Life Projects and Therapeutic Itineraries: Marriage, Fertility, and Antiretroviral Therapy in Nigeria

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Introduction

As in many parts of the world, in Nigeria access to life-saving antiretroviral drugs is just beginning to become more widely available to people infected with HIV. With more than 130 million people, Nigeria has an adult infection rate estimated to be between 2.5-5.6 percent, translating into at least three million people currently living with the virus [1]. The federal government launched a small-scale treatment program in 2001 that enrolled fewer than 10,000 people over approximately four years. In late 2005, in conjunction with increased international donor support for antiretroviral therapy (ART), Nigeria announced that all people in the country living with HIV who require ART will receive drugs free of charge. Current estimates are that approximately 72,000 Nigerians are receiving treatment through the scaled-up program, and enrollment continues to grow [2].

As ART has expanded worldwide, attention has begun to turn to the effects of treatment on prevention, and specifically the sexual behavior of recipients [3]. Much of this work has been conducted in developed countries and has focused on homosexual men [4-6]. Research in developing countries has addressed the possible connections between treatment and risky behavior utilizing mainly quantitative data from surveys [7-10]. Few studies have considered the sexual behavior of people on ART from the point of view of marital and reproductive goals [11], and little ethnographic research has been undertaken on the topic. This paper reports on preliminary ethnographic research conducted among people on ART in southeastern Nigeria, focusing particularly on the intersection between the therapeutic itineraries of people on antiretroviral treatment and the crucial life projects of marriage and reproduction.

The concept of life projects is introduced to emphasize how people's social aspirations and trajectories influence their behavior in ways that are not easily predicted by or understood

purely in terms of medical priorities. People's larger life projects intersect with and influence their therapeutic itineraries – the ways in which individuals move in and out of treatment, how they understand their medications, and how they integrate therapy into their daily routines [12-13]. Although ART enables people with HIV to hope for and undertake the life projects of marriage and childbearing, adherence to treatment also interferes with these aspirations, and achieving these larger goals frequently impinges on people's capacity to start and stay on therapy, follow recommended treatment regimens, and take adequate precautions to protect others (and themselves) from further infection. Our research suggests that understanding this intersection offers important lessons for both clinical management and public health policy. Several emblematic case studies are presented to highlight key questions and issues that emerge with the scale-up of ART.

Methods

Our findings are the result of several years of interviews and observations by the authors in the southeastern Nigerian city of Owerri, the capital of Imo State. Since 2001, the Federal Medical Centre (FMC) in Owerri has served as the only facility in the region offering ART. The FMC began offering ART to 25 people under a pilot study in 2001 and in 2002 became one of 25 sites in Nigeria offering treatment in the federal government's initial program. The FMC-Owerri enrolled 450 adults living with HIV, and from 2002 through 2005 these individuals received drugs at a highly subsidized rate. In 2006, following the new federal policy of making drugs free at point of access, the FMC-Owerri began expanding its government-supported program with a target of 2,000 patients. By July 2006, more than 1,800 people were enrolled. Interviews were conducted with 22 people receiving treatment. Participants were recruited through information provided about the study on clinic days and at meetings of a local support group for people living

with HIV. This opportunistic sample included a range of ages and marital statuses, equal numbers of men and women, and individuals who had been on treatment for as long as four years and as briefly as six months.

Results

Love, Marriage and ART

As in many African societies, in Igbo-speaking southeastern Nigeria marriage remains one of the most important individual aspirations and social duties that a person experiences [14-16]. For younger unmarried adults who learn they are HIV-positive, the devastation of the diagnosis comes not only from the fear that they will die young, but from the realization that they may die without marrying and having children. With treatment, the life projects of marriage and childbearing are again possible. For unmarried young adults and for older adults perhaps widowed by AIDS, once the shock of an HIV diagnosis is reduced and the positive effects of ART are experienced, finding a marriage partner becomes among the most pressing issues they face. Seeking marriage while taking antiretroviral drugs creates ethical dilemmas about disclosure, poses impediments to enrolling in treatment, affects adherence to drug regimens, and generates possible risks for transmission or re-infection. At counseling sessions offered in conjunction with ART, patients are made well aware of the medical necessity of strict observance of therapy protocols and the risks to themselves and others if they engage in unprotected sex. But this awareness is complicated and often overridden by the fact that in southeastern Nigeria, as in other contexts, unprotected sex is commonly seen as both a marker of trust and an expression of a willingness and desire to procreate [17]. Public health messages about how to keep oneself and others healthy collide with social expectations and conventions about how to conduct a relationship that might lead to marriage.

A young woman named Ifeoma came to the FMC-Owerri in December 2002 desperately sick.² She tested positive for both HIV1 and HIV2 and was immediately started on ART. Over time she recovered remarkably well, to the point where the hospital staff noted that her plump figure and smooth skin were prime examples of the astonishing effects of ART. Ifeoma's story illustrates some of the typical dynamics that unfold as a person on ART begins to reconstruct a life project, looking to marry but struggling with whether or how to reveal her status, and how to take her drugs while in a relationship with a man who does not know that she is HIV-positive.

Prior to getting sick and learning her HIV status, she had begun a serious relationship with a young man in a nearby city. Ifeoma and her boyfriend had had frequent unprotected sex and the man was encouraging her to get pregnant to "fast-forward" a marriage. He wanted evidence of her fecundity before formalizing their relationship. After learning that she was HIV-positive, Ifeoma felt she could not tell him her status without jeopardizing the relationship. She believed that once he found out he would make inquiries about her past and discover the rumors that her first husband had died of AIDS. This news, she thought, would make him suspect that she began having unprotected sex with him knowing that she was HIV-positive. Further, she felt it was impossible to introduce condoms into their sexual relationship given his desire for her to get pregnant. There would be no reasonable way to explain her sudden desire for protection.

Taking her drugs required vigilance to maintain her secret. Each of Ifemoa's three antiretroviral drugs was a separate pill and each had to be taken twice a day. Combined with the various vitamins she also took, it meant that a monthly supply was more than 200 pills. To navigate this problem, Ifeoma managed to take advantage of one aspect of household gender inequality. She hid the pills under the sink in the kitchen – a place, she reported, her boyfriend almost never entered. Further, she would time her dishwashing – a task he never undertook – to

coincide with her need to take her medications. In this way she managed to keep her secret and stay on her drugs. At the time that we lost contact with Ifeoma – she moved to the city of Port Harcourt with her boyfriend and planned to try to begin collecting her drugs there – she was still hoping to get pregnant, marry her boyfriend, and eventually find a way to disclose her status.

For many people on ART issues of disclosure are central to the endeavor of navigating sexual and romantic relationships, and these issues frequently come to a head around proposals and plans for marriage. With the increasing awareness of the risks of HIV in Nigeria, many churches, including the Catholic Church, now require couples to undergo HIV tests if they wish to be married in the church. The prospect of being tested before marriage produces great anxieties for individuals who already know they are HIV-positive. People invent all kinds of ways to deal with this problem, including using premarital testing as a way to gracefully disclose their infection without revealing that they have previously kept it secret.

The case of Chinyere is illustrative. She was HIV-positive and terrified that her status was going to ruin her hopes for marriage. A Nigerian man based in Europe whom her family wanted her to marry came home for a visit. The visit had gone well, so well that the man, Obi, had initiated the first steps in a traditional wedding ceremony. But just before Obi was to return to Europe, Chinyere fell sick – so sick that she could not even escort Obi to Lagos for his departure. Soon after, she enrolled in the FMC-Owerri ART program. She began to get well physically, but in Chinyere's mind she had bigger problems. Not too long after Chinyere started her treatment Obi arranged to have the next steps of the traditional wedding ceremony undertaken in his absence. The plan was that they would also be married in the church when Obi returned to Nigeria. In the week leading up to the traditional ceremony, Chinyere experienced terrible rashes all over her body, a reaction to nevirapine, one of the first-line drugs in the

combination commonly provided in Nigeria's ART program. She was frantic about her appearance, worried that someone might guess that she had HIV. She eventually told her mother-in-law that she had an allergic reaction to an everyday medication and this was the story conveyed to the larger traditional wedding party. Chinyere made it through traditional wedding without her HIV status being discovered, but she still faced the fact that Obi would soon come home for the church wedding, and she had not yet revealed her status to him.

The impending church wedding hastened her dilemma because she and Obi were Catholics and, as mentioned above, HIV tests were required of all couples wanting to marry in the church. Chinyere pleaded with her counselor for assistance either to obtain a fake HIV lab result or find someone who was HIV-negative who could take the test in her name. Her counselor refused, but they discussed other possibilities. Chinyere settled on the idea that she would go together with her fiancé for pretest counseling, pretend it was her first test, and feign horror when her result was revealed. She banked on the hope that Obi would stick by her when her status was discovered now that they were traditionally married, and that she would avoid the worse consequence of his learning of her longer-term deception.

On the appointed day, when she and Obi went for their results, Chinyere fainted dramatically. Her gamble paid off. Although Obi tested HIV-negative, he did not react angrily about her result. He even reinforced the doctor's message that Chinyere could receive treatment and lead a normal life. Perhaps the most illuminating aspect of the story is that once Chinyere's status was known Obi became a co-conspirator in figuring out how to get married in the Catholic Church. He could accept his wife's HIV status, but he could not live without the social recognition of a church wedding and he personally arranged to secure a fake result for Chinyere.

Chinyere eventually became pregnant, and with the aid of treatment her child was born HIV-negative. She did not breastfeed the baby boy and again had to invent an explanation to cover her unusual behavior. Over time we lost contact with Chinyere, but at last report her marriage remained amicable, her child was healthy, and only she and Obi knew her HIV status. *Looking for a Child*

It is hard to exaggerate the importance of childbearing in southeastern Nigeria and throughout much of Africa. As the renowned anthropologist Meyer Fortes [18] argued quite some time ago, it is "parenthood that is the primary value associated with the idea of family in West Africa" (121). "Parenthood," Fortes says, "is regarded as a *sine qua non* for the attainment of the full development of the complete person to which all aspire" (125). Having children is not only a means to individual personhood, but also a fulfillment of one's obligations to kin and community. In southeastern Nigeria every person assumes he or she will marry and have children, and childlessness is the highest of calamities. Personal lives are devastated by it and popular culture is obsessed with it.

It this context, it is no wonder that for people on ART one of the predominant aspirations once they begin to feel healthy is to have children. Many people on ART embark on or resume childbearing, but the process is fraught with ethical dilemmas, social obstacles, and potential health consequences. We have observed numerous cases where people on ART -- and even their uninfected spouses who knew their partners were HIV-positive -- had strong desires and went to great lengths to procreate. Nnamdi was a founding member of the Association for Positive Care (AsPoCa), the first support group in Owerri for people living with HIV. He learned he was HIV-positive after becoming extremely sick. When the government ART program began in 2002 he

was one of the first to enroll. He told his wife of his problem immediately. She tested negative, but stuck by him steadfastly. At the time of Nnamdi's diagnosis they had two young sons.

Nnamdi said that when he was sick he never even thought of sex, much less having another child. But when he became better after beginning ART he and his wife resumed a sexual relationship and Nnamdi reported that he always used condoms. About a year or so after he had started on ART he sought counseling because his wife began putting pressure on him to have another child. As a leader of AsPoCa he was well versed in all the most up-to-date information about risks, prevention, and treatment. He said he was not inclined to expose his wife to the risk of infection for the sake of another child when they already had two sons.

His wife, Ogechi, was, however, intensely desirous of having a third child. Nnamdi wasn't sure how to negotiate her increasing insistence so he asked if he could bring Ogechi for counseling. Ogechi was counseled about the risks of unprotected sex for herself and about the possibility of maternal to child transmission. She knew all these risks already and still wanted to get pregnant. She explained that her friends, peers and relatives had been asking for some time why she had not had another child. She said, "Everyone is always asking about my next issue (offspring). I do not feel normal with only two children. I can't tell them why we are not having more issues (children)." In addition to the social pressure to have more children, she also expressed a strong desire for a daughter. Regarding the risks of contracting HIV herself, she simply said, "My husband is healthy now that he is taking his drugs. If I become infected I will also take drugs."

Discussion and Conclusion

Marriage and childbearing remain the paramount life projects for people in southeastern Nigeria.

For individuals on treatment – or married to someone on ART – having children is the most

important path to normalcy. The life projects restored by ART are not, of course, all positive. But for most people who are enrolled in Nigeria's expanding antiretroviral therapy program the opportunity to resume a normal life is cherished and made the most of. While the vast majority of people on ART at the FMC-Owerri are mindful of the continued risks to themselves and others, and committed to keeping themselves and their loved ones safe, the physical risks to personal and public health are factored into a larger equation in which the very reasons for being alive are always paramount. In southeastern Nigeria, marriage and parenthood, the principal tasks of biological and social reproduction, reign supreme in the hierarchy of social expectations and individual aspirations.

For many people on ART the dilemmas of how to marry and make families while living with HIV are resolved, or at least addressed, by seeking partners from within the communities created through treatment and the support groups that have been established as a result. At the FMC-Owerri AsPoCa has been a principal meeting ground for people seeking sexual partners, possible spouses, and eventually pregnancy and children. Several other support groups have been established in the region and anecdotal reports suggest that they have also become arenas for sexual networking and marriage markets. As in the larger society, not all of what goes on in the support group is laudable. The inequalities of age, gender and social class are reproduced, and even more troubling, people's vulnerable emotional status is sometimes exploited. But overall, the emerging communities of people living with HIV seem to be a positive development, enabling people to forge life projects, including reproductive projects, in ways that make it easier to address both ethical and medical realities.

Of course not everyone who is HIV-positive can or will find lust, love, or marriage within the support groups. The lives of people living with HIV remain naturally intertwined with

the wider population of people who do not know their status. Life projects, especially reproductive life projects, continue to pose ethical predicaments, public health risks, and existential dilemmas. Whether, when, and how to disclose one's HIV status; how to marry and have children in ways that meet social expectations and achieve personal ambitions; and how to stay healthy and on drugs while doing all this – these are priority issues for people living with HIV who have been provided another chance at life by the availability of ART.

As the cases described above have illustrated, while the availability of drugs has commuted the social and biological death sentences previously associated with HIV/AIDS in Nigeria, the scaling up of treatment has not yet significantly reconfigured the landscape of stigma. As a result, people on ART continue to try to manage their treatment mostly in secret. In many cases the resurrection of reproductive life projects can prove to be an obstacle to adhering to therapy and vice-versa. For people who rely on antiretroviral medicines to live, the continuing stigma of the disease means that the very drugs which have restored their futures also threaten to undermine their most precious life projects. The drugs themselves, so valued for their physical effects, are reminders of the enduring difficulties and discrimination associated with HIV/AIDS.

Based on the findings from this ethnographic examination of a small population of people on ART in southeastern Nigeria, organizations that provide treatment and counseling face many challenges in promoting behaviors that are in the interest of both their individual patients and broader public health. The experiences at FMC-Owerri suggest that it is crucial to acknowledge, understand, and support the restoration of life projects. Given how important sexual relationships, marriage, and reproduction are in southeastern Nigeria – and the likelihood that these priorities will be similar in many other societies – clinicians, counselors, and other public health personnel will need to be mindful that their messages and advice will only be heeded if

they enable these life projects. There is probably no way to avoid the fact that the fulfillment of personal aspirations and social expectations sometimes directly conflicts with public health interests. But as many of the stories described here attest, people on ART are highly attuned to these issues and most take all of this into account to the extent that they can if they are given a chance. The life projects of people on ART are complicated, contradictory, and messy. Perhaps we should not expect much different if one of the glories of ART is that it allows people infected with HIV to live normal lives.

Notes

- 1. While people receive drugs free of charge at access point, there are still many costs associated with treatment that must be paid directly by patients, including a battery of lab tests necessary before treatment can begin and the costs of transportation to collect drugs and receive follow-up examinations. There is great variation in Nigeria with regard to whether and how much of these additional costs are subsidized or waived. As of 2006, at the FMC-Owerri patients incurred significant costs even though they did not pay for antiretroviral drugs.
- 2. All of the names of the individuals whose cases are described are pseudonyms and aspects of their stories have been disguised to protect their anonymity.

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