (1994): **Psychosocial counselling to improve quality of life in HIV infection**. *Patient Education and Counselling*, 24:217-235
- McDonald I. Newell C. (1996): **Measuring health: a guide to rating scales and questionnaires**. Second ed New York, Oxford University Press.
- Magnus M, Schmidt N, Brown B, Kissinger PJ. (2002): **A profile of an HIV and child specific programme in New Orleans, Louisiana**. *AIDS Care*, 14 (suppl.1):S85-S94
- Nabwire J. (2000): **The Uganda Memory Project: Mothers disclosing their HIV status to their Children**. *Sexual Health Exchange* no 2000-1
- O'Keefe EA, Wood R. (1996): **Quality of life in HIV infection**. *Scandinavian Journal of Gastroenterology*, 31 (suppl. 221) 30-32
- Paxton S. (2002): **The paradox of public HIV disclosure**. *AIDS Care*, Aug; 14(4):559-67
- Pidgeon N. (1996): **Grounded Theory: theoretical background**. In *Handbook of Qualitative Research Methods for Psychology and Social Sciences*. Edited by Richardson JTE. British Psychological Society Books; 1996:75-85

Saag MS, Schooley RT (1998): **Antiretroviral Chemotherapy**. *Current Clinical Topics Infectious Diseases*, 18:154-179

Saunders DS, Burgoyne RW. (2002): **Evaluating health related well being outcomes among outpatient adults with human immunodeficiency virus infection in the HAART era**. *International Journals of STD and AIDS*, 13:683-690

Schonnesson LN. (2002): **Psychological and existential issues and quality of life in people living with HIV infection**. *AIDS Care*, 14(3):399-404

Sherbourne CD, Stewart AL. (1991): **The MOS Social Support Survey**. *Social Science and Medicine*, 32:705-714

Sowell RL, Seals BF, Moneyham L, Demi A, Cohen L, Brake S. (1997): **Quality of Life in HV-infected women in the south-eastern United States**. *AIDS Care*, Oct; 9(5):501-12

Stansfeld SA, Bosma H, Hemingway H, Marmot MG. (1998): **Psychosocial work characteristics and social support as predictors of SF-36 health functioning: the Whitehall Study**. *Psychosom Med* 1998 May-Jun; 60(3) 247-55

The World Bank Group. (2001): **World Development Report 2000/2001: Attacking Poverty**. The World Bank, New York.

Weiss RS. (1974): **The provisions of social relationships**. In Rubin Z, ed. *Doing unto others*. Englewood Cliffs, New Jersey: Prentice-Hall.

Woloshin S, Schwartz LM, Tosteson AN, Chang CH, Wright B, Plohman J, Fisher ES. (1997): **Perceived adequacy of tangible social support and health outcomes in patients with coronary artery disease**. *Journal of General and Internal Medicine*, Oct, 12(10): 613-8

World Health Organization. (2003): **Treating 3 million by 2005: Making it happen. The WHO Strategy**. World Health Organisation , Geneva, Switzerland

Table 1- Participants' demographic and background characteristics

		Percent (N)
Sex	Male	30 (15)
	Female	70 (45)
Age	18-20	2 (1)
	21-25	12 (6)
	26-30	10 (5)
	31-35	26 (13)
	36-40	20 (10)
	41-45	20 (10)
	46+	10 (5)
Length of diagnosis	<1 year	20 (10)
	1-2 years	35 (17)
	> 2 years	45 (23)
Currently using antiretroviral	Yes	36 (18)
	No	64 (32)
Current employment status	Government employee	8 (4)
	Other employee	6 (3)
	Self employed	48 (24)
	Unemployed	32 (16)
	Other	6 (3)
Marital status	Married	46 (23)
	Separated/Widowed	34 (17)
	Never married	20 (10)
Any children	Yes	80 (40)
	No	20 (10)
Current living arrangement	Urban	40 (20)
	Rural	60 (30)
Currently living with	Parents	40 (20)
	Spouse	16 (8)
	Children	6 (3)
	Siblings	14 (7)
	Biological relatives	12 (6)
	Non-biological relatives	2 (1)
	Alone	10 (5)