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No one knows what will happen after these five years': narratives of ART, access and agency in Nigeria

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Abstract

Rural Nigerians pursue a range of strategies to maximize current and future access to HIV treatment in the context of securing livelihoods and minimizing the social and economic risks of stigma. This study reports on qualitative interviews with service providers and anti-retroviral therapy (ART) patients accessing care in Benue State, Nigeria, or travelling several hours to Abuja for treatment ($n = 34$). Nigerians living with HIV are keenly aware of the fragility and complex global and local politics of funding. Their narratives of pervasive stigma, economic and health system barriers to access, growing fears that free ART will cease, and strategies to secure access to care reveal a sophisticated synthesis of social determinants of health and clinical care, and challenge practitioners, planners, and scholars to take a similarly robust and nuanced approach to vulnerability, access, and agency. (*Global Health Promotion*, 2013; 20 Supp. 1: 45–50).

Introduction

'People go out of the state, not minding the cost or the transport because of stigma' (Executive Secretary, Benue State AIDS Control Agency – BENSACA)

'The contract [PEPFAR] is for five years. No one knows what will happen after these five years. So ... in five years, one should have a minimum of one year of drugs that you can be taking' (48-year- old man, Benue State, Nigeria)

In this paper we report on narratives of vulnerability and agency in the face of poverty, stigma, and HIV. Not waiting for 'leadership', 'political will', or even 'health systems strengthening', rural Nigerians pursue a range of strategies to maximize current and future access to treatment while exploring other means of securing livelihoods and minimizing stigma risks. Their narratives reveal a sophisticated understanding of both social determinants of health and clinical care, and challenge practitioners, planners, and scholars to take a similarly nuanced approach to vulnerability, access, agency, and health.

This paper draws on findings of an exploratory study of factors influencing access to anti-retroviral therapy (ART) in Benue State, Nigeria, aimed at improving ART programs and particularly those offered by the Institute of Human Virology, Nigeria (IHVN) (a not-for-profit agency serving 23% of the 300,000 patients on ART in Nigeria in 2009 (1)). In particular, we wanted to learn why many patients continued to make a 600 km journey

to access treatment in Abuja, the capital city, after ART had been made available in rural sites within the state. The complete findings are presented elsewhere (1).

Most respondents narrated a complex story of hope and fear, stigma and social support, uneven quality of care, economic vulnerability, and a pragmatic approach to maximizing benefits and minimizing risks. A finding not well represented in existing literature was concern about capping of services and fear of discontinuation of free HIV treatment. While 'sustainability' is now a key word in the HIV response lexicon (2–4), we found that ordinary rural Nigerians living with HIV are keenly aware of the fragility of funding. This modest study suggests that the people who are the most vulnerable to the impacts of geopolitics and donor funding crises have insights into risks and opportunities from which technically-oriented practitioners and managers could learn.

HIV and ART in Nigeria and Benue state

With an estimated 2.95 million HIV+ people and an average prevalence rate of 4.1% in the 2010 sentinel survey, Nigeria is home to the second- largest number of people living with HIV/AIDS (PLWHA) in the world after South Africa (4,5). Prevalence rates across Nigeria's 36 states and capital are, however, uneven, and at the end of 2010 ranged from 1.0% in Kebbi to 12.7% in Benue state, the site of the study (5). ART coverage in Nigeria has improved, from 11% in 2003 to 26% by 2010 (3,4). However, by December 2008 (the time of study design), only 12% of the estimated 192,400 PLWHA requiring treatment in Benue State were enrolled in an ART program, and of the 23 Local Government Areas, only 11 had a health center providing ART services (personal communication, Executive Secretary, BENSACA, March 2009).

Benue is a largely rural state situated in north- central Nigeria and is a significant contributor to Nigeria's agricultural production. The population of about 4.2 million (in 2007) includes five major ethnic groups, predominantly the Tiv, Idoma and Igede. The major religions are Christianity and African traditional religions. Since 1999, Benue State has consistently recorded among the highest HIV prevalence rates of any state in Nigeria (16.8% in 1999, 13.5% in 2001, 9.3% in 2003, 10% in 2005, 10.6% in 2008 and 12.7% in 2010), while the prevalence in Nigeria, in comparison, is dropping (5.4% in 1999, 5.8% in 2001, 5% in 2003, 4.4% in 2005, 4.6% in 2008 and 4.1% in 2010) (5–7). The published literature that might explain this high prevalence is scanty, and Benue is not known as a major crossroads or transportation hub. We were unable to find any academic sources examining the reasons for the high prevalence in Benue State. An electronic forum, Nigerian Best Forum, has posted an exchange on this issue with one blogger citing Professor John Idoko, Director General of the National Agency for the Control of AIDS, as follows: "The National Agency for the Control of AIDS (NACA) has attributed the high HIV prevalence in Benue State to poverty, illiteracy and the lack of empowerment for women" (8). One study in a Benue community found HIV prevalence to be highest among farmers, divorcees and those with educational level at primary school and below, with the main risk factor being unprotected casual sex (9). Further analysis of Benue state and how it is currently and historically situated in the larger Nigerian polity and economy may also help shed more light on the epidemiology of HIV in Benue.

Study methods

The study utilized a qualitative case study design to explore barriers and facilitators of access, including perceptions of quality of care, stigma, financial barriers, and other issues. Semi-structured and key informant interviews, exit interviews and three focus group discussions (FGDs) were held in July and August 2010 with a total of 34 respondents: 28 patients currently accessing ART in two general hospitals (one in Benue and another in Abuja), three health care providers and three policy-makers (two senior managers in Benue's AIDS Control Agency and Health Management Board and a senior manager at the National AIDS/STD Control Program). The three FGDs and the semi-structured interviews used purposive sampling to ensure different socio-economic groups, ages and sexes were represented, while exit interviews used convenience sampling. The two FGDs held in Benue State were single sex with one male and one female group; one FGD held outside the state included both sexes. All patients who participated in the study had access to ART. All interviews were in English and were recorded and transcribed. Transcripts and field notes were analyzed manually through non-hierarchical coding and thematic analysis. We categorized the themes into facilitators and barriers to access and respondents' views on how these could be addressed, and used open-ended coding of emerging themes. The interviews were complemented by database and records analysis in ART-related programs in Nigeria and Benue, including a search of the IHVN database to trace the distribution of Benue State patients accessing care in three IHVN-supported sites outside of Benue State. Ethical clearance was received from the Senate Research Committee of the University of the Western Cape, the IHVN Institutional Review Board, BENSACA, the Benue State Ministry of Health and the Head of Asokoro General Hospital.

Limitations

This was a small qualitative study not formally representative of the general population. While we did not find major differences by gender or socio-economic status, further exploration of these issues is required. Also, the study did not directly capture perspectives of people who were not accessing care.

Findings: narratives of HIV and access

Of the 28 patient respondents, all but one had already initiated ART, with duration on ART ranging from three to eight years. Nineteen respondents were women and nine were men. Ages ranged from 22–55, with a mean age of 33 for the women and 42 for the men. Half (50%) were unemployed or housewives, while another 36% were self-employed. Ten of the respondents were accessing care outside of Benue State.

According to IHVN's database as at 30 April 2010, 3.6% (205) and 9.7% (544) of the 5761 patients registered for ART in Asokoro General Hospital, Abuja, were travelling from Benue and other states to access drugs, even though ART sites were available closer to these patients' homes. The addresses of 125 (2.2%) of the Asokoro patients were unknown.

The major facilitators of access reported by the study participants were the implementation of free treatment, the beneficial effects of ART, disclosure, and having a

treatment partner. Participants emphasized the importance of taking the medication, even if that meant selling off personal possessions to pay for transport costs.

The major reported barriers to access were: stigma and discrimination (and related to this, non-disclosure); inaccurate knowledge and perception about HIV and ART and certain religious beliefs and advice; economic factors (hunger, transportation costs, poverty); health systems barriers (long wait times, unfriendly healthcare workers, costs and non-availability of other drugs for existing co-morbidities and for treatment of opportunistic infections), and structural aspects and concerns specific to ART services (coverage, capping of services and fear of discontinuation of services).

Most respondents identified disclosure and having a treatment partner as important facilitators, while stigma and discrimination were pervasive underlying themes. Stigma was described in terms of both its social and its livelihood effects:

‘Stigma is still a major problem. Patients’ relatives feel HIV is an abomination or a curse and refuse to help patients.’ (One hospital administrator)

‘There are cases like that, of people who were sacked from their offices because of going to the hospital. They don’t say it’s because you are positive. They find a little fault and use it to sack you. And everyone has faults.’ (A male patient)

The three healthcare workers interviewed identified staff shortages as a critical barrier to access, while patients viewed health workers’ negative attitudes and the non-availability of drugs for their co-morbidities as major challenges facing them. Respondents’ comments about some health facilities and health workers were acerbically eloquent:

‘Any day you want to collect drugs, that whole day is for the drugs.... Some days, you will stay till 4 p.m. As early as 5 a.m., you will go ..., you will still stay till 12 p.m. before they attend to you... If you go for drugs, you will wait, if you go for test, you will wait, if you go for consultation, you will wait, if you go for adherence, you will wait. Anywhere you go, you will wait. At times before you reach your house, it’s about 5 p.m.’ (55-year-old woman)

‘The major problem we have here is our nurses and doctors are so rude, the way they talk to patients... Like this nurse that just passed, she is very rude, very aggressive, very harsh. She doesn’t look at us as human beings. ... Patients need to know HIV is not the end of our lives, but some staff, the way they talk to you... Some patients sit outside and cry.’ (33-year-old man)

Some patients’ comments suggest risk pooling to manage clinical care and its costs:

‘[T]he major problem we are having now is concerning... treatment of opportunistic infections... [S]ometimes, they ask you to go and buy outside the pharmacy and some... do not have the money. Like acyclovir for herpes zoster, it is expensive, especially if you have to take 400mg... is about N3000 and you have to take it for 14 days so... some of us

contribute money to make sure that they get the drug. Like somebody that has cough, not really TB but general cough. They'll ask you to buy ciprofloxacin or azithromycin.....And if you have an opportunistic infection like that, without you treating... your ARV will not work because something else is disturbing you so the virus waxes stronger.' (33-year-old man)

Security of access to medication was perceived differently by managers and patients. Many of the large ART programs in the state had closed registration to new patients, yet none of the program managers or policy-makers mentioned drug supply as a challenge. While the supply of antiretroviral drugs has been fairly stable in the country in recent times, this is not the case for drugs used for managing opportunistic infections. In contrast, stockouts and fear of complete discontinuation of ART were a prominent theme in patient narratives. Several patients noted that they, as well as other people, are hoarding ARVs.

'...sometimes I think, what if the program ends, what shall we do?' (33-year-old-female)

'Like me, I have excess [drugs]. You must have extra. So whenever the drugs do not come, you continue with the one you have.' (32-year-old man)

The 48-year-old man quoted earlier spoke specifically about PEPFAR, and indeed about IHVN:

'Maybe one day IHVN will [stop] supplying the drugs and everyone will start buying. Then you will be using the drugs you have till you prepare to buy for yourself. For that we used to collect [the drugs] and [store them]' [Agreeing murmurs].

While another hopes to be among the first in line for a cure:

'... hoping that one day... there is a cure or something happens, then some of us coming here will be beneficiaries.' (28-year-old female)

Discussion: managing personal and systemic vulnerability

The flow of the interviews and FGDs among both men and women suggested an integrated awareness of overall but differentiated vulnerability at both individual and collective levels, encompassing emotional, social, livelihood and systemic dimensions. 'Access' was not perceived as secure even among these patients, all of whom were accessing ART. Planning, agency, and both individual and collective action are necessary to maintain access to existing and potential treatment in the face of many risks, from those related to interpersonal dynamics to the vicissitudes of global funding.

Poverty in general, and in particular concerns about food, transport and treatment costs, arose repeatedly. This underlying economic vulnerability was exacerbated by the potential social and livelihood impacts of stigma. While many studies have identified transport costs as a major barrier to ART access and adherence (10–12), we found patients were willing to travel long distances at some cost to access treatment, echoing other studies (13,14) which found that patients preferred to travel to access care because of non-disclosure and to avoid stigma. Studies in Namibia and India have reported non-

disclosure as a coping strategy for stigma (15,16), albeit one that could lead to non-adherence and transmission risk behaviors. Many of the patients travelling to access care outside Benue State expressed reluctance to relocate to facilities closer to their homes even though they were unemployed and the travelling was obviously inconvenient. Some expressed the view that the ART services provided in facilities close to home were inferior to services obtainable in the bigger facilities further away. One participant felt that new care developments, like a cure, would be first made available to patients accessing care in bigger facilities than in smaller facilities in the rural areas. Additionally, some travelled for business and job opportunities as well as to seek help from relatives living in the cities.

These narratives and the accounts of stigma in this study suggest a fragile equilibrium between risking exposure to social, emotional and livelihood trauma and maintaining multiple sources of social, emotional and livelihood support through a combination of silence, overt disclosure and tacit disclosure. Patients travelling out of state often did so together, on the same bus, to the same place, yet only a minority had disclosed their status or reported being in treatment support. Seven of the ten had not disclosed to family members, and only one was in a support group. While 8 out of 10 respondents travelling out of state mentioned stigma as a major or the major motivation, these respondents did not suggest that non-disclosure to family and not being part of a support group might also be relevant. These individuals may have experienced more discrimination or had less supportive families than others, but there is also a suggestion of a 'tacit support group': nothing has been said, thus offering some protection of privacy, yet the very act of regularly travelling together offers some solidarity. And the choice of travelling to the capital city rather than to another anonymous ART center closer to home suggests that concerns about future access to existing and new interventions may be part of the calculus of these individuals.

Although several studies have examined ART access in Nigeria and Africa (11,19–21), few have looked at patients' – rather than funders' – concerns about sustainability of funding. One study in Tanzania (22) reported that patients were skeptical of how long the free ART program could last.

Kyomuhangi (23), in analyzing data from Uganda and Senegal, recommends that policy makers consider lifetime costs of placing patients on ART. Our study suggests that patients are afraid that the conclusions of such a costing may not be in their favor.

Conclusion

Patient narratives of vulnerability and access six years after the advent of 'free' ART across Nigeria reflect a sophisticated understanding of the social determinants of health and the vicissitudes of health funding, and of a complex interplay between social and economic vulnerability (through poverty and stigma) and personal and collective agency to protect current and future access and minimize vulnerability and risk. In light of the November 2011 cancellation of the 11th round of funding by the Global Fund – just over a year after these interviews were conducted – these narratives of pending funding cuts, hoarding medicines, keeping a foot in the door in a major hospital, and managing complex webs of silence and solidarity seem both prescient and eminently rational.

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