The art of medicine
A decade of researching the social aspects of HIV and AIDS

My active involvement with HIV research began in 2005, after Professor Jane Anderson invited me to talk about gender to health workers involved in HIV services in the UK. Over coffee afterwards she discussed her desire to find out more about the lives of the African women for whom she was providing clinical care. I was keen to help, using my knowledge of qualitative research in the sociology of health. We, therefore, planned a collaborative study of the experiences of African women living with HIV who were receiving health care in a London hospital.

Our first study reflected the growing interest worldwide in the effects of HIV on poor women as the pandemic became increasingly “feminised”. As expected, the concerns of many participants were focused on their children, with most women living far from extended families whose members might have been a source of support. Familiar themes of both economic and physical insecurity emerged as did the complexity of relationships with intimate partners whose status might be positive, negative, or unknown, and who might or might not be willing to offer support.

After this initial study, we decided to compare these findings with the experiences of men infected with HIV, both those who identified themselves as heterosexual and men who had sex with other men (MSM). Separate studies of the two groups were undertaken to ensure that both gender and sexuality received the necessary attention. Surprisingly perhaps, our study of self-defined heterosexual men was one of the first to be done in any setting. The lives of these men after diagnosis have been largely invisible. One of the reasons for this soon became apparent to us as those men we approached seemed less willing than their female counterparts to discuss their illness. Most importantly, many men commented on the incompatibility they experienced between the physical and psychological “weakness” associated with HIV and AIDS and the social expectations placed on them as men. They told us about what they regarded as their inability to “perform” satisfactorily—as workers and sex partners—that they felt to be especially shameful. Moving on to our study of MSM, we again found ourselves in new territory. Unlike heterosexual men, this group has been more extensively researched in the richer parts of the world. The lives of these men after diagnosis have been largely invisible. One of the reasons for this soon became apparent to us as those men we approached seemed less willing than their female counterparts to discuss their illness. Most importantly, many men commented on the incompatibility they experienced between the physical and psychological “weakness” associated with HIV and AIDS and the social expectations placed on them as men. They told us about what they regarded as their inability to “perform” satisfactorily—as workers and sex partners—that they felt to be especially shameful. Moving on to our study of MSM, we again found ourselves in new territory. 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Our three studies showed how both gender and sexuality shaped the lives of these HIV-infected women and men of African origin in very different ways. But certain structural aspects of being a migrant were common to all of them. Most of the participants in our studies had fairly limited opportunities for employment and economic security and told us about how they lived in fear of losing their right to remain in the UK.

These findings raised inevitable questions about the experiences of HIV-positive people in diverse settings. How could we compare the situation of positive African migrants in the UK with their compatriots back home for example? In order to answer these questions I began a review of the research from different parts of the world with the eventual aim of providing a global perspective on living with HIV and dying from AIDS.

The geographical spread of the pandemic had already become clear by the year 2000 with some 75% of all people with HIV concentrated in the African region. At the time few studies explored affected individuals’ experiences of illness and death. However, my own visits to South Africa during this period reinforced my belief in the importance of understanding the diverse settings in which HIV was spreading.

Since 1994, I had spent time each year teaching at the University of Cape Town. Early on, the lack of available treatment threw the deprived circumstances of millions of people living with HIV into sharp relief. I vividly remember a visit in 1996 to a clinic in the township of Khayelitsha where antiretroviral therapy (ART) was being offered to a select few for the first time. That same year I sat with a 16-year-old girl as she gave birth and watched her walk away a few hours later. She had been given one dose of zidovudine to prevent transmission to the baby but there was no therapy for her. The future for this young woman and her child seemed intolerably bleak and entirely unfair.

Access to ART gradually improved over the following decade and by 2010 more than 6 million people in middle-income and low-income countries were on ART. However, major challenges remained, with many of those in need still unable to gain access to treatment. At the same time funding for HIV services was beginning to decline in the context of widespread economic recession. This, in turn, generated intense debate about the division of resources between prevention and care with new approaches, such as pre-exposure prophylaxis (PrEP), being strongly promoted as the way forward. But what of those who were already infected with HIV and in need of care? It seemed to me that this group
was becoming increasingly overlooked in the face of advances in medicalised HIV prevention. At around the same time, studies began to indicate the potential of "treatment as prevention" (TasP), which has now become a central focus of international policy. However, this "HIV optimism" flowing from centres of power, such as New York and Geneva, is based on the achievement of universal testing as well as major improvements in the adherence of individuals to prescribed medication over a lifetime. Yet it seems that this optimism is unlikely to be achieved within a narrow medical framework.

My own research and that of many other social scientists and epidemiologists point to this reality through an increasing number of studies of what has been called the "treatment cascade". Substantial numbers of people with HIV infection in the African region have never been tested and hence do not know their status. Of course, this could be improved if testing facilities were greatly extended. But some people do not take such opportunities even when they are freely available or "drop out" from treatment programmes after diagnosis. If these challenges are to be met, much more information will be needed about the daily lives and psychological concerns of those individuals involved.

Studies have shown, for example, that some people living in high prevalence settings can be especially fearful of a positive diagnosis and the expectation of painful sickness and an early death. Individuals are also afraid of rejection by significant others or stigmatisation by the wider community. These fears vary according to many factors, including gender and sexual identity, as our earlier studies in London showed. MSM, for example, may be constrained by fear of double discrimination resulting from illness combined with homophobia. The recent legislation in some African countries, notably Uganda, shows how rational such fears are. Similarly, a combination of societal stigma and discriminatory laws is a major obstacle to testing and treatment among the up to 3 million injecting drug users who are HIV positive.

With regard to women, gender inequalities have been shown to have a profound influence as they shape both testing and treatment. Furthermore, since women are likely to be diagnosed first, often as part of antenatal care, they risk being "blamed" by their partners and may be beaten or abandoned. And women who are diagnosed at the same time that they find out that they may be pregnant face extremely difficult decisions about their future.

During the research for my recent book, Living with HIV and Dying with AIDS: diversity, inequality and human rights in the global pandemic, Farnham: Ashgate Publishing, 2013 Doyal L with Doyal L. Living with HIV and dying with AIDS: diversity, inequality and human rights in the global pandemic. Farnham: Ashgate Publishing, 2013, it became ever clearer that all these factors may come into play as individuals make decisions about testing and try to negotiate a life dependent on ART. The complexity of these issues is staggering and failure to comply with the advice of health workers cannot be explained away by irrationality on the part of "non-adherent" service users. We know that HIV is transmitted by some of the most intimate and culturally symbolic actions of individuals. Hence a biomedical response can take us only part of the way. It will also be essential to treat both those individuals infected with HIV and those at risk as human beings with beliefs, habits, routines, and unconscious cognitive processes that shape their actions. At the same time, attention needs to be paid to a wide range of economic inequalities. About 95% of new cases of HIV now occur in low-income or middle-income countries, where the cost of drugs and travel to a clinic can be too onerous for many and clinic visits may interfere with opportunities to earn a living. To compound matters still further, food insecurity and other challenges of living in impoverished conditions may render it difficult to take drugs as medically mandated.

The relation between HIV and poverty is not a simple and straightforward one. But, as in so many contexts, the material circumstances of people’s lives play an important part in shaping their risk of infection from HIV and also their capacity to take care of themselves as well as accessing care from others. This context will be especially important in the next phase of the pandemic when many of those in greatest need will be in resource-poor settings. Hence, a decade on, the thread that guides my own work on HIV continues to be a commitment to interdisciplinary collaboration, with social scientists having a key role alongside biomedical colleagues.

Further reading

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