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Living with HIV in Fiji: Highlights from a qualitative study (Part 2)

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This two-part article presents selected findings from a research report entitled *Living with HIV and AIDS: Perspectives of women and men in Fiji* (2011). Prepared for the National Health Research Committee of the Ministry of Health of Fiji, the report aimed to expose, in simple language supplemented with extracts from interviews, the results of a qualitative study of the experience of people living with HIV that I conducted as part of my doctoral degree in anthropology at the School for Advanced Studies in Social Sciences (École des Hautes Études en Sciences Sociales).

Part 1 of the article (PASA 38) described the objectives, methods and sample of the research before turning to the contexts of HIV acquisition and diagnosis reported by the participants in the study. Part 2 examines the health-care practices of HIV-positive people, their experiences of HIV disclosure, and the challenges and benefits of joining an association of people living with HIV.

Health-care practices: ART, herbal medicines and spiritual healing

Antiretroviral therapy (ART) has been available free of charge in Fiji since 2004. Among the 28 people living with HIV interviewed in this study, 15 were taking HIV treatment. The majority of the 28 people living with HIV interviewed considered ART to be a medical technology that greatly improves and prolongs the life of HIV-positive people. They commonly remarked on the efficacy of ART by emphasising the weight gain it permits – largeness and corpulence being considered, in the indigenous Fijian community, as a sign of health and strength.

Those on ART, however, reported side effects and difficulties associated with treatment intake, showing that ART is no magic bullet. Transport to the clinic, hunger associated with taking HIV treatment, conjugal and family problems, feelings of depression and the difficulty of coming to terms with one's HIV status were mentioned as barriers to sustained medication adherence. Among the 15 participants who were taking ART, at least three reported that they had previously interrupted treatment for several weeks or months. One was resistant to first-line HIV medicines as a result of multiple treatment interruptions. At least one person who qualified for ART based on their medical condition had decided to refuse treatment.

People living with HIV did not turn only to ART and the biomedical health-care system to preserve their health. Several participants in the study reported that they took Fijian herbal medicines (*wainimate vakaviti*) for preventive purposes or to 'treat' minor symptoms or illnesses. Some interviewees, particularly those who had learned about their HIV status in the early 2000s, when ART was not yet accessible in the country, also reported having tried local treatments that had been presented to them as capable of 'curing' AIDS (*wai ni AIDS*).

Faith, fasting and prayer were also frequently mentioned by the respondents as means through which they tried to maintain good health and be 'cured' of HIV. This was in accordance with the fact that a majority of the research participants understood their HIV contraction to be the will of God: a way God had chosen to encourage them to come back to the 'right path' or a mission sent by God for them to raise awareness of the virus. God was seen by most of the participants

as being at the origin of their HIV contraction, and many believed that their 'recovery' lay in God's hands.

Experiences of HIV disclosure and reactions of families and communities

The decision of whether or not to disclose HIV status to family, friends and community is a difficult one for most people living with HIV. Among the women and men interviewed in this study, three had decided to keep their HIV status secret from their close ones; the only people aware of their condition were their HIV-positive partner, the medical personnel monitoring them, and the staff and members of the local association of HIV-positive people. One person had disclosed their HIV status to a few selected friends, while 13 and two people respectively had decided to inform family and community members (workplace, neighbourhood, village, etc.) about their HIV status. Nine people interviewed had gone a step further by publicly revealing their HIV status to raise consciousness about HIV in Fiji.

Reasons for HIV disclosure to close ones varied. They included the desire to obtain economic and emotional support, wanting to guarantee care for their children in the case of illness or death, and desiring to relieve themselves of the burden of keeping their condition secret. A majority of the people interviewed also considered disclosure as a duty towards their family members out of respect for them. Although most of the study participants considered HIV disclosure to close ones as a desirable thing to do, many had had little or no choice in the reveal process. Indeed, seven women and men interviewed reported having disclosed their HIV status to at least one person close to them following a breach of confidentiality by medical personnel. Similarly, several people who had not expressly revealed their condition alluded to the strong suspicions of their families and communities due to circulating rumours that they attributed principally to information leakages from health clinics and hospitals.

The participants revealed a range of experiences following disclosure or suspicions aired of their HIV status. Reproach and criticism were common in the life of many, especially women, and several reported feeling the need to speak and act cautiously so as to avoid offending or disappointing others and to be spared from disapproving remarks on their HIV status. Several respondents also said they had had the impression of being ignored, neglected or set aside by family, friends and community ever since they had disclosed their HIV status or it had become known or suspected. Likewise, some of the research participants recounted experiences of blatant rejection and discrimination, including losing their job because of their HIV status, being abandoned by their family while they were sick, and being chased out of their houses or communities. The fear of contracting the virus through 'deliberate' or 'accidental' transmission and the association of the infection with immorality and sin seem to account for most of these negative reactions.

In contrast, some participants reported very positive experiences after their HIV status was made known. They said they had received the full support of their family, that their HIV status had served as a bonding element in their relationships with their close ones, and that people had increased their demonstrations of love towards them since learning of their HIV status. Two elements seem to have played a part in these experiences of support and acceptance. Accurate information about HIV clearly constituted a key determinant of positive reactions to HIV disclosure. Being perceived as 'not deserving' their condition – for example, by being a faithful wife or by not being known to go to nightclubs and to drink alcohol – also contributed to people living with HIV being supported and accepted.

Irrespective of the support or the rejection they had experienced, a majority of the people interviewed said that being labelled as 'someone with AIDS' (*tauvi AIDS*) was one of the most difficult things they had to face. The respondents commonly reported feelings of difference and several felt ashamed (*madua*) of their condition. Due to these feelings, many had tended, at least at some point in their life, to isolate themselves and exclude themselves from other people and from social life. Self-stigma and discrimination were widespread among the research participants.

Joining an association of HIV-positive people: challenges and benefits

Organisations of people living with HIV have become integral to the creation of a continuum of care for people living with HIV. In late 2003, the Fiji Network for People Living with HIV and AIDS, or FJN+, was set up with the primary goal of improving the life of HIV-positive people. Among the 28 people who participated in the study, 20 said they were members of the organisation, although the active membership of the group seemed to be around 15 people.

According to the people interviewed, the fear of being identified as a person living with HIV by being seen near the association's office or with HIV-positive people who had disclosed their status publicly was the primary reason why a majority of people living with HIV in Fiji refused to join FJN+. The participants also mentioned other factors that could have discouraged joining. Specifically, they referred to conflicts and tensions between members, gossiping and back-talking, and issues of favouritism and nepotism.ⁱ Disturbingly, instances of people living with HIV being pressured to publicly disclose their HIV status and cases of breaches of confidentiality within the organisation were also reported by the participants and stated as a cause of distress for the women and men concerned.

The people interviewed revealed many benefits of joining FJN+. The organisation was considered by the participants as a friendly environment where they could learn about the health issues affecting them and about ways to preserve and improve their health. FJN+ was also viewed as a place where people living with HIV could access much-needed material and financial assistance for a range of acute needs, including paying for transport costs to visit the health clinic and paying for treatments of opportunistic infections. Similarly, the organisation helped its members to achieve a certain level of economic independence through income-generating activities and training. As was frequently stressed by the study participants, FJN+ was also a space where people living with HIV could talk together, discuss their situation and access the emotional support of their peers. Joining a group of people living with HIV is a fundamental way through which HIV-positive people can reduce social isolation and regain a sense of belonging.

For more details or for a copy of the full research report, please email Fabienne Labbé at fabiennelabbe@gmail.com.

ⁱ These situations are certainly not exclusive to FJN+, nor to associations of people living with HIV. They can be considered common occurrences in any collective movement.

Erratum: Part 1 of this article, published in *PASA* 38, p.8, 1st column, last paragraph should have read: 3) the pressure to adopt normative male behaviour, including the practice of seducing women, that exists in a society organised along gender lines and where male friendship is fundamental.