Living well with HIV in Nigeria? Stigma and survival challenges preventing optimum benefit from an ART clinic

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Abstract: Thirty years into the HIV pandemic, the interactions of stigma, social and economic survival, and clinical interventions continue to be key to understanding and managing HIV at both personal and societal levels. With antiretroviral therapy, HIV is increasingly a chronic condition requiring lifelong treatment, near-perfect adherence, and support from both social networks and formal services. This study asked: is stigma still a significant problem for people living with HIV (PLHIV) who have secured access to antiretrovirals (ARVs)? How do PLHIV accessing ARVs in Nigeria experience the social, economic and health service supports intended to address their needs? What are the concerns and challenges of PLHIV and health workers regarding these supports? What are the implications for approaches to stigma and discrimination? This qualitative study at the Antiretroviral (ART) Clinic of the Osogbo State Hospital, Osun State, Nigeria involved in-depth interviews with 15 PLHIV who have been attending the clinic for at least one year, and three health workers. The results reveal both the diversity among even a small number of patients, and persistent cross-cutting themes of stigma, discrimination, poverty, and the psychological impacts of insecure livelihoods and well-intentioned but ultimately stigmatizing supports such as selective food parcels. Both population-based interventions against stigma and poverty, as well as micro-level, contextualized attention to patients’, families’ and health workers’ fear of social exclusion and infection at a clinic and community level are needed if patients – and society – are to live well with HIV in Nigeria. (Global Health Promotion, 2014; 21(1): 13–22).

Keywords: HIV, stigma, discrimination, Nigeria, social determinants of health, ART, psychosocial support, human rights

Introduction

Thirty years into the HIV pandemic, the interactions of stigma, social and economic survival, and clinical interventions continue to be key to understanding and managing HIV at both personal and societal levels. With antiretroviral therapy (ART), HIV is increasingly a chronic condition requiring lifelong treatment, near-perfect adherence, and support from both social networks and formal services (1). Current national strategic plans emphasize care and wellness as well as prevention and human rights (2). This study reports on patients’ experiences of HIV and ART in the context of one Nigerian hospital’s efforts at facilitating both access to treatment and holistic care and support.

At the end of 2011, about 3.3 million of the world’s 43 million people living with HIV were in...
Nigeria, the country with the second highest number of HIV-positive people in the world after South Africa (1,3,4). In 2000, the Nigerian government established the National Agency for the Control of AIDS (NACA) to lead the country’s response to the control of HIV and AIDS, including prevention, treatment and coordinated advocacy against stigma. By the end of 2009 only 31% of those potentially eligible for ARV treatment were receiving it (5).

In resource-constrained countries, most people living with HIV (PLHIV) face important social, personal, and health challenges (6) beyond the problem of accessing ARVs, many of them – such as food and livelihood insecurity, poor access to health facilities, unaffordability of treatment, poor quality of health services – not specific to HIV (1,7,9). In addition, HIV infection continues to be associated with symptoms such as despair and guilt, anxiety and adjustment disorders and depressive disorders (13–15), with lifetime prevalence rates of up to 40% (8). Focused empirical studies find that stigma remains one of the foremost barriers to the integration of HIV- and AIDS-infected individuals in Nigerian society (9,10), echoing findings nearly a decade earlier that stigma, prejudice and discrimination had eaten deep into the fabric of societies resulting in the violations of human rights of PLHIV across the globe (11,12). All of these problems have negative effects on the health status, functional status, psychological wellbeing, satisfaction of needs, and life chances of PLHIV.

Current efforts of both government and non-governmental organizations (NGOs) seek to provide supports to help mitigate these pervasive challenges, as well as combating stigma. This study asked: is stigma still a significant problem for PLHIV who have secured access to ARVs? How do PLHIV accessing ARVs in Nigeria experience the social, economic and health service supports intended to address their needs? What are the concerns and challenges of PLHIV and health workers regarding these supports? The study was designed and conducted with the participation of a physician at a state hospital, who wanted to understand the current experiences and perspectives of patients and health workers in order to inform ongoing and potential new interventions that might be implemented at the hospital, as well as to understand the likely limitations of local, micro-level interventions.

Reflecting on the findings of this study also led us to re-examine the tacit understandings of stigma manifest in Nigerian policy statements such as the NACA strategy, as well as in clinic-based approaches to HIV. In a recent review of theoretical and programmatic approaches to stigma in public health (12), Parker argues against decontextualized and depoliticized models of stigma and discrimination as primarily psychological and interpersonal behavioural problems caused by incorrect beliefs, and in favour of an integrated approach anchored in both human rights and social justice traditions in public health. Our understanding of the NACA vision and the approach of clinicians and clinic-based approaches to HIV, particularly to ensuring access to ART, is that they approach stigma as a powerful social force with material as well as psychological impacts, and see false beliefs as the underlying causes (13). In a sense, then, these tacit models reflect the ‘individual beliefs and behaviours’ model challenged by Parker. Our approach was nevertheless to take this dimension seriously, to ask almost at face value whether stigma and discrimination – as tacitly understood by ordinary Nigerians – are still a problem in relation to HIV, and to apply psychological and social psychological theoretical models such as the theory of stress and coping (13,14) and Goffman’s ideas about ‘spoilt identity’ (16) to the interpretation of the interviews. We began therefore with a theoretical orientation that privileged individual lived experience and narrative around HIV, stigma, discrimination, support and coping, but that took the ‘social’ in ‘social psychology’ seriously. In interrogating access and optimum benefit from an ART clinic, we sought also to learn whether, and how, ‘stigma’ understood in psychological and micro-social relational terms intersected with medical, livelihood, and other concerns.

Methods

Study setting

This qualitative study was undertaken in 2011 at the Antiretroviral (ART) Clinic of the Osogbo State Hospital, Osun State, Nigeria, a 64-bed hospital and a secondary health care facility. The ART Clinic was established in September 2008 by the Osun State Government in collaboration with the Federal Ministry of Health of Nigeria and the
Global HIV and AIDS Initiative in Nigeria (GHAIN). The over 1000 registered clients have a mean age of 33.2 years, about 60% are women, 20% have no formal education and the occupations reflect the mixed educational background: over 25% are civil servants, 22% traders, 24% artisans and the remaining 29% includes farmers, students, unemployed and clergy. The clinic is staffed by 15 health workers and provides comprehensive HIV and AIDS care which includes HIV counselling and testing, prevention of mother to child transmission, antiretroviral therapy and treatment of opportunistic infections, with regular clients seen on a monthly basis. The clinic does not directly engage in advocacy or human rights work, but hosts a PLHIV support group. In addition, some meetings are sponsored by the state government in Osogbo, the state capital, to bring together community-based organizations, local government workers, PLHIV and other stakeholders.

Study participants: A ‘best case’ scenario?

Purposive sampling was employed to select 15 PLHIV who had been attending the clinic for at least one year preceding the study, and three health workers (one doctor, one nurse and one medical records officer) who were willing to participate. There is only one support group in the clinic and participants were invited through the support group. As the clinic population in general appears to be more educated and with more secure social and financial circumstances than the general population, and the support group participants had volunteered to meet together and disclose their status to each other, the sample for this study could be expected to be better positioned to deal with both HIV-specific stigma and socioeconomic challenges than the ‘average’ HIV-positive Nigerian. It might thus represent a ‘best case scenario’ of the effects of strategies to combat stigma and cope with HIV (and conversely may not capture potentially different experiences of PLHIV who have not joined the support group).

Among the PLHIV participants, ages ranged from 25–40 years. Five (33%) were male, three each were single or widowed and the remainder married, one had primary education, eight had completed high school and three had a BSc degree. One had been diagnosed HIV+ in 2002 with the remainder diagnosed between 2007 and 2010.

Ethical approval was obtained from the State Hospital Ethics and Research Committee.

Data collection

In-depth semi-structured individual interviews conducted after receiving voluntary informed consent were recorded, and then transcribed. The interviews were conducted in either English and Yoruba (the local language of the respondents) depending on the preference of each respondent. Interviews conducted in Yoruba were translated to English before the data were imported into ATLAS.ti for analysis. The interview included introductory and demographic questions, followed by open-ended questions aimed at understanding the problems associated with the stigma and challenges confronting PLHIV in coping with their illness and utilizing the available services. The interviews were conducted at places preferred by the participants to ensure confidentiality and lasted about 50 minutes.

Data analysis

A rapid analysis of the field notes was done first to identify major patterns and preliminary themes and codes. Interviews were transcribed and transcripts edited for accuracy. Data analysis was supported by ATLAS.ti software. Themes were developed in line with the objectives of the study. Open coding, informed by grounded theory approaches to remain open to unexpected themes, was used and the data were coded for new categories until saturation was reached. Analysis and presentation includes content analysis with frequency counts of identified themes/codes, illustrative quotations, as well as aggregated and disaggregated thematic and network mapping of disclosure patterns and challenges reported by respondents.

Results

The findings are presented in three sections, reflecting the major issues or themes identified by the respondents: attitudes to PLHIV, disclosure of HIV status and the challenges impeding optimal access to ART. In addition, Figure 1 shows the disclosure patterns among our respondents, and Figure 2 maps the challenges and some of the coping strategies reported.
Figure 1. Pattern of disclosure of HIV-positive status among the PLHIV.
Figure 2. Network showing the challenges and their effects on other variables.
Attitudes towards PLHIV

Despite various efforts targeted at changing people’s perceptions about HIV, this study suggests that there has been little or no noticeable change in the perception of Nigerians about the disease. Our respondents reported that HIV status continues to be attributed to victims’ promiscuity and waywardness and that PLHIV are considered not to be worth caring for. Pervasive experiences and expectations of discrimination and exclusion were reported by the participants. One respondent asserted:

They believed that people who have HIV are promiscuous. Some even believed that it is not worth spending your money to improve their health because they think HIV is a time bomb that will explode at a set time no matter what you do. (PLHIV, Female, 40 years, Trader)

Another respondent expressed:

There is a lot of stigmatization and discrimination in the society. Once people know your status, you become the subject of discussion around. People will begin to give you space. They may stop dealing with you in any way. You may not be able to do good business because people are very careful that you will not infect them and this is discouraging and killing. You are technically ostracized. (PLHIV, Female, 29 years, Civil servant)

This position was further supported by a non-clinical officer working in the ART clinic who affirmed:

Stigmatization of HIV patients is much even among the health workers, one expects that at least health workers should have a good/proper orientation about HIV and AIDS, surprisingly most of them still discriminate [against] the clients, and most of them do not want to work in this clinic. If you get to the labour ward, HIV-positive people are separated from the other patients.

However, there is a difference between patients’ experience of society in general, and their experience of family members’ and close friends’ reactions and actions. While the attitudes of society members in general and of some health professionals are negative to PLHIV, the attitudes of the family members and some friends are reported as predominantly positive. Respondents used words such as ‘normal’, ‘understanding’, ‘supportive’, ‘encouraging’ and ‘had energized my spirits’. One respondent affirmed:

The reactions of my family members has not changed since they know my HIV status, in fact, my husband still uses the same plates, cutleries and every other things with me, even when I try to stop him, he is not bothered at all and he is HIV-negative. (PLHIV, Female, 30 years, Civil servant)

Although there are a few instances in which family members also discriminated against some PLHIV, these negative attitudes from family members are reported as temporary: family members of these patients come to accept the reality of the situation and have positive and supportive attitudes.

Disclosure of HIV status

Disclosure of HIV-positive status was usually limited to members of the family and very close friends that respondents trusted would not divulge the information, reflecting once more the pervasiveness of stigmatization and discrimination in Nigeria. A respondent reported:

Sometimes, when I am in the midst of some people and they are talking about the disease, I realize that if they should know that I am HIV-positive, their reactions to me would be terrible. So I usually pretend as if I am negative. (PLHIV, Male, 30 years, Artisan)

There were a few instances in which the respondents did not disclose their status to anyone, including members of their family. Conversely, the instances of disclosure to other members of society were all among HIV-positive persons who had become active members of NGOs supporting PLHIV and leading various advocacy programmes organized by NGOs. Figure 1 shows the pattern of disclosure of HIV status among our respondents.

Beyond the clinic: challenges impeding optimal access to ART

Although the ART Clinic was meant to support PLHIV by providing treatment, counseling and
psychosocial support, such as creating support groups, numerous challenges prevent PLHIV from making optimum use of the facilities. These include challenges related to the health system structure, the nature of support provided, and patients’ interpretations of health personnel’s attitudes as negative, which in turn is partially a product of the health workers’ fear of being infected. Work-related problems and patients’ fears for the future of their families compound the pervasive stigma described above. Figure 2 shows the links among these problems, as reported by study participants.

Underlying many of the comments and concerns was a heavy psychological burden of anxiety and fear: the disease has no cure, is associated with stigma and discrimination and the fear of infecting loved ones and caregivers, especially husbands and children. Some are also worried that they may die while their children are still young while others are poor and are unable to access the health facility regularly due to lack of money to pay for transport to collect medication. An informant expressed:

I have also lost my husband and I am scared that I will die with nobody to take care of my children while they are still very small. (PLHIV, Female, 29 years, Civil servant)

The health workers were also concerned about how to avoid being infected by the patients.

Both PLHIV and health workers reported the non-availability of local ART sites and inadequate numbers of health workers in the clinic. Conversely, some PLHIV feel reluctant to attend clinics as they are afraid of meeting someone who knows them. An ART clinic staff member reported:

When they come for the refill of their drugs most of them are filled with the fear of meeting people they know and are always in a hurry to leave. (Non-clinical Officer)

The fear of being fired if the employer or their colleagues know their HIV status or being denied appointment based on their HIV status is also evident. Some also suspected that customers may stop patronizing their businesses if their HIV status is known. One respondent stressed the difficulty of seeking permission to attend clinics on a regular basis without the employer suspecting and eventually knowing their HIV status, which may lead to termination of their employment.

The support system available through and beyond the clinic did not provide for income-generating activities nor financially empower the patients, thereby making them dependent on the support provided, exacerbating fear that the support may stop suddenly with no alternative care for them. The distribution of food items in the clinic was viewed negatively as patronizing. Some informants stated:

We need to be financially buoyant to take care of ourselves instead of depending on NGOs or government, who may stop such assistance one day. (PLHIV, Female, 29 years, Unemployed)

Another informant noted:

They should stop giving us things like food, we are not beggars. (PLHIV, Female, 35 years, Self-employed)

All these challenges contribute to the PLHIV overall perceptions of how well they are coping with the burden of the disease. In this study, most of the participants expressed that they were not coping well, even though as noted above this purposive sample might be expected to present a ‘best case’ scenario. Some informants noted:

Discrimination affects our health because many times we fall into depression and worries. It is also difficult for those who are not married to get married due to their status because nobody wants to marry [an] HIV-positive person. (PLHIV, Female, 35 years, Self-employed)

It is not the illness that kills but the stigma kills gradually. (PLHIV, Female, 40 years, Trader)

Discussion and implications for policy and practice

This study explored the challenges experienced by PLHIV who are already receiving ART. Although the vast majority of Nigerians are faced with the consequences of economic difficulties, the problem of stigma exacerbates the situation for PLHIV. Many respondents reported that they know people who have been sacked in their places of employment.
or have experienced other forms of discrimination and maltreatment directly because of being HIV-positive. Similarly, studies in Southern/South Africa revealed that 40% of persons with HIV and AIDS had experienced discrimination as a result of their HIV-positive status and one in five had lost a place to stay or a job because of their HIV status (16), while the internalized stigma by the PLHIV themselves significantly predicted cognitive-affective depression (16–19). Despite the prevalence of HIV and AIDS and availability of treatment making HIV a chronic disease that can be managed for several years in similar settings, stigmatization and discrimination against PLHIV is still endemic (20–22).

This has implications for services and interventions meant to support PLHIV to cope and live better with their illness. The organization of clinics and health services, support and training for health workers, and interventions to address stigma, discrimination, and household vulnerability to economic and social losses need both micro- and macro-level attention. Discussion of the study findings in the hospital and community raised a range of possible actions, from re-strategizing the campaign methods against discrimination to involve local community members and opinion leaders, to advocating for more numerous and better integrated clinics with clinic hours that are compatible with holding a job, to better-trained and better-supported health workers who are protected from occupational exposure to HIV, to financial empowerment and life insurance for PLHIV with young families. Legislation related to HIV on issues such as employment, treatment and reporting of discrimination would help to promote HIV testing, disclosure, treatment adherence, and planning for the future of PLHIV and their families. At present, ‘enactment of laws lags well behind the trajectory of the epidemic as there is no legislation addressing a number of HIV- and AIDS-related issues in Nigeria’ (10).

It is interesting in this study that stigma appears to be less pervasive in familial relationships than relationships with other society members, in contrast to some findings reported from South Africa and elsewhere (20). This finding suggests that the social psychology of HIV stigma, and its relative weighting on the sociopolitical/economic, sociomoral, and disease avoidance dimensions that Parker (11) and Phelan and colleagues (23) identify, needs further analysis in specific social and cultural contexts. Stigma against non-family members was reported as both intense and pervasive and was linked both in our study and in other recent work in Nigeria (24) to public morality and, especially, to security of employment and livelihood. These reports of concurrent social inclusion and exclusion within a community suggests to us an affectively and morally charged context where family loyalty with both material and personal support is in dynamic tension with a rigidly enforced public morality involving fear of moral and physical contagion, and pervasive economic and livelihood competition and insecurity. On a practical level, family members are widely seen as central actors for supporting PLHIV to cope with HIV (17). In this context, it appears that family members can indeed be enrolled to enhance both medical and psychosocial support – and perhaps to begin to put into practice the human rights and anti-stigma ideas promoted by NACA, the clinic, and the support group. However, given that family members of one PLHIV are potentially stigmatizing ‘non-family’ to others, this enrollment of family would require care and the active leadership of PLHIV in order to achieve the desired results.

The theory of ‘spoilt identity’ developed by Erving Goffman half a century ago (16) remains painfully relevant to this context. Goffman argued that when individuals possess attributes perceived to be undesirable to the society’s cultural norms, they are seen to have spoilt their identity and must be separated from society. The situation is at its worst when the origin of the attribute is perceived to be a result of deliberate actions or moral transgressions on the part of the stigmatized and the ‘peril’ is contagious (25). PLHIV continue to be stigmatized and discriminated against in different societies including Nigeria, with HIV perceived as resulting primarily from social and sexual moral transgression and, paradoxically, fears of contagion and one’s own infection (despite one’s own assumed ‘innocence’) increased through the many misperceptions about the modes of transmission of the disease (4,26,27). Our study found that many of the obstacles to accessing clinical care are related to stigma and discrimination, including by health workers whose legitimate concerns about workplace exposure to HIV is compounded by generally negative societal attitudes.
Conclusion

This study focused on the lived experience of people living with HIV, including their experience of stigma and socioeconomic vulnerability. Thirty years into the pandemic and with HIV increasingly managed as a chronic illness, it might be expected that HIV-related stigma would be decreasing. Our findings suggest that even for a relatively privileged sample of Nigerians, in a support group, this is not yet the case. Further research is needed in this area – as well as efforts such as those proposed in the workshopping of the study findings that would increasingly mainstream and integrate better quality of care, anti-discrimination initiatives, and attention to livelihoods of all.

The answer to the core study question of whether stigma is still a significant problem for PLHIV who have secured access to treatment in this part of Nigeria is ‘Yes’. The broader reflection on tacit and explicit models of stigma and discrimination suggests that indeed psychological mechanisms of ‘othering’, devaluing and excluding individuals perceived as ‘spoilt’, transgressive and a threat are critical to the experience and impacts of stigma on PLHV – but that these processes reflect a complex and contradictory mix of misinformation, real and imagined risk, loyalty within the family and intense competition and moral scrutiny in the public domain, and pervasive personal and economic insecurity. In our view, there is continued value and need for deeper analysis on the psychological and interpersonal aspects of stigma and discrimination, in addition to a shift to the holistic, comprehensive frameworks suggested by Parker and others – frameworks that take seriously both lived experience and structural violence, as well as resilience and the possibility of change. Both population-based interventions against stigma and poverty, as well as micro-level, contextualized attention to patients’, families’ and health workers’ fear of social exclusion and infection at a clinic and community level are needed if patients and society are to live well with – or without – HIV in Nigeria.

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