

Impact of Care and Social Support on Wellbeing among people living with HIV/AIDS in Nigeria

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(Received 27 Jul 2009; accepted 7 Feb 2010)

Abstract

Background: Availability of antiretroviral therapies has transformed AIDS into a manageable chronic condition and improved well-being among people living with HIV/AIDS (PHA) in developed countries. In developing countries however, such transformations are yet to occur due to socio-economic, systemic and environmental constraint. This study examined the impact of social, economic, psychological and environmental factors on health and wellbeing among PHA living in southwest Nigeria.

Methods: Using qualitative participatory methodology, 50 HIV positive people, 8 health personnel and 32 care providers were interviewed to explore how care and social support affect wellbeing among PHA in view of constraints to accessing antiretroviral drugs. Analysis of data used the grounded theory (GT) approach to identify themes, which are considered crucial to the wellbeing of PHA.

Results: The findings highlight several factors, apart from antiretroviral drugs, that impact the wellbeing of PHA in southwest Nigeria. These include concerns about deteriorating physical health, family and children's welfare, pervasive stigma, financial pressures and systemic failures relating to care among others. We describe how psychosocial and social support structures can considerably contribute to improving health outcomes among them because of how they affect the functioning of immune system, self-care activities and other illness behaviours.

Conclusion: We recommend that interventions should address the psychosocial, socio-economic and other systemic issues that negatively influence the wellbeing of PHA and governments need to strengthen the policy environment that empowers PHA support groups.

Keywords: *HIV/AIDS, Nigeria, Care support, Social support*

Introduction

Human immunodeficiency virus (HIV) infection and Acquired Immune Deficiency Syndrome (AIDS) have become one of the greatest health challenges for humankind. In Nigeria, where the epidemic already constitutes a public health burden, figures from sentinel surveys (1) have continued to show a consistent rise in prevalence rates, morbidity and mortality. While efforts to develop a vaccine for HIV are underway, hopes for mitigating impact depend on effective prevention, care and treatment strategies, including antiretroviral therapies (ARV), which can delay disease progression, improve well-being and increase life expectancy (2, 3).

In high-income countries, the availability of anti-retroviral therapy (ARV) has helped in improving health outcomes and maximising well-being among large numbers of people living with HIV/AIDS (PHA), thus transforming AIDS from a fatal disease to a manageable, chronic illness. This is however not the case in poorer parts of the world, particularly 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 due to social, economic and structural obstacles, only 8% of the 6 million persons who need ARV have access to them. The "Treat 3 million by 2005 (3 by 5)" (4) initiative was designed to address these constraints.

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 in maintaining psychosocial balance and ensuring adherence to ARV, may compromise individual well-being and jeopardize the modest gains achieved through expanded access to ARVs. This is particularly important in resource poor settings where many PHA are faced with psychosocial and economic challenges (5-7) and where uncertainties regarding the side effects of medications may stimulate feelings of loneliness, abandonment and isolation. It is therefore important to consider maximising well-being when prolonging survival (8).

Available evidence suggests that social support can attenuate the adverse effects of HIV infection on individual's health (9-11). Studies among HIV infected persons in high-income countries (12, 13) have documented a positive relationship between social support and health outcomes. However, the literature on the impact of care and social support on the health and well-being of PHA in resource poor settings is scant (9), especially in sub-Saharan Africa where the epidemic has exerted a considerable toll on individuals, communities and the health system. Examining the role of care and social support and its relationship to well-being is important for several reasons; first, HIV related stigma and discrimination make access to treatment and care more difficult for victims; second, PHA in Africa face restricted access to ARVs due to socio-economic, structural and other constraints; third, ambivalent attitudes and behaviours from family members, caregivers and friends; (14) and finally, the challenge that the scale of the epidemic pose to the fragile socio-economic, cultural and health institutions (15). Such knowledge will aid our understanding of how care and support structures can contribute to improving the overall well-being and coping mechanisms among PHA.

Given the foregoing, the study examined the impact of care and social support on health outcomes amongst PHA living in southwest Nigeria. It appraised the effect of social, economic, psychologi-

cal and environmental factors on health and well-being among them. Based on the hypothesis that individuals who have access to care, social support and ARV therapy will experience better health outcomes than those who do not, it documents how these factors impact on the livelihood, coping mechanisms and health outcomes among this population group.

Materials and Methods

Study Design

This was an exploratory study that obtained data through a qualitative 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 seek care and availability of support groups. The difficulty with recruiting respondents required the involvement of health personnel and support associations in gaining 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 members' contributions.

Subjects

Subjects were a sample of PHA aged 18 yr 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 PHA (25 from each study location); using simple random sampling techniques, from a list of registered members obtained from the support groups. Registered members are those 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 purposive 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 and data collection

Individual Interviews

Based on the issues identified in the literature, an interview guide containing issues that are considered relevant to PHA well-being 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.

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. In depth Interviews (IDIs) lasting between 60 and 90 min were held with PHA respondents in various locations- homes, health facility, support

group offices, workplaces, etc- depending on what was convenient for them. 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 with Caregivers and health workers

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' general health status, availability of care and social support, stigma, coping styles and access to drugs and treatment.

A total of thirty-two respondents participated in 4 Focus group sessions 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. Given the nature of participant recruitment, it was not entirely possible to strictly apply the rules of homogeneity in allocating individuals to discussion groups. However, discussion groups were separated on the basis of gender. Each discussion session, which consisted of 8 participants and lasted an average of 90 min, was moderated by the lead author and assisted by a note taker. Interviews were also held with 8 health personnel in the health facilities where they work.

Demographic Questionnaire and Non-verbal tools

In addition to the interviews, a demographic questionnaire, and other non-verbal participatory techniques were used to collect additional information from the respondents. The demographic questionnaire was designed to collect information on the socio-demographic characteristics of the respondents, including sex, age, length since diagnosis, current antiretroviral status, socioeconomic status, residence and living arrangements, etc.

The non-verbal methods used were flow charts and pair wise rankings. Flow charts are a graphical illustration of how various issues that affect the health of PHA fit together. They enable respondents iden-

tify and understand the crucial factors as well as analyze how the situation could be improved. Pair wise ranking, on the other hand, is a structured method for ranking or prioritizing factors that are recognised as contributing to a defined situation.

We combined both tools to enable participants identify and graphically illustrate factors that affect their health and how these fit together. Having identified these factors and presenting them in a flow chart diagram, pair wise ranking was used to prioritize the factor they considered most crucial to their health and wellbeing. Using this process, each respondent was asked to prioritize the factor they considered most crucial to their health. The responses were scored and calculated via simple percentages.

Data Analysis

The study used the grounded theory (GT) approach (16), 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 (17). 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 interview and discussion session was analysed before the next one was conducted.

In line with this procedure, 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 the well-being of PHA. 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 each transcript being read by 3 persons who did not participate in the interview and there was complete agreement on the themes, which emerged.

Ethical approval

The Research 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 any-time during the interview if they felt compelled to do so. No refusal was recorded at this stage.

Results

Demographic characteristics

Table 1 presents participants' demographic and health characteristics. Two thirds of the study participants are females and are 31-35 yr old. Forty-eight percent reported being self-employed and 32% were unemployed. Less than half (46%) of respondents were married and one in four reported having biological children. The reported length of HIV diagnosis ranges from 8 mo to 6 yr with 45% reporting at least 2 yr since diagnosis.

Emerging Themes

The following six themes that emerged from the data highlight the factors that impact on wellbeing among the study population.

Health concerns and the impact of counselling

Participants' experiences and reactions reflect the difficulties in coming to terms with testing positive for HIV. Initial reaction to news of a positive

test included denial, surprise, despair, confusion, anger and suicidal thoughts. Others expressed a deep sense of sorrow and hopelessness regarding the future particularly in view of the constant interaction with the medical system, which continuously reminds them of their HIV positive status. Despite such reactions, many participants reported that the counselling they received from health workers helped them to cope with and adjust to the reality of being HIV positive.

Family commitments and children's welfare

Family commitments and children's welfare is an important issue with huge implications for wellbeing among PHA and those with such commitments were concerned about the future of close relatives. For many this was a source of mental stress that worsened their condition. As a single mother reported:

'My greatest concern is for my two children and the situation has worsened since my illness started. I often have to deny myself food so that my children can eat. 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]'

Many others expressed concerns regarding how people in the community will treat their children once they get to know their parent(s) is HIV positive or with children taking on adult responsibilities like working to earn income that will sustain the family. These concerns however strengthened the resolve to remain healthy as long as possible. Participants who had no children were equally concerned about family welfare particularly where they have contributed financially to the welfare of parents and younger siblings before the onset of illness.

Financial constraints

Almost all the participants reported that limited access to medication, treatment and care because of financial constraints. For example, those who live in urban areas spend an average of N2500 [\$19] while those living in the rural areas spend N5000 [\$38] on the average every month to access drugs. For those who are unemployed or

with irregular income, it is a huge challenge to raise such amounts on a monthly basis. The lack of money critically affects wellbeing among respondents, especially women and for most participants, membership of a support group was one of the few options they had in meeting these financial obligations. However there was a limit to the assistance that support groups could provide because of limited resources and the large number of those needing assistance. One participant and one official of a support group 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?

'Helping members with financial needs is the most challenging aspect of our work. Most of them do not have a source of income and we have to ensure they have access to the only lifeline [ARV] by proving it free to those least able to afford it. We are desperately in need of help regarding this..'

Experiences of Stigma

Experiencing stigma negatively affects wellbeing of PHA and contributes to lack of disclosure of a sero-positive status. For most respondents, disclosure of HIV status is restricted to support group members or trusted relatives in anticipation of and/or return for care and support. To avoid disclosure, participants would often enrol for treatment or join support groups in places where they can remain anonymous. These stigmatising experiences were linked to persons in the community and institutions involved in service delivery, including hospitals and health personnel. Some participants pointed out 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'

Access to drugs, treatment and health services

Access to antiretroviral medication enhances well-being and reduces opportunistic infections among PHA. Despite ongoing interventions to expand access to ARVs in Nigeria, only few PHA are able to get the necessary supply of drugs because cost remains a major barrier to access. Apart from the cost of ARVs, there are other expenses related to transportation, feeding and accommodation whenever they go for their supply. At other times, it is the availability of drugs that is the issue or access to treatment and health services. When asked how people with no 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’.

Care support

Concerns relating to care support were extensively discussed. As reported earlier, the desire for care support considerably influenced the decision to disclose a sero-status. Therefore when support is not expected, information is withheld. Moreover, the desire to care for and support sick individuals is influenced by prevailing cultural norms and perception of illness. Because HIV/HAIDS is still largely perceived as a disease associated with a promiscuous lifestyle and highly contagious, only close family members are willing to care for and support PHA because they consider it an obligation to take care of their own. As one family member reported:

‘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’.

Ranking of factors determining well-being

Using the flow charts and pair wise rankings, PHA respondents were able to identify and rank issues they considered important to their well-being. 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 well-being. The issue that ranked highest was availability of care and social support from family members and close friends (93%). Other issues that rank highly 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%).

Table 1: Participants’ demographic and background characteristics

Characters	(n= 50) Percent	
Sex	Male	30
	Female	70
Age	18-20	2
	21-25	12
	26-30	10
	31-35	26
	36-40	20
	41-45	20
Length of diagnosis	46+	10
	<1 year	20
	1-2 years	35
Currently using antiretroviral	> 2 years	45
	Yes	36
Current employment status	No	64
	Government employee	8
	Other employee	6
	Self employed	48
	Unemployed	32
Marital status	Other	6
	Married	46
	Separated/Widowed	34
Any children	Never married	20
	Yes	80
Current living arrangement	No	20
	Urban	40
Currently living with	Rural	60
	Parents	40
	Spouse	16
	Children	6
	Siblings	14
	Biological relatives	12
	Non-biological relatives	2
Alone	10	

Discussion

Epidemiological studies highlight the importance of social support in attenuating the impact of stressful events and reducing the incidence of disease (18). Social support is generally defined in terms of the availability of people whom the individual trusts, who can be relied upon and who makes a person feel valued and cared for (19). Weiss (20) 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 (21) distinguished five categories of support: (a) emotional- love and empathy, (b) instrumental or tangible, (c) information, guidance or feedback on behaviour, (d) offering appraisal, which helps the person to evaluate him/herself and (e) companionship in leisure and recreational activities. The importance of the themes reported in this study is in the way they connect to and buttress the categories of support identified in previous studies. The findings of this study corroborate other studies (10, 22), which suggest that psycho-social factors and social support influence health outcomes among HIV positive individuals through its impact on the functioning of immune system (23), self-care activities and other illness behaviours (24). These results are important considering that the psychological and existential issues that dominate the lives of PHA impact heavily their wellbeing. Whereas, constant worry, stress and anxieties about the future can contribute to poor health outcomes, they could also become catalysts for adopting health-enhancing behaviours. In addition, HIV related stigma and social isolation pose considerable barriers to sero-status disclosure with huge implications for access to treatment (25), compliance with medications (26) and other efforts to reduce the impact of HIV/AIDS. Contrastingly, expectations of economic and social benefits considerably influenced individual's willingness to disclose HIV status (27, 28). Although there is compelling evidence suggesting that antiretroviral therapy considerably improves

the physical health of PHA (29), few of the participants in this study currently have access to ARVs. This means that systemic, financial and other constraints to access and availability of ARVs require urgent attention. Presently, ARVs are available in few government-designated centres throughout the country far from where most PHA reside and accessing them puts a strain on the resources and health of PHA and those of their families and support workers. In addition, the cost of enrolling on ARV, which include laboratory tests for CD4 count, viral load and screening for TB co-infection can be overwhelming for those without any source of income. In a country where 70% of people live below the poverty line (30), policy interventions are needed to redress this situation. Apart from negatively affecting the wellbeing of PHA, these difficulties have also given rise to a black market where ARVs (which are often fakes and/or expired) are sold to those who desperately need them with the potential for the development of drug resistance. There are a host of social, economic, psychological and cultural concerns about living with HIV in the study areas. Our findings show the importance of psychosocial counselling and other forms of support for all categories of PHA in order to improve well-being. Social support structures will enable PHA to cope better with the disease, leading to a sense of fulfilment, satisfaction and hope. It can also encourage open disclosure about disease status and a reduction in stigmatizing and discriminatory attitudes. The government has an important role in terms of improving the situation particularly with regard to education and policy intervention. This study demonstrates that provision of ARV is important but not sufficient to guarantee improvements in the well-being people living with AIDS. Any effort towards mitigating the impact of the epidemic, particularly in resource-constrained settings like Nigeria, needs to focus on the factors that can improve well-being in addition to expanding access to antiretroviral drugs. This will 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 in this regard. This study has also highlighted the need to bring ARVs closer to where PHA resides to eliminate cost and access constraints. Perhaps, reviving the primary health care structure and training a core of auxiliary health workers who can deliver and administer ARVs at the community level will be an appropriate step in this regard.

It is important to give PHA a voice and encourage social inclusion as this can facilitate improved well-being among them. To this extent, support groups should play an important role in planning and providing care support that can lead to better health outcomes. This will require an enabling environment to ensure that support groups are better organized to make them more effective in assisting their members. The constraints, which currently incapacitate support groups, demand the collaboration of governments, non-governmental agencies or organisations and philanthropic individuals to address these. What is needed is to strengthen and 'support' the support groups by encouraging their formation at community levels since strong and vibrant support associations are avenues through which scarce resources devoted to addressing HIV/AIDS programs can be equitably efficiently allocated.

Study Limitations

Infection with HIV/AIDS is a highly stigmatized condition in the study setting, therefore many PHA were unwilling to disclose information about their condition or they may deny the condition when asked even at the health facilities where they receive treatment. This made 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. Thus the results presented in this paper may have limited application to other populations of PHA who are not members of support groups.

Ethical Consideration

All Ethical issues (such as informed consent, conflict of interest, plagiarism, misconduct, co-authorship, double submission, etc) have been considered carefully.

Acknowledgements

We are grateful to Adeolu Ajala, Tunde Adebola, Ibikunle Fakande and Oba Ladapo for facilitating the data collection and all members of Living Hope Foundation/Network of People Living with HIV/AIDS in Nigeria for providing valuable data.

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