

Living with HIV and AIDS: Perspectives of women and men in Fiji

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Introduction

This report presents the results of the study entitled *Discourses and Representations of HIV in Fiji and their Impact on the Experience of People Living with HIV and AIDS*. This study was conducted in collaboration with the Reproductive Health Clinics of Suva, Lautoka and Labasa and the Fiji Network for People Living with HIV and AIDS (FJN+) between November 2007 and December 2008. The necessary approvals and authorizations had been previously obtained from the Fiji National Health Research Committee, the Fiji National Research Ethics Review Committee (FNRERC Reference Number 009-2007), the Ministry of Education and the Immigration Department. This research was funded by a doctoral scholarship from the Social Sciences and Humanities Research Council of Canada (752-2006-1062).

Archival research, HIV document collection, participant observation, focus groups and interviews were among the methods and approaches employed in the context of this study. Several social actors (health workers, AIDS advocates, church representatives, etc.) were also invited to participate. However, it is the life stories of 28 women and men living with HIV that constitute the core of this study and of this report. Analysing life stories is a privileged way of examining social and cultural realities as experienced by the individuals. Collecting and presenting the life stories of people living with HIV is also an important way of showing solidarity with people affected by the infection.

This report first provides information on the objectives and methods of this research as it was originally conceived and eventually conducted. It then presents the results of this study as they emerged from the collection of the life stories of the 28 women and men. To conclude, the report deals with implications and recommendations for the control, prevention and treatment of HIV in Fiji. In this, improving the quality of life of people living with HIV and addressing stigma and discrimination should always be a priority.¹

Objectives

This study, as originally conceived and described in the research proposal submitted to the Fiji National Health Research Committee, aimed to investigate the discourses and representations of HIV and AIDS in Fiji and how they impact the experience of people living with the virus. This research had three initial objectives: 1) to examine how HIV and AIDS had been presented and represented at the institutional level (government, non-governmental organizations (NGOs), churches) since the advent of the first reported cases in 1989; 2) to explore how the population of Fiji perceived and interpreted the infection; 3) to analyse the biographies of people living with HIV and how they experienced the virus in the Fijian context.

Interviews conducted with key informants at the onset of this research led, however, to my recognition of an acute need to document the intimate experience of people living with HIV and to make their voices heard by the Fijian population. By studying the

biographies of those affected, it also became clear that their lived experiences should be fundamental in the elaboration of programmes and policies for the improvement of the lives of these individuals and in the prevention of the infection. This research was therefore refocused so as to accord particular importance to investigating the experience of people living with HIV, leaving the study of the impact of popular discourses on the lives of those affected to only one aspect. This research specifically tried to answer four questions:

- 1) According to the life stories of people living with HIV, what are the factors or realities that contribute to an increased risk of the virus in Fiji?
- 2) How do people living with HIV make sense of the infection?
- 3) What are the therapeutic trajectories of people living with HIV in Fiji?
- 4) What are the continuities and changes brought about by HIV in the life of those living with the virus?

Methods

Semi-structured interviews were conducted with 28 people living with HIV in the country's three divisions (Central-Eastern, Western and Northern).¹ The women and men interviewed were recruited through the Fiji Network for People Living with HIV and AIDS and the Reproductive Health Clinics of Suva, Lautoka and Labasa. One participant was also referred by a Fijian medicine specialist (*vuniwai vakaviti*). Thirteen people were interviewed only once while 15 people were met on more than one occasion. The latter procedure had not been envisaged in the original proposal but was necessary in order to confirm the information provided, to overcome difficulties associated with the use of interpreters and to allow relationships of trust to be established. The multi-interviews with these 15 women and men living with HIV were also highly beneficial for they made it possible to follow up on their experience and to carry out a deeper investigation. A total of 44 interviews were conducted with people living with HIV.² It should be noted that the women and men interviewed were mostly indigenous Fijians (25/28). Despite many attempts I made, I was unsuccessful in recruiting people of Indian descent to participate in this study.

The interviews varied in length from 50 minutes to two hours 25 minutes (mean = one hour 25 minutes). The services of an interpreter – a medical practitioner from the reproductive health clinic or a volunteer from FJN+ – were available when required. The interviews were recorded on audiotape when permitted by the participants. Only one person refused, requiring notes to be taken during and after the discussion. Consent to participate in this study was recorded according to the interviewees' wishes. Oral consent was generally obtained and recorded on audiotape. For the person who refused to be

¹ One participant has been excluded from the sample due to concerns over their real desire to collaborate on this study.

² One interview has not been taken into consideration (see previous footnote).

recorded, consent was obtained verbally and the conditions noted. Contrary to expectations, some participants also preferred to sign a consent form. An information sheet on this study was given to all the interviewees. It is worth mentioning that some participants refused to keep the document for fear that family members might find it.

The people living with HIV who agreed to take part in this study received compensation for their involvement. The payment proposed in the original research proposal (5 FJD), which had been suggested by health professionals working with HIV positive people, was judged insufficient to cover the potential expenses involved in participation (transport, food, accommodation, etc.), to compensate for the time investment and to show the researcher's appreciation. At the beginning of this study, I was also told about previous research that had set the compensation for interviews with people living with HIV at 15 FJD. Considering the hardship faced by most of the people interviewed, this payment was regarded as fair and 15 FJD, plus a variable, small reimbursement for transport, was given to the people living with HIV who collaborated on this study. Participants were informed that their refusal to answer any particular question or their desire to put an end to the interview would not preclude in any way their right to be compensated. In fact, one participant asked to stop the interview after 30 minutes of discussion. They were given the 15 FJD and thanked for their collaboration.

Interviews were also carried out with key informants. For the purpose of this study, key informants were defined as people who had extensive knowledge of the issues surrounding HIV in Fiji or who had established significant relationships with people affected by the virus. These included family members and friends of people living with HIV, medical practitioners working on sexual health issues, representatives of NGOs involved in HIV work, health policy makers, Fijian medicine specialists and church ministers. Fifty-three interviews were conducted with key informants.

Formal interviews with members of the "general population"³, planned in the original proposal, proved not to be the best way to investigate local perceptions and discourses on HIV in Fiji. Due to the sensitive nature of the topic or the fear of being questioned about their personal life, people seemed to feel uneasy about this research activity. Some who had known the researcher for a long time even started to avoid her after she had raised the possibility of an interview. The people who agreed to participate, however, reported positively upon their experience, saying that the interview was not as they had expected, despite the fact that the objectives of this study had been clearly explained beforehand. Nonetheless, informal discussions where people were made aware of the researcher's aims were preferred to semi-directed interviews. Five interviews and two focus groups with 13 young people aged 20 to 23 were also conducted.

The data collected were analysed using the thematic analysis method. The main steps of the analysis were the following: 1) transcription of interviews; 2) brief initial reading of transcripts; 3) choice and definition of themes; 4) coding; 5) classification and categorization; 6) scientific description of themes; 7) interpretation. The results of the

³ The general population, here, means the people of Fiji who were not living with HIV and who did not have specific knowledge about the infection.

analysis underwent a consultation process. First, people living with HIV, either personally or via their representative organizations (the Fiji Network for People Living with HIV and AIDS and the Pacific Islands AIDS Foundation), and later, key informants were invited to comment on draft versions of this research report. Feedback regarding the extracts from the interviews was particularly solicited in order for the report to convey the complexity and the richness of the experience of women and men living with HIV in Fiji but, at the same time, to ensure their anonymity.ⁱⁱ

Results

The following sections present findings of this study as they emerged from the 44 interviews conducted with the 28 women and men living with HIV whom I interviewed in 2007 and 2008.⁴ Between 1989 and 2008, a total of 283 people were diagnosed with HIV in Fiji (Ministry of Health December 2008). During this same period of time, about half were presumed to have died.⁵ Therefore, the 28 people interviewed represent approximately one fifth of those officially recorded as having HIV and who were still alive at the end of 2008. The narratives of these women and men also afford certain insights into the experiences of their past and present partners living with HIV who did not participate in this research.⁶

This report makes extensive use of extracts from interviews to ensure that the voices of the women and men living with HIV are heard. Particular care has been taken to convey their words as authentically as possible. On occasion, excerpts have been slightly modified so as to facilitate the transfer from spoken into written language. Minor changes, for example in verb tenses, have also been made in order to assist understanding. Personal details have sometimes been altered in order to preserve anonymity.

The use of pseudonyms was first envisaged but it was finally abandoned for fear that combining the extracts from interviews might allow for identification. No personal details of the participants (age, matrimonial status, educational level, etc.) are provided with the excerpts for this same reason. However, the sociodemographic characteristics of the sample as a whole are presented in the following section.

⁴ The coding and analysis of data from the interviews with key informants and members of the general public are still underway. A systematic content analysis of the articles on sexuality, sexually transmitted infections (STIs), HIV and AIDS which appeared in the *Fiji Times* in 1989 and between 2000-2008 and in the *Fiji Daily Post* and *Fiji Sun* in 2007 and 2008 should also be conducted.

⁵ This estimate was made to me by key informants involved at the Ministry of Health in the control of HIV. It corresponds with data from the three reproductive health clinics offering HIV treatment and follow-up in the country which reported, at different times in 2007, proportions of deaths among patients that varied from 22% to 54%. However, deaths in one of these clinics (22%) were certainly underestimated as cases “lost to follow-up” amounted to 35% (unpublished documents).

⁶ By the end of 2010, the number of people who had received an HIV diagnosis had increased to 366 (Ministry of Health December 2010). However, the trends in the statistics were still similar to those evidenced by the figures for 2008.

Sociodemographics

As previously mentioned (p.6), the people living with HIV who took part in this study were mostly indigenous Fijians (25/28). Three participants were of mixed origin according to local criteria: one was part European and two were part Solomon Islander. The sample reflects the national statistics on HIV as 82% of reported cases are indigenous Fijians. However, it differs from national figures in which Fijians of Indian descent, or Indo-Fijians, account for 12% of cumulative cases of the infection (Ministry of Health December 2008). It is not surprising that no Indo-Fijians were available to participate in this study for they do not join the Fiji Network for People Living with HIV and AIDS and the health care system has difficulty following up on them. The latter seems to be a reflection of the secrecy that surrounds the infection in this community and research on the experience of Indo-Fijians living with HIV is much needed.

Seventeen women and eleven men were interviewed for the purpose of this study. This contrasts with national statistics on the infection which indicate that, at the end of 2008, 44.5% of people living with HIV were women while 55.5% were men (Ministry of Health December 2008). On the contrary, data obtained from the Reproductive Health Clinic of Suva on the sex distribution of patients accord with the trend in the sample. In May 2008, out of 61 patients who were attending the clinic for follow-up due to their HIV status, 36 were women (59%) and 25 were men (41%) (Reproductive Health Clinic Suva May 2008, unpublished). This shows that though more men seem to be affected by HIV in Fiji, more women seek health care appropriate to their condition.

The interviewees ranged in age from 22 to 45, the median age being 31.5. The men were markedly older than the women. The median age at the time of interview for men in the sample was 33 while it was 28.5 yrs for women.

The people living with HIV interviewed for the purpose of this study came from – as conventionally defined within the indigenous Fijian community, i.e. according to their father's origin – the different provinces of the archipelago. However, at the time of interview, a large majority were living in urban areas (22/28). To be more specific, the bulk of participants were living in the suburb of Lami and along the Suva-Nausori corridor (18/28).

About three quarters of the respondents were in what was considered a long-term relationship at the time of HIV acquisition, being either married or on the way to marriage (9/23) or in a *de facto* relationship (8/23) (based on 23 people because of unknown conditions of HIV acquisition for the others). When interviewed, however, many were widowed (5/28) or had separated or divorced (6/28), frequently as a result of their serologic status. Approximately half the people living with HIV interviewed (15/28) had at least one child when they contracted the infection. Nine people learned about their HIV seropositivity in the context of a pregnancy. Four had had at least one child after learning about their HIV status. On average, the people living with HIV interviewed had 1.5 children.

The research participants' level of education varied from Class 4 to a university diploma. At the time of interview, the majority were unemployed (18/28) while two were studying. Eight people were engaged in salaried work, six of them being employed in HIV-related jobs. It is worth noting that seven people reported having had to leave employment or abandon studies following episodes of illness caused by the infection. Two people also reported having lost their job because of their HIV status. Among those who were unemployed, thirteen (13/18) had never had waged work or had only been employed in occasional and unstable jobs.

Learning about HIV status

The women and men who participated in this study had been living with a diagnosis of HIV for periods varying from two weeks to more than eight years (mean = 3.5 years, calculation based on 26 people because of unknown time of diagnosis for the others). However, based on information such as the timing of the beginning of a relationship, of a previous pregnancy during which a woman had been tested for HIV antibodies, thus allowing her to say that she (and probably her partner too) was then HIV negative or of signs appearing on their body, they estimated the time lapse between their contraction and their diagnosis of the infection to be from three months to four years, which would indicate these individuals could have been living with HIV for periods as diverse as a year and a half to more than 10 years.

Contexts of diagnosis

Almost half the people interviewed received their diagnosis after they (9/26) or their partners (2/26) had experienced HIV-related symptoms (based on 26 people because of unknown context of diagnosis for the others). This was particularly the case for the men, 50% (5/10) of whom learned of their HIV status because of episodes of illnesses (based on 10 men due to unknown conditions of HIV diagnosis for the other one). Symptoms reported included weight loss, diarrhoea, general weakness, a cough, rashes, fever and hair loss. Another situation in which the interviewees frequently learned of their HIV seropositivity was that of a pregnancy, where eight people were diagnosed in this context. Obviously, more women reported this situation as the one leading to their HIV diagnosis (6/16, based on 16 women because of unknown context of HIV diagnosis for the other one). Nevertheless, two men reported having learned about their HIV status as a result of their partner's pregnancy. Other HIV diagnosis contexts included sexually transmitted infection treatment and follow-up (2/26), medical examinations in prison (1/26)⁷ and compulsory medical examinations for a scholarship application (1/26). Only three of the people interviewed reported that they had been diagnosed with HIV following self-initiated testing for the infection in the absence of symptoms. In the three cases, the HIV positive status of their sexual partner was either clearly known or strongly suspected.

⁷ It is not clear whether this person was pressured into having an HIV test or if they voluntarily requested to be tested.

Reacting to the news

For at least a quarter of the interviewees (7/28), the news of the infection first came in the form of rumours about their partner's HIV status. Three people also reported having had doubts about their condition after recognizing symptoms of the virus in their partners or themselves. Yet, almost all the people interviewed spoke of the diagnosis as a complete surprise. This excerpt from an interview with a woman living with HIV captures the feeling of shock reported by most of the people who accepted to share their life stories:

[...] for two weeks, I was numb out of shock. I wasn't talking, I wasn't eating, I wasn't sleeping. The only thing that people could see was the tears that just kept rolling down. But I couldn't talk for two weeks nearly because I was shocked. (Woman living with HIV, April 2008)

In addition to shock and incomprehension, many people mentioned having been through periods of sorrow and depression and having had suicidal thoughts after learning about their HIV status. Helplessness was also a feeling commonly experienced by the women and men interviewed:

I was very saddened, eh? I was really saddened by the news that he [the doctor] broke to me. And at that time too, I just, like, didn't know what to do: what to say to him, what to say to my boyfriend. I was just, like, blank, eh? My mind was just blank. I just... I just didn't know what to do. (Woman living with HIV, November 2008)

When I knew that I'd got the virus, you know what? I was shocked. I was shocked. I cried, I cried and I tried to hang myself. [...] I was in my fifth month with her [meaning five months pregnant]. I went to the clinic. It was the first time I'd been to the clinic. [...] The next month, at six months, I went back. I went back to the clinic again and I knew that I'd got the virus. I started crying, crying. [...] I couldn't stop. I was pulling out my hair. I didn't know what to do! [...] I was shocked *saraga!*⁸ I wanted to die. I wanted to take a knife and kill myself. (Woman living with HIV, October 2008)

Other respondents said they knew that they could not do much about the situation and had tried their best to come to terms with their condition:

So when I found it out, when they told me, I was, like, "How? How?" 'Cos I was shocked, you know? 'Cos my two kids... So they checked all my files from the last two kids. Everything was clear until this one. I was, like, "Okay, how am I gonna deal with it?" I cried anyway the first time. I cried and I said "Okay, I'll think of my son's future, how am I gonna do with my life, how am I gonna react with my relatives, to my relatives... how am I gonna do with my life! It's simple as that." I said "Okay, I really don't know what to do. I have to accept it. It's already in my blood. I can't just say 'Take it away!' I just have to follow the doctor's... whatever the doctor says, I have to do it." (Woman living with HIV, October 2008)

⁸ *Saraga*: with emphasis, very much.

The women and men interviewed talked of three main concerns following their HIV diagnosis. The first was that of dying prematurely and of having a very short life. This fear was general among people diagnosed in the early 2000s and was surprisingly still widespread among those diagnosed more recently, despite the public testimonies of people living with HIV and the availability of antiretroviral therapies since 2004. A second concern frequently expressed by the interviewees was the possible circulation of rumours regarding their condition and the resulting blame and social stigmatization. In fact, women and men living with HIV frequently talked of the shame (*madua*) of being known to be HIV positive, shame that originates primarily in the association of the infection with sin and immorality (see pp.42-43). The third concern mentioned by the study participants was the dishonour their condition could bring to their family (*vuvale*) and community. Tarnishing the reputation of their family or of the groups to which they belong, or possible exclusion from these groups, seemed to be the consequence most feared by these individuals. This reveals that an HIV diagnosis, in the indigenous Fijian community, involves many more people than just the individual themselves – it affects the groups which give the person their full identity.⁹ This excerpt from an interview with a man living with HIV summarizes the concerns expressed by HIV positive people on receiving their diagnosis:

[...] what concerned me... First, I didn't know. All I knew is that with AIDS, you have a very short life. Okay. And the other thing, I heard that this disease is a very shameful disease. It's very... like, it's a sexual disease. [...] I was thinking "Myself, I used to hang around so much." Yeah. I was thinking of that habit "Okay, fingers will point at me. 'Yeah, that's the consequences of what he...' " *Qori*.¹⁰ Yeah. (He laughs) "That's the consequences of what he has been doing. That's all of it. So we don't have to bother about it." What the people would say, eh? I was thinking of my family and my village because, you know, the Fijian culture is different [from Western cultures]. If you do something wrong, it brings the shame to the family, shame to the community: *mataqali*, *yavusa*, *koro*¹¹, all. And the province, eh? That also came to my mind. Okay. And I knew no information about HIV at that time. (Man living with HIV, February 2008)

Knowledge about HIV prior to diagnosis

When questioned on their knowledge about the infection prior to diagnosis, most of the people living with HIV interviewed spontaneously replied that they had known nothing about the disease. However, this assertion should be considered in light of the learning process an HIV diagnosis implies, which commonly entails familiarization with highly specialized language (including terms such as CD4 count, viral load, antiretroviral regimens, etc.). Most of the study participants knew the basics about HIV before being diagnosed: that it is a sexually transmitted infection for which there is no cure but against which condom use can be an effective form of protection. Many also mentioned having

⁹ The stigma attached to people living with HIV and to their family and community is examined more thoroughly later in this report (see pp.45-47,49)

¹⁰ *Qori*: expression commonly employed to suggest that someone deserves what is happening to them.

¹¹ Lineage, clan, village.

heard of Maire Bopp-Dupont, a well-known activist and one of the first Pacific Islanders to have publicly disclosed her serologic status in the region. Some, nonetheless, mentioned that they had thought at first that HIV was transmissible through casual contact (through the use of the same spoon or of the same toilet, for example). The possibility of transmitting the infection to family members was a concern reported by some people living with HIV, particularly in the early 2000s. Other respondents said that they had been very well informed about the infection. Two even reported having been involved in awareness activities about the infection on a voluntary basis or as part of their work. However, regardless of their level of knowledge about HIV, all the people living with the infection mentioned they had not been concerned by the disease. Some of them, mainly women, alluded to the allegedly “at risk groups” (homosexuals and sex workers) and said that they had felt safe because they did not belong to these groups. However, it seems as though the risk of HIV had simply not been part of the picture rather than something which could have been excluded after a fairly rational assessment of the situation. These excerpts from interviews with women and men living with HIV illustrate these points:

When I was in Form 5, I heard about that Maire or... *Maire Bopp-Dupont?*¹² Yeah. That was the only thing I knew. I never thought it was gonna... I was gonna be one of the... yeah. I was still in school then. Form 5. [...] I was, like... I wouldn't really care, you know, like, “Oh, it's Maire, it's someone else.” I was young then. I was still having fun. (She laughs) And Maire went around to schools, eh? [...] She came on a tour in Fiji schools. We never really took any note, you know, especially me, eh? I never bothered. I thought “HIV is just a disease. Some people have it, some people don't”, you know? I never took it seriously... until now. (Woman living with HIV, September 2008)

All I knew is that it was a deadly disease, eh? I'm just going to die from that and I won't have a long life to spend. My years are, like... The number of my days is just... And I'll get sick easily. [...] *You knew how it was transmitted?* Mmm [affirmation]. *You knew how it could be prevented too?* Mmm [affirmation]. *But you didn't know much about HIV. You thought that...* Yeah, I... All the time, I was just thinking that I was safe with him and all that, eh? Having sex with him was safe. I... I didn't believe I was going to contract the virus. I had no idea that I was going to get it. (Woman living with HIV, November 2008)

Well, I knew... I knew... I think I knew everything, you know, like, the main things that have always been publicized about HIV and, you know, how you get it and all that stuff, yeah, what precautions to take and all. Yeah, I knew quite... a fair bit about HIV. Yeah. Yeah. I knew what was to be known about HIV, like... but the medication part and all the things that I know now, that I didn't know then. Yeah. *But how to prevent it?* Yeah, how to prevent it and all that, I knew all that. [...] I never really thought, like [...], you know, that only prostitutes and girls like that get it. Yeah. I just told me... I just knew I wouldn't gonna get it. I've never looked at anybody else like he's gonna have it because she is a prostitute or he is a gay, he is a homosexual, no. It was all about *me*, I can't get it. (Woman living with HIV, December 2007)

¹² The italicized portions in the extracts from interviews consist of my questions and comments.

Modes of HIV acquisition

As the national cumulative figures on HIV might have suggested, almost all the people living with HIV interviewed in the context of this study reported having contracted the infection through heterosexual sex (27/28). Heterosexual sex seems to be the main mode of HIV acquisition and transmission in Fiji, but the occurrence of sexual activity between individuals of the same sex could also be considerably under-reported in the country. The legislation that, until recently, penalized the act of sodomy was clearly a barrier in reporting homosexual practices.¹³ The cultural and religious condemnation and stigmatization of same-sex desire and sexuality (pooftas, point five (0.5), *qauri*, *wadua*, *panikeke*, etc.) are also strong deterrents to disclosure. Anecdotal evidence indicates, however, that these practices are relatively common, at least among young men.¹⁴ Other socially unacceptable behaviour might also have been under-reported by the people living with HIV interviewed for this research. Two women in this sample reported having occasionally engaged in sex in exchange for money or gifts in order to make a living or to pay for their children's necessities, but no men explicitly reported having paid for sex.¹⁵ In a similar perspective, it is probable that premarital and extramarital sex were also under-reported by both women and men in the sample. While the narratives collected as part of this study were not focused on the identification of specific sexual behaviour associated with the acquisition and transmission of HIV in Fiji¹⁶, they nevertheless bring to light social realities that contribute to an increased risk of exposure to the virus. These social risks are the subject of the following section.

Social risks of HIV

Tabu on discussing sexuality

When asked about the social realities which might contribute to an increased risk of being exposed to HIV in Fiji, the people living with the virus interviewed identified two main elements. The first concerned the rules (*tabu*)¹⁷ which govern the discussion of or reference to sexuality among indigenous Fijians.¹⁸ In general, sexuality is a topic

¹³ The act of sodomy was considered an unnatural offence liable to a sentence of up to 14 years detention under the Criminal Penal Code of Fiji. The new Crime Decree, which was promulgated in February 2010 and replaced the Criminal Penal Code, contains no such provision.

¹⁴ On homosexuality in Fiji see Besnier (1994), White (2005) and George (2008).

¹⁵ Data from the recent study funded by the United Nations Development Program and conducted by Lawrence Hammar (2011) seem to confirm the under-reporting of transactional sex activities by the respondents of this research. Of the women and men interviewed by Hammar and his co-investigators in Fiji, "52/73 (71%) reported ever having given or received anything directly for sex (multiple answers were possible); 25/52 (48%) had given or received money; 19 (37%), alcohol/other drugs; 17 (36%) [sic, 33%], clothing; 12 (23%), food; 10 (20%) [sic, 19%] rides; four (8%), *yaqona* (kava)" (2011:9). On sex work in Fiji see also McMillan and Worth (2010).

¹⁶ Hammar's study (2011) has made important contributions to this subject.

¹⁷ *Tabu*: used as a noun or as an adjective. It signifies something that is prohibited, forbidden, subject to rules and regulations, set apart.

¹⁸ For more on the rules that apply to talking about sex in the indigenous Fijian community see, among others, Hocart (1929), Thompson (1940), Nayacakalou (1955; 1957), Sahlins (1962) and Kaitani (2003).

considered by and large to be inappropriate for public discussion within the indigenous Fijian community and is seldomly talked about. Reference to sexuality or to anything associated with it – for example alluding to private parts or underwear – is moreover strictly prohibited among most categories of kin, especially those of the opposite sex. This is particularly the case for people in a *veiganeni* relationship (brothers and sisters, real or classificatory) who must show the greatest deference and respect to one another. Only the *veidavolani* (cross-cousins of the opposite sex), who are the sole relatives who can potentially marry, are authorized and even encouraged to refer to sexuality in each others' presence. However, this is always done in a humorous context in which they pretend to flirt with one another and make dirty references and jokes. According to the interviewees, this silence on sexuality is responsible for a lack of information about sexual and reproductive health among indigenous Fijians and at the origin of an increased risk of HIV in this community:

First of all, it's because of this *tabu* thing, eh? You know, for us, Fijians, like, discussing this, eh, discussing sex and all that, it's considered *tabu* for us. So, like, many young people, I mean they are not told about all the, you know... consequences. I mean they're maybe aware but they are not given proper advice and guidance by the parents and all that, eh? That can put them at risk too. (Woman living with HIV, November 2008)

Because I see that Fijians, something that we've been... something that we've been worried about or something that stops us is about our *tabu*, eh? Because a lot of us, Fijians, we are, like... uncles and their nieces and all that, eh, they are not supposed to talk and all that, to talk badly. So at this time, if we want to stop HIV, we should start talking about HIV now. (Man living with HIV, December 2007)

Nightclubs and alcohol

A second social risk related to HIV in Fiji identified in the interviews by the study participants was that of nightclubs and alcohol consumption. Indigenous Fijians generally establish a direct link between nightclubs, alcohol and premarital or extramarital sex. In popular discourse, alcohol consumption is considered to be the only reason for women possibly forgetting their social obligation to confine sexuality to the context of marriage and to respect the cultural and religious ideal of premarital virginity. At the same time, alcohol is said to arouse irresistible sex urges in men who then want to try or “taste” (*tovolea*) different girls. It is worth noting that it is also in reference to this connection between nightclubs, alcohol and sexuality that HIV positive people explain the over-representation of indigenous Fijians with HIV in the national statistics. According to them, the other ethnic groups in Fiji simply do not drink as much alcohol and go to nightclubs as frequently as indigenous Fijians:

Because if you go to the nightclubs and all that, you don't see the Indians or the Chinese. Only Fijians. (Man living with HIV, February 2008)¹⁹

And because only the Fijians are around the places where HIV is around. *You mean?* During nightclubbing. That's the place where HIV is around. And plenty Fijians are... Because Indians, you don't see Indians nightclubbing around. (Woman living with HIV, October 2008)

[...] when they [indigenous Fijians] go to the clubs, they just can't control themselves. They can't stick to one partner, eh? They're, like... you know, Fijians get plenty partners like that, eh? (Woman living with HIV, December 2007)

You know why? 'Cos the clubs, nightclubs. (She laughs) There's too much nightclubs right now. [...] Young people, instead of going to school, they're in nightclubs. They're doing this, they're doing things they're not supposed to do. So that's why it's the 20 to 29 that have this kind of disease. Because of the intercourse around. People get drunk, they don't even know who they've slept with and do this and that. That's the only thing. That's how it happens. (Woman living with HIV, October 2008)

Referring to nightclubs and alcohol is clearly a socially valid and recognized way to justify sexual practices which do not correspond to cultural norms and ideals. Anecdotal evidence indicates that the influence of alcohol is even commonly invoked when it clearly has had no part in a "problematic" situation, for example a pregnancy in an unmarried couple or an elopement. It is also obvious that nightclubs are portrayed more frequently than not as the most sinful and dangerous of places (see also p.41). Nonetheless, beyond popular discourses and representations, this link between nightclubs, alcohol and HIV seems to have a basis in reality as nightclubs had been a dating place for many of the people interviewed and several women and men reported having had sex while under the influence of alcohol. This was the case, for example, for one man who explained how he had met a woman in a nightclub, had invited her to go to drink on a piece of vacant land and how they had finally "stayed together" (*tiko vata*), an expression commonly employed to mean having sexual intercourse. Three months later, this man learned he had contracted HIV. This was also the case for a woman who related how she had gone out to a nightclub with a friend and how, because she was drunk, she had felt sexually aroused and had accepted the advances of a man whom she did not know. Months later, she found he had transmitted HIV to her. Another woman explained that she had been dating her boyfriend for more than a year when he invited her to a house party with friends. At the end of the night, the couple was drunk and had sex for the first time, which eventually resulted in her contracting the virus. As the following extract indicates, one man was absolutely sure about why he had contracted HIV. Nightclubs and alcohol had had a prominent role in his exposure to the virus:

¹⁹ Though this man meant that Indo-Fijians and people of Chinese origin do not frequent nightclubs, it is worth mentioning that most Suva nightclubs are ethnically segregated. For example, *Purple Hale* is considered to be the Indo-Fijians' nightclub while the clientele of *Signals* is mostly Asiatic (including seamen working on foreign vessels).

I think alcohol is the main... I think it takes a main part in this, eh? For me, it's alcohol, eh? Not only alcohol. Even alcohol and drugs, eh? Because when I go out, I do drink a lot and I take anybody anyhow. Sad. (Man living with HIV, September 2008)

The *tabu* on talking about sex in the indigenous Fijian community along with nightclubbing and alcohol consumption, as suggested by those interviewed, affect the HIV contraction experience of both women and men. However, the narratives of people living with HIV collected in this study also shed light on gender specific social risks of the infection. These risks are presented separately below, first for men and then for women.

Mobility, masculinity and homosociality: social risks of HIV among men

Labour mobility and migration have long been recognized as social dynamics associated with the acquisition and transmission of HIV. By requiring the separation of couples for long periods of time, labour mobility and migration make extramarital sexuality, and consequently the risk of contracting HIV, more likely. By accelerating the circulation of people, labour mobility and migration also contribute to the diffusion of the virus. The early history of HIV in Fiji attests to the impact of these social dynamics as several of the first cases of the infection were recorded among police and military officers sent to the Middle East and other regions on peacekeeping missions. HIV transmission then followed the sexual network routes of these men, affecting their wives and their more or less occasional sexual partners who, in turn, transmitted the virus to other people.²⁰ Several cases of the infection have also been reported among people involved in the fishery or maritime transport industry. In this study's sample, at least 10 people (10/28) were either seamen or the sexual partners of men working at sea when they contracted HIV. The men interviewed explained how they and their colleagues used to look for two "entertainments" while on shore: alcohol and girls. In towns or in villages close to the ports, they drank and had sex to forget their missing families, friends and wives, to satisfy their sexual urges and to reward themselves for the hard work done. The risk of contracting HIV seems obvious:

[...] most of the seafarers, when they go [on sea]... when they come back, they're looking for a drink and for a girl. Because long time [without sex]... (He laughs) [...] That can be a contributing factor to being a seafarer: staying away from [girlfriends and wives]... so long. For me, all the time, I knew it "When I'll come back, okay, just one girl, drink and one girl." (He laughs) And when we get drunk, oh! Any girl can do! (He laughs) Because we know the next morning we'll be going back. (He laughs) [...] I can see that seafarers... because most of the time, we go on shore. When we're out at sea for two weeks and then... any shore you go... you go to Labasa, you go to Savusavu... you look for a girl. (He laughs) All you have to do is to look for a girl. Even in villages. (Man living with HIV, October 2008)

²⁰ Data on the early history of HIV in Fiji come from anonymized statistics provided by the Reproductive Health Clinics of Suva, Lautoka and Labasa and from discussions with key informants involved in HIV control.

Like, when they went out [on sea] for a month... Because they not even entered any other port, eh? So they just went and came back [to Fiji]. Just from the wharf? Nightclubs. Wharf? Nightclubs. It would be something like that. [...] Because they only came [to Fiji] for... just because they got off for one day or even one night, they went to nightclubs, got a girl on the boat. So the next morning, the boat went and the girl got off. So it was like that every time. [...] *Did you use condoms at that time?* No condom. Seafarers? Condom is no good. Flesh to flesh is good. (He laughs) (Translation, man living with HIV, October 2008)

The prevailing culture of masculinity and the great freedom of movement that is granted to young men in the indigenous Fijian community also impact their risk of exposure to HIV. For most indigenous Fijians, it is deemed normal for men to have more than one sexual partner. Men's sexuality is said to be stronger than women's and men are said to have difficulty controlling their sexual urges. It is thus the responsibility of women to ensure they do not engage in sexual intercourse by avoiding circumstances where they might not be able to refuse men's sexual advances. The corollary of this "men are men" attitude is that it is women who are blamed if norms of socially appropriate sexual behaviour are not upheld. One woman's remarks on the personal story of an HIV positive woman who had publicly revealed her HIV status are exemplary. Commenting on the HIV positive woman's testimony, this woman in her 50s said she had been furious every time she had heard it on TV because the HIV positive woman "accused" her boyfriend of having passed the virus on to her. Men being men, the HIV positive woman was, in the view of this woman, the one to be blamed because she had "let it [sexual intercourse] happen." However, having many sexual partners is not only deemed normal and of little consequence for men, it is also regarded by many to be a sign of their capability. In the past, the polygyny of certain chiefs was considered as such; a chief who had great power and prestige was believed to be able to acquire many wives. Today, a man's ability to seduce women is still considered an expression of his masculinity. A man who is not sexually active is said to be *malumalumu*, a term that means physically weak and usually used in reference to women. Therefore, to be considered a man in the eyes of other men, at least at a certain period of his life, a man must have many women.²¹

The freedom of movement granted to young men in the indigenous Fijian community was also mentioned by some of the men interviewed as a factor that increased their risk of being exposed to HIV. After puberty, the comings and goings of women are strictly supervised. Their sexuality, as Christina Toren (1990:52) has pointed out, has to be "taken care of" (*maroroi*), which means they have to be monitored so that they observe the ideal of female virginity which is still "highly valued, if rarely a fact on marriage." Conversely, young men are allowed a great deal of liberty and are expected to look for adventure and to wander about the streets with their age-mates. As the following extract shows, some of the men who participated in this study thought this independence and this "parental" permissiveness had had a strong impact on their contracting of HIV as it had allowed them to do what they wanted, notably to go to nightclubs, drink alcohol and, "consequently", have sex with different girls. A few reported they had continued these habits in their married life:

²¹ For more on masculinities in Fiji see Kaitani (2003), Teaiwa (2005), White (2005) and George (2008).

My parents, like, they never... they never told me to stay home or do this or do that. Yeah. They just left me alone and I just led my own life. I wanted to go to the club? I went to the club. I wanted to go to play [rugby]? I went to play. Anywhere I wanted to go, I just went. And, I mean, that's a disadvantage of my family because they couldn't control me. But deep in me, inside me, I knew I would respect them if they told me "Don't do this." Even something I really wanted to do, I would never do it. But I knew they didn't, uh... they didn't see what I did and if it was something that could turn me bad. That's why I took advantage and did whatever I wanted to do. *So you didn't feel like there were rules at home. You could do what you wanted to do. [...] Was it the same thing for your sisters? [...] My father only... like, the Fijian families, they just... the only thing they do look after, it's the girls. And the boys, they just leave them alone. They don't care where we go and what we do. But for the girls, they're very strict, looking after them: "Stay home", "Do this", "Do that."* (Man living with HIV, October 2008)

Finally, almost all the men interviewed mentioned peer pressure and the desire to conform to sex and age-mates' expectations as factors associated with the risk of HIV for men in Fiji. This seems to hold particularly true for indigenous Fijians when we consider the "homosocial" nature of adolescent and adult life in this community. After puberty, indigenous Fijian men and women are indeed supposed to have minimal contact. As Carmen White has put it (2005:319), men and women "rarely interact beyond superficial mingling" and most of "the intensive interaction and social networking occur with same-sex relations." Even husband and wife, when in public, do not interact on a personal level. As a result, indigenous Fijian men spend much of their time together, be it during church activities, sports or around the kava (*yaqona*) bowl. A man who stays too close to his wife or who prefers to be in the company of women is, moreover, mocked by both men and women and called a *turaga ni marama* (chief of the women). Male camaraderie is hence a fundamental aspect of any indigenous Fijian man's experience, which results in them attaching a great deal of importance to the opinions of other men. The following quotation from an HIV positive man illustrates this point. In this excerpt, this man relates how his friends' esteem had become very important as he had become a young man. After he moved to Suva for secondary education, he began going to nightclubs, drinking alcohol and taking drugs so as to be accepted by his peers. As already mentioned, these forms of behaviour are considered to be directly associated with having sex:

When I came to Suva, I adapted a new, new lifestyle, eh? It's... Even seeing my peers... seeing them doing this, that... I was carried away by what they did, eh? And to me... I used to think that I could do anything. Uh... And I didn't want to be looked down upon. Uh... Whatever they did... they did this, I wanted to follow them in doing it. I didn't want to... for them to look at me and say "Oh! He's a coward!" (he laughs), "He can't do this and I can do." That's why I adapted their... got carried away with their behaviour [...]. *Their behaviour... you mean? Yah some... Clubbing... Some drugs, eh? "These peers take drugs. Okay, I can do it."* But I didn't want (he laughs) but the peers... (He laughs) Drinking... Even we drank in class rooms. (He laughs) [...] I think I changed a lot when I came to Suva. I followed my friends. (Man living with HIV, October 2008)

In a society organized along gender lines, male friendship and judgement are particularly important, which makes the adoption of normative male behaviour – including the practice of seducing women – more compelling.

Difficult access to economic resources, gender ideology and violence, and double sexual standards: social risks of HIV among women

As the previous points should have made clear, it is mainly through their intimate partners' sexual infidelities that married women and women in a relationship are exposed to HIV in Fiji.²² However, various social realities combine to increase the risk of the infection in women. One of these realities is that of their difficulty in accessing economic resources. For women who have no education, work in the formal salaried job market often represents a dream only. As for land, 83% of which is collectively owned by indigenous Fijians, it is only accessible to women through men, either their husbands or brothers. Divorced, separated or single women without the support of family networks are thus confronted with difficulties in making a living. This is often the case for women who have had children at a young age and have been blamed and excluded by their family for this reason. It is also the case for women who were adopted or sent to relatives after the death or divorce of parents and who are often not given the same care as biological children. For these women who have limited access to economic resources and support, accepting marriage offers from men whom they do not know constitutes a strategy for improving their quality of life, albeit a risky one. Other women facing similar difficulties resort to exchanging sex for money or gifts in order to make a living and pay for their children's necessities. The increased possibility of contracting HIV is obvious here. At least five of the 17 women living with HIV interviewed for this research had found themselves in one of these situations at some point in their life.

A second reality that strongly impacts women's risk of exposure to HIV in Fiji is that of the existing gender ideology which tends to assign women to a subordinate position in the couple, where they are expected to listen to and obey (*vakarorogo*) their male partners.²³ In the case of wrongdoing or noncompliance, men are allowed to use moderate violence as a means of persuasion or dissuasion. The women interviewed mentioned that the threat or fear of violence prevented them from challenging or even questioning their partners' infidelities which, in turn, precluded any possible attempts at protecting themselves from sexually transmitted infections such as HIV. Some of the women interviewed also talked of the reality of domestic violence as something they had sometimes tried to forget by going to nightclubs and drinking. There, some had liaisons that exposed them to HIV. The following extracts afford an insight into a reality faced by many women:

²² This is not to say, however, that women do not have extramarital relationships. As extracts from interviews will show, some of the women interviewed did get involved in sexual affairs.

²³ On this subject see, among others, Ravuvu (1983), Toren (1990) and Aucoin (1990; 2002).

He knew that I knew that he was sleeping around and, you know... but whenever I asked him, he always, you know, used these physical, eh? He became physical. (Woman living with HIV, November 2008)

Because in Fijian culture, the men, they are the bosses, eh? Women... They [men] don't listen to what women want. If they want to go out and have fun, they go out and have fun. We, we just stay home. If we talk, we get a hiding. So I think that's the reason why: because they just do what they want. And I don't think, you know, most of these Fijians are aware of how serious the HIV thing is, eh? It's the ones that have got it. It's too late. They can't do anything. *So you think that... When you say that they can do what they want, you mean that...* They can sleep with whoever they want and we just have to sit home and wait. 'Cos if we ask them [...] "You've been out with someone else?", we get a hiding. But, you know, women's instinct. Our instinct tells us yes, they were with someone. [...] So there is nothing much we can do. They've gone out with someone else. This is the worst case in our youth: getting HIV. But I think that's... This is the way we're brought up. Women have to listen. [...] *Vakarorogo*. Yeah, *vakarorogo*. Don't... *Don't talk back?* Yeah, 'cos otherwise... There's some men that don't hit but most of the Fijian men I know hit. (She laughs) My dad hit my mom, so my husband hit me. So it's, like, normal, eh? Not always, but when they do something wrong, that's when they... (Woman living with HIV, September 2008)

Women are struggling at home too. They need... they need to move on with their life so maybe they're doing clubbing and all so that's why they get that kind of disease, I mean this disease. So that's probably how women are getting this thing: because of the men's attitude at home, you know? But they'll... they will never know that they will end up to this kind of situation, of the HIV thing. (Woman living with HIV, October 2008)

Finally, a third social HIV risk for women in Fiji that emerged from the interviews is the double standard characterizing the exercise of sexuality. Differences in regards to the acceptability of premarital and extramarital sex for women and men have already been evoked (pp.18-19). A practice that people call elopement (*veidrotaki*), but which is more like abduction, deserves particular comment.²⁴ In Fiji, for women at least, spending the night at one's partner's place when not married amounts to a promise of union. Two people who wish to get married but whose respective families oppose the marriage can thus spend the night together and deliberately arrange to be seen so as to leave their family no other choice than to agree. A woman whose union has been planned with a man that she does not like can also run away to the house of a man of her choice in order to frustrate her family or lineage's projects. Neither is it infrequent for a man and a woman to meet, fall in love and decide to spend the very first night together in order to make their relationship official. It happens, obviously, that a marriage desired at night may not seem so attractive the morning after. Both partners are therefore asked if they still want the union. Though the man can change his mind without too much difficulty, it is difficult for a woman – because of the ideal of virginity at marriage – to back out as sexual intercourse is assumed to have taken place. Some men take advantage of this “cultural” norm; looking for life partners, they visit bars and nightclubs in search of

²⁴ For more on elopement see Seniloli (1982), Williksen-Bakker (1992) and Kaitani (2003).

women, strongly under the influence of alcohol, to take back to their place. It is hard for women trapped in these circumstances to return to their family afterwards without feeling profoundly ashamed and fearing rejection. At least three women in this study's sample (3/17) reported having contracted HIV in this context. While drunk in nightclubs, they were "caught" by men who were aware of their own HIV serologic status but who needed partners to look after them. These women had no other choice than to stay with these men after having spent the night at their place. Quite evidently, these women did not have the possibility to make an informed decision about their health under these circumstances. In spite of themselves, they ended up in a relationship and living with HIV.²⁵

Condom use and accessibility

The realities and dynamics described above have a particularly strong impact on women's and men's HIV risk in Fiji as condoms are either seldom or not systematically used. The following excerpts from interviews with people living with HIV are informative about the multiplicity of reasons put forward to explain this non-use of condoms:

Like, they're [young Fijian people] shy to go to the hospital or to buy... (Woman living with HIV, December 2007)²⁶

To be very honest, that night, I was just too drunk and there was no condom so I just... And I saw the guy and I thought... I had the thing in my head, eh? I had the thing in my head, you know, HIV was around and all this because I just had syphilis, but then I said "Oh! What the hell. He doesn't look like a [HIV positive person]..." Yeah. So I just went on with it. (Woman living with HIV, September 2008)

I think it was just... I didn't care. I didn't really look after myself. I didn't even bother to... I had the condom but I didn't bother. It was just there and I didn't use it. (Man living with HIV, September 2008)

We were using condoms. Yeah. Then later, you know, like, he said "Oh..." *He said "I want to feel" or something like that?* Yeah! You know? (Woman living with HIV, October 2008)

[...] in the other instances, I was always careful. If I wanted to engage in any sexual activity, I knew that I had to use a condom. [...] *Can I ask you why you didn't use a condom with your husband [to be]?* Uh... Because at that stage, I knew that it was the person that I wanted to marry. Yeah. In spite of everything else that was a bit different with him [...] I knew that... after being in two relationships, I knew that this was the person. [...] Yeah. So at that age [...] I knew for sure that I wanted a

²⁵ The Pacific Islands AIDS Foundation's recent work (2011), conducted under the leadership of Hilary Gorman, has made important contributions to the understanding of the impact of gender on the lived experience of HIV in the Pacific. By examining the experiences of 25 women living with HIV, 17 Papua New Guineans and eight indigenous Fijians, it shows how gender inequality in marriage, domestic violence, limited economic choices and sexual and moral double standards not only shape women's risk of exposure to the virus but also their experience of living with HIV.

²⁶ Note that this woman is, herself, shy or uncomfortable using the word "condom."

family. So that is one of the reasons why. Yeah. (Woman living with HIV, April 2008)

People don't like to use condoms, especially young people, eh? *Why, according to you?* Because... Last week, I attended a workshop [...] and we discussed about condoms and some of them said that there's no feeling with condoms, eh? Flesh to flesh is the best. And secondly, they don't know how... They're afraid to use it, eh? They can't use it. And when they are drunk, like that, they don't know what to do, eh? [...] And another... the difficulty is to buy condoms, eh? [...] We should give it free because, you know, that's the only way we can prevent some other diseases. [...] Some of us can't afford it. (Woman living with HIV, December 2007)²⁷

The Christian churches' opposition to condom use for prevention purposes, although not mentioned in interviews by the people living with HIV, also clearly acts as a background to this non-use of condom. It is worth noting that, when this study was conducted, condoms were surprisingly unavailable in places perceived as propitious to HIV transmission by people living with the infection. In fact, in 2008, only nine out of 20 nightclubs surveyed in Suva generally had condoms accessible to clients; moreover, three had been out of stock for periods varying from one to three months due to provisioning difficulties. So 11 of the Suva nightclubs surveyed reported having never made condoms available to their clients or having never been approached by the Ministry of Health or non-governmental organizations for that purpose. If HIV is to be prevented in Fiji, an essential first step is to make preventive means available where they are perceived as most necessary.²⁸

Making sense of HIV

When confronted with serious illnesses, humans universally tend to ask themselves questions such as “why me?”, “why this specific illness?”, “why at this particular time?” People living with HIV in Fiji are no exception. The 28 women and men interviewed for this study had all been attempting, more or less actively and more or less consciously, to make sense of their condition.

It is important to note here that the interviewees did not question their diagnosis; doubts were not cast on the validity of the medical verdict and the possibility of a mistake was never evoked. Moreover, the diagnosis of HIV took precedence over any other interpretation of symptoms or illnesses that might had been put forward by biomedical institutions or by Fijian medicine specialists. This was notably the case for *kalou ni draki*, a well-known local illness in which symptoms are said to be similar to those of some

²⁷ Hammar's study confirms the low rate and inconsistent use of condoms in Fiji. Of the 73 women and men he and his co-investigators interviewed, only 18 (25%) – among whom 13 university students – reported having used a condom the last time they had had sexual intercourse. Reasons provided to explain their non-use of this prevention method were similar to those expressed by the participants in this research (2011: 10).

²⁸ I must state here that a new HIV project officer was appointed to the Ministry of Health during the last weeks of this research. With a collaborative team, she assumed responsibility for condom distribution in Suva. It is therefore possible that condom accessibility in nightclubs has since been improved.

HIV-related infections and for which people living with HIV had frequently received treatment prior to their HIV diagnosis.²⁹

Acquiring HIV because of individual choices and decisions

In an attempt to make sense of their condition, the women and men interviewed expressed three interpretations of why they had contracted the virus. The first, as the title of this section indicates, combined the role of chance and of individual responsibility in the acquisition of HIV. In a context where no one really knows who is living with HIV, my respondents believed that it was the actions or decisions of the individual that exposed him or her to the infection. The following extracts from interviews illustrate this first interpretation of the infection:

Why me? Now I just believe that I, you know... because I didn't do the right thing. So I just blame myself for that, eh? I just didn't make the right choices... I didn't make the right... I didn't follow what my parents said, what my other elders said about, you know... when they heard about me having a relationship with him. In the first place, they didn't like him because they knew that he already had got kids somewhere. I just didn't care [...]. Now, when I ask myself questions, "Why me?", I just blame me for not listening to their advice. And for not taking precautions. In fact, I blame him because I believe he was the one who passed the virus to me, eh? But I also blame myself for that. (Woman living with HIV, November 2008)

Why? That's my fault. Why did I get drunk! (Woman living with HIV, October 2008)

'Cos at that moment, I didn't have a steady girlfriend. I just... I think that's why. And I didn't use condoms. And I didn't know her: where she came from and all that. *You met her and then...* Ya. Just one night. *And then you got married?* Ya. We stayed home. We stayed... She didn't want to go back. We stayed home. And then she was pregnant. [...] It was because of my choices. It was because of my behaviour. That's why. (Man living with HIV, February 2008)

HIV as *mate ni vanua*

Though the women and men living with HIV never denied the sexual acts that led to them contracting the infection, for many of the research participants, their exposure to HIV was certainly not a coincidence nor the result of their actions alone. Other influences, particularly some of a supernatural kind, were clearly involved. Thus, for

²⁹ *Kalou ni draki*, which literally means "god of weather", is an illness said to come from inland Fiji, specifically from Ra province, on the island of Viti Levu. Its main symptom is a drastic loss of weight in spite of a normal food intake. People commonly say that a person who contracts *kalou ni draki* has a black pig in their stomach who eats whatever the person eats. Another symptom of *kalou ni draki* is to see piglets in dreams. Only one woman interviewed, after being diagnosed with HIV, maintained that she had contracted *kalou ni draki*. In fact, she considered that she had been affected by both – being affected by HIV, she believed she was more vulnerable to attacks of sorcery, the origin of *kalou ni draki*.

some of the interviewees, HIV was a *mate ni vanua*, an illness that results from a breach of rules or norms pertaining to “the way of the land” (*vakavanua*). The excerpts below are illustrative of this interpretation. In the first extract, a woman explains how she believes that her HIV acquisition is the consequence of a curse that has affected her extended family for two generations due to possible wrong done in the past. In the second, another woman explains how she thought, upon learning about her HIV status, that her contraction of the virus was the result of her not respecting her parents’ wishes and indigenous Fijians rules of alliance in marrying a man who was below her in terms of social status:

Because my family, actually there’s a curse passed down to them. Like I said in the first place, my *ta levu*³⁰ had no children. *Because of that?* Because of that. Only my father had the five of us. And I’m the eldest. See?³¹ (Woman living with HIV, October 2008)

Initially, when I was diagnosed, I thought it was more like a curse. Because I went against my parents and I went against tradition to marry my husband. *Because he’s not Fijian?* No, he’s Fijian but the thing is that my status, as in family status, is different from his as I come from a chiefly sort of background so... And as such I wasn't supposed to... That's what my parents and my family thought, that I should marry someone within my rank, and I thought no. I left home and I married him. So initially, when I was diagnosed, I thought that it was because of the curse from my family that I got HIV. *You mean a curse by some kind of sorcery?* No, more like they say things... “You're not supposed to do this” and I ended up doing exactly what I'm not supposed to do? *Okay.* That. (Woman living with HIV, April 2008)

It is necessary to say here that the interpretations given by HIV positive people to their acquisition of the virus are not fixed and definitive and may change over time. The way people living with HIV make sense of their condition is also influenced by different life experiences, notably involvement in HIV work or activism, or conversion to new church denominations. The woman quoted above, after having undergone counselling with a psychotherapist and contributed to awareness activities on the infection, gave a new meaning to her condition. From a *mate ni vanua* HIV became solely the result of her decisions.

HIV as an infection sent by God

Finally, the third and most common interpretation of HIV acquisition by people living with the virus was that of an infection sent by God. Unlike popular discourse in Fiji which presents HIV as a punishment for individual and collective sins (see pp.42-43),

³⁰ *Ta levu*: father’s eldest brother or mother’s eldest sister’s husband. In this context: father’s eldest brother.

³¹ This woman is referring to the fact that *mate ni vanua* (illnesses of the land) do not only affect people who have breached social norms and obligations. The *vu* (spirit-ancestors) who cause these illnesses can also choose to punish their descendants. Dorothy M. Spencer, in her book *Disease, Religion and Society in the Fiji Islands* (1941), is very clear on this subject: “One very important element in the theories regarding *mate ni vanua*, is that not only the offending person himself may be punished by the *vu*, but his children and his children’s children for generations may suffer as a consequence, until the *vu* has been appeased” (p.21). In this specific quotation, the woman evokes the fact that first-borns are particularly susceptible to *mate ni vanua*. For more on *mate ni vanua* see also Katz (1983).

several people living with HIV believe that God, in sending them the infection, wants to teach them something. In this perspective, the study participants said that they had needed to change, either because they had not been listening, which is contrary to the ideal of *vakaturaga* (manner befitting the presence of a chief)³², because they had been drifting away from God and had not been going to church enough or because of their “reprehensible” conduct like going to nightclubs, drinking, smoking or having homosexual sex. For these women and men, HIV was a call from God to return to the right path. Other people living with HIV preferred to talk of HIV as a mission sent to them by God. They said that God had chosen them to raise awareness of the infection and to promote the “rightful” ways of preventing it, that is, to abstain from sex before marriage and to remain faithful to one’s partner afterwards. In their own words, they had been chosen to be living testimonies to the power of God. The following quotations illustrate what many people living with HIV said:

[...] I think God has chosen me to be infected with this disease so that I can humanize this disease and be a source of strength to youth. Yeah. (Man living with HIV, December 2007)

[...] I think God, you know, just gave me this sickness [...] so that I can learn, eh? God is teaching me about what I’m doing, eh? To go back to him, you know? Because when I was young, I joined the youth group. I went to church. I couldn't wait to go to church. But one thing spoiled me: my friends. My friends. I got plenty of friends. When they came, they wanted to take me to that place, to that place... [referring to nightclubs]. And then now that I’ve got the sickness, nobody helps me, eh? (Woman living with HIV, December 2007)

Because at that time, I was recommitting myself to the Lord and I knew that the Bible says “Anybody that applies to Christ all the olds are gone.”³³ I knew it. Everything is new. [...] We've got the spirit and the body. Everything has to change. But I think that... I see that... I had a level of faith. Right. I was not fully correct in my faith, committed with God. But God wanted to see me at that time, how I had faith in him. (Man living with HIV, February 2008)

Why me? [...] After being diagnosed, it was, like... Then I realised, you know... like, because of where I was coming from, my family, question background spirituality. “Why me?” And I said “Oh! Well that’s it” because... I had finally found God had a reason for me. I had a purpose. He had a purpose for me: to be a living witness, to testify that he is God. *So you think it was a message or a way God chose to talk to you?* Mmm [affirmation]. Instant from the hospital. *He wanted you to...* Just changed my life, that’s what I said. I just repented from the hospital bed. I just read my Bible and I prayed. I saw God in everything: I had a special treatment from the doctors, the loving support from my family. You know, in that, I say “God, you’re awesome. Thank you so much.” [...] *You say that you had to repent. I don’t really see from what. You didn’t have a “bad” life.* Yeah, no, because as I said, I was clubbing, you know, and I’m a career woman, like, my first priority was work, work, work and not going to church. Like, God came last, you know? I had no time with

³² For more on the characteristics of the Fijian ideal of *vakaturaga* see Ravuvu (1983).

³³ Reference to 2 Corinthians 5:17 “Therefore, if anyone is in Christ, he is a new creation; the old are gone, the new has come” (New Testament, New International Version).

God. *He wanted you to come back to him. Yeah, yeah, that's it. So you think that's why you contracted HIV. It was for you to...* Just to repent and to be a purpose for him. Yeah. To be a living witness and testify that he is God. (Woman living with HIV, October 2008)

The last two excerpts are evocative of the discourse about the need to repent and the transformative power of God that is common to many evangelical, charismatic and Pentecostal church denominations. As will be pinpointed later in this report (see pp.54-56), a renewed relationship with God and conversion to these new church movements in Fiji are among the main life changes reported by people living with HIV following their diagnosis.

Looking for health care and treatments

As just seen, interpretations of HIV contraction by those living with the virus in Fiji are numerous. So too are their therapeutic trajectories. To be “cured” of HIV, to be relieved from undesirable symptoms or to prevent deterioration of their condition and to stay healthy, women and men living with HIV in Fiji resort to several means, either successively or simultaneously.

ARV and the biomedical follow-up of HIV

The biomedical health care system, with its evaluations (CD4 count, viral load) and treatments (antiretroviral therapy, antibiotics), was at the heart of the therapeutic practices reported by people living with HIV.³⁴ The women and men interviewed were appreciative of the health care and follow-up received at the Reproductive Health Clinics of Suva, Lautoka and Labasa and expressed their trust in the medical practitioners and nurses of these institutions.³⁵ They were also grateful to have access to antiretroviral treatments (ARVs). The women and men diagnosed with HIV at the end of the 1990s or in the early 2000s emphasized the improvements that ARVs had brought to their quality of life. Those diagnosed after the arrival of ARVs in 2004, for their part, highlighted the efficacy of the treatment, often assessed through the weight gain it permits. This last aspect is in line with the indigenous Fijian conception of the body which, as Anne Becker (1995) has pointed out, associates largeness and corpulence with health, strength and social connectedness. For indigenous Fijians, to be fat equates to being in good physical health, in a good state of mind and having a rich and dense network of social

³⁴ As previously noted, the people living with HIV interviewed for this research were recruited mainly through the Fiji Network for People living with HIV and AIDS and through the Reproductive Health Clinics of Suva, Lautoka and Labasa. The respondents were thus “by definition” part of the biomedical circuit of health care for HIV. When comparing the number of reported cases of HIV and the number of cases seen in reproductive health clinics, it becomes evident, however, that quite a large proportion of people living with HIV in Fiji have left the biomedical health care system. These people, if interviewed, would have probably reported different therapeutic itineraries than those described in this report.

³⁵ The experience of people living with HIV with other medical centres and hospitals does not seem as positive. Many interviewees mentioned having experienced stigma and discrimination within the biomedical health care system. This aspect needs further investigation.

relationships. Thinness, conversely, reflects a lack of body vigour, restlessness, deprivation and social neglect.³⁶ It is thus common practice to greet someone who has not been seen for a long period of time with the compliment “*O iko sa levulevu!*” (You are fat!). Fluctuations in the body shape and weight of others are also the subject of much social attention and conjecturing. Losing weight was therefore a major fear in people living with HIV as it might have lead people to suspect that something was wrong. This conception of the body should be borne in mind when reading the excerpts below:

I'm on ARVs now, for the past two years, and a lot has changed for the better. All those opportunistic infections that I used to have, like pneumonia, asthma, it's all gone. I'm living a normal life just like anybody else. And it's been good. (Woman living with HIV, April 2008)

I've been taking ARVs for nine months now. *And it helps?* Yeah. It's a big help. *Yeah?* Yes. Before I started to take ARVs, I was losing weight, a lot of weight. And after six months... so I came here for clinic. From 34, from 34 I went up to 71 kg. That's a *big* change. Yes. (Man living with HIV, December 2007)

I'm happy dealing with that ARV thing. Yeah. The thing is I couldn't wait to take it since I found out that I'd got... [...] since I found it out. I couldn't wait to take it. Yeah. [...] ‘Cos I always think of Maire [Bopp-Dupont] or what's her name again? How beautiful she is, how, you know... We can't even tell that she's got that sickness, you know, she is... she's healthy! How come Maire is... She looks so beautiful because she's taking ARVs. (Woman living with HIV, October 2008)

However, antiretroviral therapy is not a panacea. Though they represent a medical advance that has significantly transformed the lived experience of HIV, ARVs nonetheless bring their own share of difficulties and worries. For instance, several of the research participants said that ARVs increase appetite, which, for people with limited means of livelihood, presents an extra burden. Some of the interviewees also expressed the difficulty they had respecting the rigid schedule of ARV intake, particularly when under the stress of conjugal and family problems or during periods of discouragement. Another remark frequently made concerning ARVs was that the treatment was a daily reminder of their condition, which was emotionally demanding for people who had difficulties coming to terms with their HIV seropositivity. The following quotation captures this feeling expressed by the people interviewed:

I never wanted to go for ARVs, eh? *Why?* Like, I think, like... My thinking was “If I'm going to take that, it's going to be a lifetime thing for me.” Yeah. It's going to be a lifetime thing for me, eh? So I just didn't want to be taking tablets [...]. [T]o me... I mean... that's going to be... reminding me too that I'm positive so, you know... taking that, eh? It will be a daily reminder for me so... (Woman living with HIV, November 2008)

³⁶ This has tended to change as Anne Becker has shown in her work on body image and eating disorders among adolescent Fijian girls (Becker 2004).

These elements should certainly be kept in mind when reflecting on the issue of adherence to antiretroviral therapy. Additionally, transport costs and availability were frequently mentioned as barriers to seeking treatment at the Reproductive Health Clinic. Due to irregular pill intake, at least two out of the 12 people interviewed who were taking ARVs at the time of this study had developed resistance to antiretroviral agents available in Fiji. These two people needed second-line ARV regimens. Unfortunately, these treatments were not available due to excessive costs.³⁷

Wainimate vakaviti

The therapeutic practices of people living with HIV are not limited to health care proposed by the biomedical system, however. The Fijian pharmacopoeia also occupies a privileged place in the therapeutic itineraries of women and men living with HIV. Moreover, as is generally the case with any illness, it is towards indigenous Fijian medicine, and not towards biomedical institutions, that people who experienced symptoms of HIV turned for care before being diagnosed. Fijian medicines (*wainimate vakaviti* or *wai vakaviti*) were therefore the first resources sought by people living with HIV to regain their health. The HIV diagnosis marked a breaking point in the usual care seeking behaviour of most of the women and men interviewed. After being diagnosed with HIV, people generally stated they then visited the clinic or the hospital first if they had problems or were worried. Nevertheless, several of the interviewees still resorted to Fijian concoctions for preventive purposes or to treat minor symptoms or illnesses.³⁸ Most commonly mentioned were preparations made of *kura* (noni) juice (*Morinda citrifolia*). Also frequently mentioned were medicines containing *botebote koro* (*Ageratum conyzoides* L.), *totodro* (*Centella asiatica*), lemon leaves, *wa bosucu* (*Mikania micrantha*) and *coqaloqalo* (*Commelina diffusa*). For some, taking Fijian medicines (*gunu wai vakaviti*) was a habit preceding diagnosis. For others, it was a strategy put in place in response to their new condition. Conversely, some of the people living with HIV interviewed declared they had stopped taking *wainimate vakaviti* after their diagnosis. These people generally said they were afraid of potential adverse interactions with their antiretroviral treatment. This fear, as the following excerpts show, clearly stemmed from general practitioners' directives:

I think I'll stick to the tablets because they told me it's better to stick to the tablets rather than taking the tablets with Fijian medicines. You know, it might... *Affect the ARVs?* Yeah. (Man living with HIV, September 2008)

My family says... sometimes they say "You can just drink that medicine", "You try that, try that." And I tell them "See. Because of the tablets that I'm having now, I can't take another Fijian medicine. If I wasn't taking these ARVs, I could have taken that." I always tell them like that and they say "*Oi?* Oh, okay." (Woman living with HIV, October 2008)

³⁷ For more on HIV positive people's experience of ARV therapy, and particularly on women's experience of receiving treatment to prevent mother-to-child transmission of the virus, see PIAF (2011).

³⁸ Massages (*bobo*) were also mentioned by some but in a far smaller proportion than *wai vakaviti*. For more on indigenous Fijian medicine see Spencer (1941), Katz (1983), Wainimate (1997) and Weiner (not dated).

Because I don't want to drink a lot of Fijian medicines too because Dr. [X] told me "Don't drink a lot of Fijian medicines. [...] Just eat normally or you take ARV, the treatment." (Woman living with HIV, December 2007)

Wai ni AIDS

In the face of an infection that biomedical science says is incurable, some people living with HIV are prepared to try local treatments which claim to be capable of curing AIDS (*wai ni AIDS*). Unsurprisingly, people who were diagnosed in the early 2000s, when antiretroviral therapy was not yet accessible in the country, were more numerous in reporting having used these treatments. Nonetheless, at the time of the interviews, medicines to "cure" AIDS were still available and women and men continued to try them.

Two main types of treatments for "curing" AIDS existed at the time of this study. The first could be compared to conventional Fijian medicines in their composition (herbs, plants, bark, water, etc.) and administration (length of treatment, prohibitions accompanying the intake, role of the specialist, etc.). This was the case for the treatment prepared by Alipate Raicebe, a well-known Fijian medicine specialist (*vuniwai vakaviti*) who, in the *Fiji Daily Post*, claimed he had the cure for AIDS and had successfully treated 15 of the 17 patients he had attended (*Fiji Daily Post*, 4 June 2008). This was also the case for a treatment called "V3" or *veitokoni e lewe tolu*, a preparation made of *kura* (noni), *budamu* (ripe coconut) and *qaliki* (garlic) that "promises freedom, healing and relief from cancer, hypertension, heart diseases, diabetes, arthritis, ulcers, depression, migraines, VD [venereal diseases] and *HIV AIDS*, obesity and also the rest of the diseases of civilization" (unpublished document, italics added). Many of this study participants reported having been visited by *vuniwai* offering them similar concoctions. The second type of treatments could be qualified as "hybrids" since they combine spiritual healing and elements of Fijian medicine. This was the case for the treatment of *Marama Vada* (the servant) which consisted of the blessing of coconut oil which was then drunk according to Fijian medicine conventions. It was also the case for the treatment prepared by the *Loloma* group.³⁹ This treatment consisted of a concoction said to kill HIV which was drunk from Friday to Sunday in remembrance of the days of the crucifixion and resurrection of Jesus Christ. Specific Bible verses were also recited beforehand. This was followed by a second concoction which cleansed the body of the waste created by the attack on the virus. The latter, a common medicine of the Fijian pharmacopoeia called *wai savasava* (medicine for cleaning), had to be taken for four days, the normal length of most Fijian medicine treatments. Despite their differences, the common characteristic of these treatments is the fact that they offer people "definitive" solutions to their HIV infection.

³⁹ The description provided comes from an interview conducted with the leader of the movement in April 2008. Accounts of the treatment's procedure given by people living with HIV, however, do not tally on every point. It seems possible that the *Loloma* treatment has changed over time.

Looking for healing in God's hands

Finally, people living with HIV also look to God for support in their pursuit of well-being and health. In the same way that those living with HIV believe that God is the cause and the origin of their HIV acquisition, numerous women and men also believe that their "recovery" lies in God's hands. This man, for example, recalled how the prayers of two pastors of a new church denomination enabled him to get over a severe period of illness:

In 2003, I got jaundice at that time. Yeah. Okay. At that time, the doctor was not allowing anybody to pop into my room. And Dr. [X]'s hopes too had completely run out. He said... he thought that I was gonna die. I just thank the Lord for my prayer, he heard my prayer and he gave me another chance. There were two... They are senior pastors now... At that time, they prayed for me [...]. Soon after they prayed for me that afternoon, there was no more jaundice. When the doctor came back in that afternoon, he was shocked. There was nothing more. I just thank the Lord. After another week in the hospital, I was released. (Man living with HIV, February 2008)

Other narratives of people living with HIV refer to episodes of illness ended by the power of the imposition of hands. This woman, for instance, explained how her health had been restored by the touch of a pastor after she had had a vision:

I walked in and he was sitting there. I interrupted him and I just told him "You have to lay your hands on me." That's all I said. And in a state of shock he asked me "Can you please explain yourself? What is it that you want me to do?" And I explained... I gave him a brief history about myself. [...] "I'm an HIV positive person. I had that vision this morning. I don't know who you are but God is telling me for you to lay your hands on me and I need you to do it now." Without hesitating, he stood... he came down from the pulpit where he was and he called everybody [other pastors assembled for a church conference]. And I was standing in the middle of the circle. They had to come into the circle. And he prayed for me. And ever since that day, Fabienne, I've been walking and I'm still walking. And three months after that, I went for my test only to be told that my HIV... After, the test said my virus... my viral load was undetectable and until now, it's still undetectable. (Woman living with HIV, November 2008)

In general, my respondents talked of their confidence in the possibility of being cured from HIV if they repented, if they prayed hard and if their faith was strong. For some, this trust in God's healing power was so unshakeable that they considered refusing or abandoning ARV therapy:

I really converted myself to Christ 'cos I know that he's the only one that will save me. If I really do believe, eh? (Man living with HIV, September 2008)

One time, I had lost weight, eh? So these people [the medical personnel from the reproductive health clinic] said for me to have ARV treatment and I told them that I wouldn't have ARV treatment. *You don't want to take ARVs? Why?* I just don't like it. 'Cos I told them that one day I'd be healed. That's what I believe. That's why I confess all the time. (Woman living with HIV, March 2008)

[...] for me myself, because I believe in one God, I know God can take away this. [...] For me myself, now I can... 2004, 2005, 6, 7, 8 now that I've been living with this. [...] I'll never have ARVs. *Because you don't want to take them or because you think you won't need them?* I think I won't need them. Because I have a healer too, a big healer. (Woman living with HIV, October 2008)

I don't know about you but now... I mean for me, myself, I believe that there's a God, eh, and I just believe that he is my healer. I read the Bible every day, I read his words and I know that he's just going to do miracles. (Woman living with HIV, November 2008)

Although the belief of people living with HIV in the power of God and the efficacy of indigenous Fijian medicine are valid and cannot be condemned, strict adherence to them to the detriment of antiretroviral therapies, which have proved to be highly effective in improving the health and prolonging the life of HIV positive people, is dangerous and should be a cause for concern.⁴⁰

Disclosing HIV status

HIV disclosure is always a sensitive question. If someone reveals their condition, they may face stigma, discrimination and ostracism, which add to the already traumatic news of the infection. If they conceal their HIV status, they may deprive themselves of the extensive support that family, friends and the community might be prepared to offer. Between these two extremes of total acceptance or rejection, there are also more subtle reactions to HIV, ranging from polite recognition, to pity and blame, which can nonetheless strongly impact the experience of the infection. Consequently, much reflection goes into the question of whether or not to disclose one's HIV status.

Time of disclosure

Among the women and men interviewed for the purpose of this study, three had chosen to keep their HIV status secret, the only people aware of their condition being their HIV positive partner, the medical personnel monitoring them and the staff and members of the Fiji Network for People Living with HIV and AIDS to which they belonged. The remaining 25 women and men had all revealed their HIV seropositivity to at least one person from outside HIV circles, either a friend, family member, pastor or fellow church member.

The bulk of the interviewees disclosed their HIV status for the first time within six months of their diagnosis (16/21, based on 21 people because of unknown time of HIV disclosure for the others). Six people – among whom were a majority of women (5/6) – moreover revealed their HIV status within the first week of learning about their

⁴⁰ Hammar and his co-investigators (2011) found a similar belief in the efficacy of faith, prayer, the laying on of hands, Fijian medicines and other means (for example, virgin coconut oil and deep seawater) of treating if not curing HIV among their research participants.

condition. Conversely, two HIV positive people disclosed their serologic status one year and two years, respectively, after diagnosis, while one person had been living with the virus for as long as five years at the time of disclosure.

Choice of whom to disclose to

Interviews bore witness to a plurality of experiences regarding the people to whom HIV status was revealed. Nonetheless, some general remarks on disclosure trajectories can be made. In almost all cases, mothers were the first, or among the first, to learn about their children's HIV status. Mothers were considered more loving and more inclined to show acceptance following disclosure. They were also seen as the best person to relay the news of HIV seropositivity to the rest of the family (*vuvale*). Fathers, on the contrary, were frequently mentioned by those living with HIV as people to whom they did not want to disclose their status. This might be explained by the fact that interactions between indigenous Fijian fathers and their children are generally more formal than those between indigenous Fijian mothers and their children.⁴¹ As heads of households, fathers also have authority over family members and are expected to discipline those living under their roof in case of wrongdoing. Although no HIV positive woman or man clearly asserted it in interviews, it seems the father's role of representing the family to the extended family (*i tokatoka*), the lineage (*mataqali*), the clan (*yavusa*) and the village (*koro*) also deters offspring from disclosing their infection to them, as HIV is thought to tarnish the reputation of or bring shame to these groups (see pp.45-47). For all these reasons, the respondents expressed anxiety, even fear, at disclosing their HIV status to their fathers:

You told your mom and your sister at the same time? Yeah. Did you tell yourself your dad or... Uh... My dad found out just before I had my baby. [...] My dad found out. You didn't want to tell him? No, I didn't want to tell him. Uh... 'Cos I was scared, eh? I was scared to tell my dad. I knew he would accept me and I knew, you know, he would support me but I just couldn't. I didn't know how to tell him. And my sister kept telling me, you know, "Try." I was asking my biggest sister, "You tell him." And my big sister, "No, you have to change. You have to be strong. You have to tell him what... You know, if you can tell him, you can tell anyone that you have contracted the virus and you'll be fine." Yeah. So my dad... So my sister came in very early one morning. She didn't sleep at all the night before. It was just one week before I gave birth [...]. So my sister came in very early in the morning. She woke me up, she sat down and she passed the news to dad. Yeah. (Woman living with HIV, December 2007)

Because my father is, like... Uh... He's, like... He's rough or what? Yeah. When you tell him something about... like, my status... he usually is in a... he'll be... angry. (Man living with HIV, December 2007)

The people living with HIV interviewed also expressed embarrassment at the idea of sharing the news of their HIV diagnosis with their siblings of the opposite sex. This tallies with the respect and certain degree of avoidance that is meant to characterize

⁴¹ For more on typical attitudes between household members see Nayacakalou (1957) and Biturogoiwasia (2001).

relationships between *veiganeni* (brothers and sisters, real or classificatory), which includes the prohibition of referring to sexuality and HIV⁴² (see pp.14-15) This extract from an interview with an HIV positive woman is unequivocal:

Because tradition is such that we can't! We just don't talk about those kinds of things with our brothers. (Woman living with HIV, April 2008)

Finally, very few wished to inform their extended family, lineage, clan or village of their HIV status. HIV disclosure was, almost without exception, reserved for the immediate family, that is to say for real (non classificatory) fathers, mothers and siblings, or for very close relatives, often people who had lived with them. This does not mean, however, that only family members suspected or knew about the HIV status of the people interviewed. As will be seen in the following lines, rumours had strongly impacted the experience of all the women and men who took part in this study.

Breach of confidentiality, rumours and contexts of HIV disclosure

HIV disclosure to family members, friends or fellow church members was made in a variety of ways. Many of the interviewees revealed their HIV seropositivity to those close to them personally, face-to-face. Some used the phone or even wrote letters to relay the news of their condition. Several, as an extract from an interview above has shown (see p.33), asked people (doctors, counsellors, family members, etc.) to act as an intermediary and to speak on their behalf. Other women and men interviewed chose to inform those close to them of their HIV status in a more formal manner. Thus, for a number of the research participants, disclosure took the form of a confession during prayer sessions with family or fellow church members. At least one person also revealed their condition during a reconciliation ritual (*veivosoti*) organized by their family before the New Year. One woman, for her part, decided to disclose her HIV status in “the way of the land” (*vakavanua*) and formally informed her paternal lineage of her diagnosis by making a kava presentation (*sevusevu*). Public disclosure, which will be examined further in this section (see pp.38-40), was also clearly a way for some women and men to reveal their HIV diagnosis to family members and close kin and friends.

Disclosure of HIV status, however, was not always as intentional, desired and planned as one might expect it to be. Indeed, many of the respondents revealed their HIV status to those close to them after being confronted by rumours circulating. Though some of these rumours might have stemmed from striking changes in physical appearance and recurrent illness and hospitalization, many of them, according to the people interviewed, were the results of breaches of confidentiality on the part of medical personnel, especially of nurses. One woman, for instance, explained how her mother came to know about her HIV seropositivity after a hospital nurse told the village nurse about her condition. The news

⁴² For a majority of people in Fiji, HIV equals sexuality. It is true that reports of other modes of transmission/acquisition of the infection at the national level, such as those by injection drug use and by contact with contaminated blood products, are almost non-existent. Mother-to-child transmission, however, accounts for an increasing number of cases of HIV in the country (Ministry of Health December 2010).

then travelled through the “coconut wireless” until it reached her “mother’s ears.” Another woman related how a doctor allegedly divulged her HIV status to a woman from her home village who then called the HIV positive woman’s sister to tell the latter about her status, even before she herself had been officially informed of her condition. One man also explained how his sister, a nurse herself, learned about his HIV status after calling the medical centre for his blood test results. With no regard for confidentiality, a member of the medical staff revealed his HIV seropositivity.⁴³ For some of the people interviewed, these breaches of confidentiality were of no real consequence. This was the case for one woman who explained how glad she was that a nurse called her eldest brother and revealed her HIV status for she wanted to tell him but could not find the words. Other said that it was “okay” for medical personnel to have revealed their condition to family members. Yet, for other women and men, these breaches of confidentiality had dramatic results, including discrimination by colleagues, loss of job or housing, rejection and mistreatment by the family. Whatever their consequences, these breaches of confidentiality are unjustifiable and should be strongly condemned.⁴⁴

To disclose or not to disclose

Why do some people living with HIV choose to disclose their HIV status to family and friends and some do not? What are the perceived risks and benefits in revealing one’s HIV status? What are the concerns and fears regarding disclosure? As mentioned above, many women and men interviewed for this research did not really make the decision to reveal their HIV seropositivity for they had no other choice than to answer their family’s and friends’ questions following rumours that were circulating about them. However, almost without exception, all the women and men stated that disclosing HIV status to family (*vuvale*) was the appropriate thing to do. In addition, almost all of those who had not yet revealed their condition to family members expressed their intention or their wish to do so at some point in the future. Few specific reasons for this were put forward in interviews, however. Some mentioned the need to guarantee support for their children in the case of illness or death. Some mentioned the desire to relieve themselves of the burden linked with keeping their condition secret. Disclosure so as to obtain support, both economic and emotional, was also implied in what many women and men said. Nevertheless, it seems as if disclosing their status was first and foremost considered by women and men living with HIV as a responsibility or duty they had towards family members out of respect for them, not because they perceived there to be any particular benefits to themselves. Two women who did not have the opportunity to reveal their HIV status to their mother and father before they died were thus full of regret:

⁴³ The pioneering work of the Pacific Islands AIDS Foundation on the experience of people living with HIV in the Pacific, which includes data from interviews with 15 HIV positive women and men from Fiji, documents similar cases of breaches of confidentiality. It says: “Of the 19 participants in this study, 12 had their confidentiality breached by health care workers. Nurses in particular are perceived to be the origin of several breaches of confidentiality” (PIAF 2009: 37).

⁴⁴ The HIV/AIDS Decree 2011, which was promulgated at the beginning of this year (January 29th 2011), now makes unauthorized disclosure of HIV status by people in the course of their duties, whether paid or not, an offence (see section 34, HIV/AIDS Decree 2011, Republic of Fiji Islands Government Gazette, 12 (2), Government of Fiji). The HIV/AIDS Decree is a major step towards respecting the dignity of people living with HIV and the improvement of their quality of life. Let us hope, however, that it will be enforced and not become a toothless tiger.

I wanted to tell my dad and all that, eh, and he [her boyfriend] said “No, it’s better we don’t. We just keep it to ourselves. This is our own problem. This is our own problem so let’s just deal with it.” So I regret not telling my dad. *How do you think he would have taken the news?* Oh! He would have been very understanding ‘cos he was a very nice man, very open, a nice supporter, a big heart. He always cared for everyone so why wouldn’t he care for his own daughter? (She laughs) It was just because I was trying, you know, to protect my boyfriend, eh? (Woman living with HIV, November 2008)

It was hard... it was hard lying to the people I loved, eh, especially my mother. [...] It was hard because... When I told my husband “I’ll tell my family I’m HIV positive”, he’d say “You’re not thinking of me! What about me? No, let’s just keep it to ourselves.” See? Because of him, I never disclosed to my mother. And then my mother passed away last year without knowing anything. And now I still feel bad. (Woman living with HIV, September 2008)

The women and men interviewed were more prompt to express reasons that had prevented them from disclosing their HIV status to their family, colleagues or friends. Some mentioned age as the factor that had stopped them from revealing their condition: children being considered too young to understand the reality of HIV and elderly people part of a generation too different to accept it. Some mentioned that a family member’s health was the reason they had decided not to disclose their status, the news of the infection being thought likely to cause a deterioration of their close one’s condition or, worse, to provoke their death. The following extracts are evocative of remarks made by the interviewees:

But I want to tell first my son. *He’s in class...* He’s in class 8. *So he’s about...* 13 years old. [...] A few months ago, he came home and told me “Mom, I heard rumours. One of my friends told me ‘Yeah, your mom’s got HIV.’ Mom, it’s true or false?” [...] You know, I felt ashamed, eh? [...] I have to disclose to my son because he’s still wondering about me. But I mean... He’s the first one I will disclose my status [to]. *For the moment you’re not ready?* Mmm [affirmation]. *Why? Is it because you fear his reaction?* I don’t know how he’s gonna... That’s why I’m still waiting for him to get mature. I’m thinking of 16, something like that. (Woman living with HIV, October 2008)

Have you told your parents about your HIV status? My mom is 88 years old. If your mom was 88, would you tell her that you’re HIV positive? *I understand what you mean.* My parents are from another generation. They won’t understand. And this could precipitate their [death]... (Woman living with HIV, February 2008)

Mom has high blood pressure and that’s one of the reasons why I couldn’t tell her. It might just kill her knowing that. (Woman living with HIV, November 2008)

Some people also talked of their fear that family members might want to avenge themselves on their partner on learning about their condition. In this context, not disclosing their status was a way of protecting their companion. For some women, however, not disclosing HIV status to family and friends was not so much a decision as something forced onto them by their boyfriends or husbands who did not want their status to be known. Two previous extracts from interviews have illustrated this quite unambiguously (see p.36). Nonetheless, the main reason for not disclosing their status was the impact it might have on themselves. Many women and men interviewed mentioned the feelings of inadequacy and shame (*madua*) associated with having to reveal their HIV seropositivity to those close to them. A majority also expressed their fear of being rejected and thrown out by family members if living under their roof. The following quotations from women and men living with HIV exemplify the preoccupations reported by several of the respondents:

[...] my mother and my brothers have such a high respect for me and they look up to me for everything. And for me to come... I'll feel like a total failure if I [disclose her HIV status]... you know ... (Woman living with HIV, November 2008)

Why did you wait two years? Like, uh... I was thinking of my family. Like, if I told them, like, they would uh ... But I knew by the time I told them that they wouldn't... like, they wouldn't push me away. But only to me, like... it was really hard for me to tell them 'cos I knew they would blame me, said this and that. [...] Like, I was ashamed. (Woman living with HIV, October 2008)

He thinks that he might be chased away, be told to leave the house, be rejected. (Translation, man living with HIV, February 2008)

As for myself, you know the reason why? Why I don't want anybody to know it? [...] People are just gonna walk away from me. [...] Because you know.... you know how these topics come in Fiji. I mean not only in Fiji. Everywhere in the world. HIV is like "Okay. Oh! That's not a person to be with." (Woman living with HIV, October 2008)

Disclosure of HIV to their spouse or partner was also a concern for many people living with the virus. In fact, interviews showed that several women and men were not able to do so or acquired HIV after someone had failed to do so:

[...] I sat him down one Sunday. It was just the two of us and we sat down and we talked. Then I asked him "Can you tell me when was the first time you knew that you were positive?" And he told me it was back in 2003-2004. And then I asked him "Why didn't you say anything sooner? Why didn't you tell me earlier on about it?" And he said "*Oi*. I didn't know how to tell you." He was saying like that "I didn't know how to tell you. I knew you were gonna leave me." And all these excuses he was giving. (Woman living with HIV, December 2007)

Yes, he knew before we met. He knew all about his status and... but he didn't tell me when we met. It was probably... It was hard for me initially to accept, you know, because he lied, he hid that fact from me. But then I came to understand that the stigma attached to being HIV positive was one of the main reasons why he was

afraid to tell me. [...] *You think he was scared to tell you because he thought that he would lose you?* Yeah, basically. That's basically what it was. He was scared of losing me. [...] He just needed someone to be there for him. (Woman living with HIV, April 2008)

She told me she was afraid. I told her "See. If you would had told me before, I could have walked out." And she said she loved me and... (Man living with HIV, February 2008)

I was scared, eh? I wanted to tell him but I was afraid. [...] Like, I loved him too, eh? [...] I did the same thing that my [previous] husband did to me. 'Cos I loved him [...]. He got a house, eh, where we are now staying, eh? And I was thinking "Man, I think this is my blessing, eh? I have been from there, from there [meaning having no stable place to live]. This is our house. He said he loved me." Like, I shut my mouth and didn't tell him. (Woman living with HIV, September 2008)

As these excerpts from interviews illustrate, love and the fear of being rejected were the main reasons for not revealing their status to a partner. It should be added that disclosure of HIV to their partner entails other risks for women. After marriage, women usually relocate to the home or village of their partner. If disclosing their condition results in abandonment by their companion, they risk losing their place to live and means of livelihood (see p.20). Again, disclosure of HIV status attests to the pervasive influence of gender on the lived experience of HIV in Fiji.

"Coming out public"

Despite the risks that HIV disclosure involves, some women and men living with HIV choose not only to reveal their condition to their close friends and family but also to disclose their status publicly or to "come out public" as the popular expression has it. At the end of 2008, when the fieldwork for this research was completed, nine people – five women and four men – had publicly disclosed their HIV seropositivity in the media while one man had been giving testimonies to communities around the country.⁴⁵

In interviews, these people said they had decided to publicly disclose their HIV status to educate the population and increase its awareness about the virus. They stated the need to put a human face on HIV and to make the infection less alarming or normalize it. They asserted that people needed to see in order to believe and that involving people living with HIV in prevention activities was the most efficient way to raise consciousness and to control the infection. They also expressed their hope that no one would again go through what they had experienced:

[...] I decided to go out public to humanize the disease. (Man living with HIV, December 2007)

⁴⁵ I am aware of at least six people living with HIV – five women and one man – who have chosen to make their stories known to the Fijian public since then, five through the use of the media and one on more of a community basis.

It's a sickness you don't have to hide it. You have to let other people know that it's just a sickness. (Man living with HIV, September 2008)

The way I think is when they actually see someone who's got it, you know, like, a positive person, that's when they actually do wake up. Yeah. 'Cos if it's just a volunteer, somebody who's just there talking and... and not really someone who has... who is positive, someone that they *know* that is positive, it's very, you know... It teaches them more, yeah, they're more up to that and they wake up and they really do something about it. (Woman living with HIV, December 2007)

I'm going to spend the rest of my life advocating for HIV because I wouldn't want anybody else to go through the experience I went through. (Woman living with HIV, April 2008)

[...] I want to tell... share my story so that... for the benefit of the community. Not for me! I've everything to lose, eh? I'm gonna lose my reputation. I'm gonna lose my friends if I tell my story. Those are the risky... the risks I'm taking. (Man living with HIV, April 2008)

Notwithstanding what this man says (see last quotation), people living with HIV also found personal benefits in “coming out public” about their HIV status. One commonly mentioned, as the following extracts show, was the fact of not having to hide it anymore and the feeling of ease that this procured:

And one thing was that... you know, enough hiding, eh, you know, enough excuses. Uh... When my parents accepted it and I knew they were, you know, supporting 100% [...] I said “Okay. I might just as well go the full length and go for, you know... do the work and do it real and, you know, just be honest about everything.” Yeah. [...] I just wanted to be open and honest about everything [...]. (Woman living with HIV, September 2008)

One of the reasons I did that was just to get it off my chest. Because even though... yeah... even though my relatives knew it, there were other people who knew me who were asking questions. And I just thought, you know, “This is it. It can't be. It's too much for me when people... every second person I meet on the street ask me ‘What's wrong?’ and they say ‘You've lost a lot of weight.’” And I said “I can't take this anymore. It's just bothering me and every time I go home, I go home with a sense of dread knowing that, you know, the other people have the heaviest options about, you know, why [...] this and that.” And I said “Why not just, you know, put everybody's mind at ease and just tell them the truth and be done with it?” So, yeah. That was one of the things: just to take it out of me and release it so I could actually start again and move on. (Woman living with HIV, April 2008)

“Coming out public” about their status was also a way for some people living with HIV to respect what they considered as their obligation to disclose their condition to family members. At least three people among the ten who had publicly divulged their HIV status at the end of 2008 had used the media or accounts given to communities as ways of revealing their condition to those close to them to whom they were not able to talk. Some also publicly disclosed their HIV status in the hope that this would improve their living conditions. For people facing economically challenging situations, participating in HIV

prevention activities and receiving small salaries and allowances for their efforts can help to ease the hardship of everyday life. In a context of employment scarcity, having publicly acknowledged one's HIV seropositivity and being able to recount one's experience in communities is clearly an advantage in finding a job. A few people living with HIV also mentioned the opportunity to travel in and out of the country, to meet new people and to discover new horizons as motivating factors in public disclosure of HIV status. In a different perspective, "coming out public" was finally said to be something that people living with HIV do after being encouraged to do so. As will be seen further on in this report (see pp.60-61), the Fiji Network for People Living with HIV and AIDS, as the main organization for HIV positive people at the time of data collection, promotes public disclosure of HIV status as a way to raise awareness about the virus and prevent new infections but also as a way to foster acceptance of people living with HIV among the population. Unfortunately, stigma and discrimination are still unexceptional responses to HIV in Fiji. These experiences of people living with HIV, as well as other reactions to the disclosure or suspicion of an HIV status, are the subject of the following section.⁴⁶

Perceptions of HIV and attitudes towards those affected

Popular discourses and representations of HIV

As noted in the introduction to this report, one of this study's initial aims was to investigate the popular discourses and representations of HIV in Fiji and to analyse how these impact the experience of people living with the virus. Social scientists have long emphasized the fact that the HIV epidemic is simultaneously an epidemic of an incurable transmissible infection and an "epidemic of signification" (Treichler 1988). From interpretations of the geographical, historical and ethnic origins of the virus to the designation of social culprits and scapegoats and the correlation of HIV with depravity and perversion, HIV has never been merely a virus. For people living with HIV, these meanings attached to the infection often have effects as profound as HIV itself.

Two representations or popular discourses on HIV were prevalent in Fiji at the time this study was conducted. The first portrayed people living with HIV as "contagious" and "dangerous." Many people considered casual contact with an HIV positive person to be risky. The people from the general population with whom HIV was discussed frequently reported fearing HIV contraction if they shared a cigarette with an HIV positive person, if they drank kava (*yaqona*) from the same cup (*bilo*) or if they ate from the same plate. Residing in the same house as an HIV positive person was also considered to put one "at risk." One woman, for example, related how her sister had put her mattress outside to dry in the sun for several days after a person living with HIV had slept on it. Although this woman was well aware of HIV transmission modes, she preferred "not to take the chance." The assessment of the "residual risk of transmission" was also perceptible in the

⁴⁶ The research conducted by PIAF in 2007 on the reality of Pacific people living with HIV has abundantly described the experiences of stigma and discrimination faced by these individuals and is compulsory reading for anyone concerned with this issue (PIAF 2009; see also PIAF 2011).

numerous “what if” questions people asked about HIV such as “what if a person living with HIV has a car accident and bleeds?”, “what if an HIV positive person is drunk, gets involved in a brawl and gets hurt?” or “what if a person living with HIV plays rugby and gets injured?” A woman reacting to the wish expressed by an HIV positive person to return to live in their home village in the near future said that the community would oppose this because of the “risk” that it could involve. The fear of “contagion” by HIV was an enduring one when this study was conducted. Proximity with people living with HIV was still considered by many to be so risky to them as to wish to avoid it.

Women and men living with HIV were also frequently depicted as “malevolent” people who “deliberately” tried to transmit the virus. At the time of data collection, rumours about people living with HIV who apparently visited bars and nightclubs and lured people into having sex with them were rife. People also frequently reported stories about women and men living with HIV who allegedly collected their blood in syringes and injected it into people on the dance floors of nightclubs. Rumours about people living with HIV who supposedly tried to contaminate the juice sold in dispensers in public markets were also widespread. According to those interviewed, people living with HIV intentionally attempted to transmit the virus in order to increase their number and to avenge themselves for being looked down upon by society. For both their “dangerousness” and “contagiousness”, the authorities were regularly called on to have people living with HIV isolated on a distant island, the most commonly mentioned being Makogai Island where leprosy patients were sent under a segregation policy during the first half of the twentieth century.⁴⁷ The people living with HIV who took part in this study were well aware of the fear they inspired, as the following extracts from interviews show:

In the Fijian community, [if you have HIV], it's like if you were walking with a bomb. Like that, eh? (He laughs) They are so scared. (Man living with HIV, February 2008)

How would you say that Fijian people see HIV and people living with HIV? I've seen two... two ways. One is those who've been educated and others who've just heard about HIV. I see that... that's two differing perceptions all together, eh? The ones who've been educated about HIV, they can understand. They come close to us, they listen to us. For those who are not so much educated about HIV, they have fear, they're afraid, they just stay away from us. (Man living with HIV, February 2008)

From one o'clock to two o'clock last two weeks, there was a radio programme on HIV and the announcer asked people from around Fiji to call. And they said “People with HIV should be taken to Makogai.” You know Makogai? Where the leprosy people were taken? There. You know, if they love us, they should not say that to us. Because of some who give us a bad name, they all point finger at us. “These people should go. If not, they're gonna keep on...”, you know, giving the risk, eh, so... Because I can hear. They say “*Sa rauta ga* for them to have HIV.”⁴⁸ Chase them.

⁴⁷ For an interesting historical account of leprosy in Fiji see Stella (1978).

⁴⁸ *Sa rauta ga me ra tauvi HIV*, meaning they deserve to have HIV. This affirmation suggests that HIV contraction is the result of deviant sexual behaviour.

They should go to another [island]...”, you know? (Woman living with HIV, December 2007)

I think they [indigenous Fijians] still regard this disease, you know, as... what?... a very dangerous one and they believe... many of them still look down on people living with HIV, eh? They still don’t understand that... that HIV is just like diabetes and all that, eh, all those diseases, eh? To them, HIV is just... what?... different. It’s just a different disease. So people who have... who are living with HIV and AIDS, they... many of them I think they’d just prefer that... “These people should be out of the society.” *Makogai Island?* Yeah. Mmm [affirmation]. That’s what they think, eh? (Woman living with HIV, November 2008)

The second popular discourse about HIV in Fiji when this study was conducted was that the virus was a punishment from God for immorality and sin. Referring to the Christian understanding of sexual normality and morality, people commonly associated HIV with “homosexuals” and with people who had many sexual partners – particularly women, “prostitutes” or women considered as such.⁴⁹ Premarital sex, which people invariably claimed happens today but did not in the past, was also considered as one of the main causes of the HIV epidemic, both locally and globally. Many people interviewed emphasized the fact that the Bible had predicted the advent of an era of natural disasters and incurable diseases. This age of calamities, announced in the Book of Revelation and of which HIV was considered part, was said to be symptomatic of the world’s depravity and to announce the imminence of the end of time. HIV was hence considered the result of God’s wrath due to individual and collective sins. These excerpts from interviews with HIV positive and non-HIV positive people illustrate these points of view:

The only thing I can say, the uneducated people really, you know... it’s a real big issue to them, eh? [...] They are scared, they like to think kind of... they are very negative on everything that they see and say about HIV and people living with HIV in the sense that... Okay, you know... “Oh! That one there is a prostitute!” You know? (Woman living with HIV, December 2007)

“HIV is sent by God.” You’re gonna meet a lot of people who’ll say that. People usually say that it’s a wrath of God, a kind of punishment for all this mucking around, going from one partner to the other that didn’t happen before. (Indigenous Fijian woman in her 50s, reflecting on common Fijians beliefs that she, herself, shared, February 2008)

AIDS is a sickness that comes from God. God has imposed one *tabu*: to have more than one partner. People who don’t respect the *tabu* get AIDS. (Indigenous Fijian man in his 40s, March 2008)

⁴⁹ The recent study by Lawrence Hammar (2011) has shown how people in Fiji tend to externalize the risk of HIV and to locate it primarily among sex workers. “Homosexuals” are also considered by the population as particularly “at risk.” People living with HIV share this perception to some extent. At least four people among those interviewed – all women (4/17) – mentioned that homosexuals were responsible for the infection or tried to explain their HIV contraction by assessing the possibility that their partners might have had homosexual sex.

[...] I also believe that, you know, many of these homosexuals are... they are the ones who are passing the virus around, eh? (Woman living with HIV, November 2008)

Oh! This one is different. It comes from above. Imagine how much premarital sex there would be if it wasn't for HIV! (Indigenous Fijian woman in her 50s, December 2007)

As will be seen in the following pages, these representations of HIV as associated with sin and immorality and of people living with HIV as “contagious” and “dangerous” have profoundly shaped people’s attitudes towards women and men living with HIV in Fiji.

Experiencing criticism, rejection and discrimination

People living with HIV in Fiji do not easily talk about the rejection and discrimination faced after diagnosis. Not only might it affect their reputation, suggesting that they might have, in some way, deserved such treatment, but to openly recognize these experiences could also tarnish their families’ and communities’ name in revealing they might not have been as caring and as loving as indigenous Fijians are proud to be thought. Nonetheless, these experiences exist.

Many of the people interviewed, and particularly women, reported having suffered reproach and criticism in their families. One woman, for instance, related how her sister accused her of being responsible every time a child from the household fell sick. Another woman, who had had no other choice than to leave the family house, explained how her mother had prevented her from drinking tea, saying she did not deserve it, and accused her of eating too much. Another woman related how her mother talked to her nastily and frequently reminded her that she had contracted HIV because she was a “naughty”, “cheeky” girl. Some of the interviewees, like the woman quoted below, thus felt the need to control their behaviour and to act as irreproachably as possible so as to avoid criticism. Others had chosen to keep their condition secret so as to be spared disapproving remarks:

And the way I’m acting. I had to change the way I’m acting, like, to talk nicely to everyone. (Woman living with HIV, December 2007)

[...] I know my mother, I know how my father talks and I don’t want... If I’m gonna tell them anything about this kind of cases, you know, there will be a day they will say “See! I’ve been trying to tell you this and that, this and that...” That’s why... With this kind of sickness, you just need to relax and enjoy whatever you do so you don’t... If it’s gonna keep on coming up... sometimes I’ll... the way I think, I’ll get suicidal, you know? I’ll have to do something else. I’ll just have to run away. If I run away from this end, they’ll use the phone! They’ll call and say “Oh! She’s having this, she’s having that...” [...] There will be no support in the family. (Woman living with HIV, October 2008)

Several respondents also reported they had had the impression of being ignored, neglected and excluded since their HIV status had been known or suspected. One young man, for example, related how friends had stopped visiting him and had avoided him, a change that he explained by rumours circulating about the cause of his drastic weight loss. A woman recounted how her female relatives had made her feel unwelcome at home by not talking to her, by looking askance at her and by refusing to give her money to pay for transport to go to hospital. A man who had spent time in jail reported how the other inmates had not wanted to sit with him and “tell stories” (*talanoa*) after information about his status had leaked out. Yet, almost as much as they reported attitudes of rejection from family and friends, the women and men living with HIV who participated in this study also said they had tended, at least at some point in their life, to isolate *themselves* and to exclude *themselves* from people and social life. One couple, for instance, explained how they had gone to live in seclusion on a farm for more than two years after having learned about their HIV status. A young man interviewed said he had not spent much time with his family since receiving his diagnosis but had preferred to be alone. A woman explained that she had decided to leave her parents’ house because rumours about her HIV seropositivity were rampant in their neighbourhood and she did not want her parents to feel bad because of her. These two extracts from interviews clearly attest to the existence of self-exclusionary behaviour among people living with HIV in Fiji:

He feels that before, he hung around, he mixed around and he socialized. He was a social person. But with HIV... since he's been living with HIV... now it's like he controls himself. “I have to stay home. I can't feel like going out. I don't feel like hanging around with people.” That's also the way it's changed, the way it's changed his life. (Translation, man living with HIV, February 2008)

With my friends... like, I didn't want to stay near to them, like, I was... you know? And I knew it can't... like, I knew that cigarettes can't spread the [virus]... but I was afraid to give puffs of cigarettes, eh, at that time. And, like, with my family members, eh, I said “I should have one spoon. I should have one cup”, and they said “No! No!” I was feeling... like, I felt bad because of that [her HIV status], eh? Yeah. You know, like, I didn't want to... I knew all the transmission modes, eh, but you know, like, I was holding myself back, eh, I excluded myself. (Woman living with HIV, December 2007)

Some of the research participants also reported experiences of blatant rejection, ill-treatment and discrimination. One woman, for instance, related how her very sick husband was abandoned by his family and how one of her husband’s female kin suggested she should do the same and look for another man instead of staying with a “dog.” A man explained how two of his sisters joined together – in vain – to pressure their eldest brother into banishing him from the family. Similarly, a woman told how the wife of the landowner (*turaga ni mataqali*) of the settlement where she had once lived had asked her husband to turn her (the HIV positive woman) off their land, which he had refused to do. As already suggested at the beginning of this report (p.10), two respondents reported having been dismissed from their job because of their HIV status. One man who had been jailed at a certain point in his life related how he had been isolated from the other inmates. The people interviewed also reported how at least two out of the 10 HIV positive women and men who had publicly revealed their status at the

end of 2008 had been physically assaulted by people who did not want them to “bring” HIV to their region. Discrimination of people living with HIV in Fiji is still a reality. It is worth noting that if women are rightly considered at greater risk of contracting HIV, because of social realities which make them vulnerable to the infection (pp.20-22), they also feature prominently in stories of rejection and discrimination, both as persecutors and as victims.⁵⁰

Why are many people living with HIV in Fiji subjected to criticism and reproach? Why are they frequently ignored, neglected and excluded? Why are they victims of rejection and discrimination? According to those interviewed, it is first the fear of contracting the virus that explains people’s attitudes towards HIV positive women and men. As explained in the previous pages, people living with HIV in Fiji are often portrayed as “dangerous” and “contagious” and other people fear as much “deliberate” HIV transmission as “accidental” transmission through casual contact. The fear of “contagion” is particularly salient when HIV positive people are in an advanced stage of the infection and suffer from opportunistic infections and diseases. Among the people interviewed for this study, at least two reported that they or their partners were abandoned by their families while they were sick. Their families ultimately returned when they had recovered. This fact points to the fundamental role of antiretroviral therapies and highly effective treatments of opportunistic infections in the improvement of the quality of life of people living with HIV, not only in terms of health but also in terms of acceptance and social support.

The second factor mentioned by those interviewed as underlying attitudes of rejection towards HIV positive women and men in Fiji was the association of the infection with immorality and sin and the resulting shame and dishonour. As suggested earlier, sex outside of marriage transgresses the indigenous Fijian community’s religious and cultural ideals which celebrate kinship and alliance and is deemed shameful if it comes to public attention. Although not all HIV infections are contracted extramaritally, the fact of being affected by HIV is popularly considered as revealing a deviant sexual history and brings dishonour which is all the greater for the infection being generally regarded as a punishment from God. Moreover, the resulting shame or embarrassment (*madua*) is not restricted to the individual who has transgressed. It is also deemed to apply to their family (*vuvale*) and extended family (*i tokatoka*) and, ultimately, to their lineage (*mataqali*), clan (*yavusa*) or village (*koro*) which are thought to be accountable for their members’ actions. It is this shared responsibility that allowed one woman interviewed to confront her partner upon learning about his HIV status and to tell him “You’ve got the virus. You’ve got AIDS in this family” (Woman living with HIV, October 2008). Ignoring and excluding people living with HIV therefore constitutes an attempt at distancing oneself from the shame and dishonour associated with the infection and at preserving one’s name and reputation:

⁵⁰ The HIV/AIDS Decree 2011 also makes it unlawful to stigmatize or discriminate against a person living with HIV or affected by HIV (see Part 3, HIV/AIDS Decree 2011, Republic of Fiji Islands Government Gazette, 12 (2), Government of Fiji).

It's both. It's lack of information, lack of knowledge about the... They're scared. The other one is a punishment kind of thing, an immoral kind of activity. They don't want to be associated with it because it's a prostitutes' disease and all the people who make their sexual behaviour... [...] Maybe they associate this with sin, eh? It's a sin to be associated with, you know, with the killer disease. (Man living with HIV, April 2008)

No, they're not scared but they hate me because of what I did. You know, 'cos I come... I've already said we come from a very religious family, a very strict family, from my mother's side, eh? My mother's.... they are so strict that they hate me because I was... I'm the one, eh, who's been doing that. *You say doing that, you mean...* Like, I've contracted... I had sex before marriage... They are not scared. Like, they hate me. (Woman living with HIV, March 2008)

In fact, in a Fijian.... in a traditional Fijian setting I would be bringing bad luck to the family.⁵¹ [...] *Because? Can you explain to me?* Because, you know, it's reputation. They would say, you know, "This family has this going on and their daughter is now HIV positive. You know, something is really wrong with them." (Woman living with HIV, February 2008)

[...] I keep on telling them "Whether you accept my status or no, I will still be positive for life. And secondly, if you kick me out of the house today, if I die today, you can go out and tell everybody that he is not your brother but everybody knows that [X] was your brother. So you will still be... people will still associate a person living with HIV with your family. You cannot change that. It doesn't matter how much you want to try." (Man living with HIV, April 2008)

Many of the people who took part in this study also believed they had tarnished the reputation of their family and of their community by contracting HIV and some had resolved to ask for forgiveness or to conduct reconciliation rituals (*bulubulu*)⁵² aimed at restoring harmony in their relations with them. A few who had not undertaken such a process nonetheless expressed their wish to do so, saying that prejudice, if any, had to be redressed and bad feelings buried:

But for me, personally, I still feel *madua* about it, eh? Because, like, I've given my family a bad name. That's what I feel, eh? That's what some of them will be thinking too. (Woman living with HIV, November 2008)

[...] I said initially that I've brought shame to the family because of that, because of that [chiefly] status. (Woman living with HIV, November 2008)

Because here, in Fiji, we... like... we are representing the village, eh? Like, I come from [X]. So when I came out public... HIV is, like, a big issue here in Fiji. HIV is,

⁵¹ This woman living with HIV uses the words "bad luck" but her subsequent explanation indicates that she is talking more of shame or dishonour.

⁵² *Bulubulu* is now commonly used as a general word for any performed act of reconciliation. In an unpublished text, Paul Geraghty explains, however, that the term *bulubulu* refers specifically to the act of apology made by the family of a man to the family of a woman after an elopement. The general word for an equal or inferior performing an act of reconciliation is *i soro* (*Traditional Fijian Reconciliation*). For more on reconciliation rituals in the indigenous Fijian community see also Hickson (1975), Arno (1976) and Merry (2006).

like, a big issue, eh? So when somebody's been infected with HIV... people will be looking at you and point finger at you "Where do you come from?" and... yeah. "He's from there, from [X]", all that... [...] So when I disclosed my status in the newspaper and in the media, I also disclosed where I come from. Yeah. So they [his parents] went to apologize [to the community] because I've been mentioning where I come from and all that. (Man living with HIV, December 2007)

[...] one thing I think about is to do a *bulubulu* with my community, eh, to buy something and to go to my community because in my family [...] [w]e are the chiefs of the village. I want to go and do a *bulubulu* because, you know, that [HIV] spoils our family's name [...]. That's what I think about, eh, to do a *bulubulu* with them so that we can have a good relationship to each other. (Woman living with HIV, December 2007)

It should finally be noted that other factors which have nothing to do with HIV sometimes play a part in negative attitudes towards HIV positive people. For example, one man interviewed explained how attempts by family members at excluding him related as much to the sharing of land lease benefits as to his HIV status. Key informants who worked in close proximity with people living with HIV also reported how a few had been rejected after they had been involved in incidents deemed unacceptable, such as having been violent with a family member or having had an affair with someone from the community. In these last instances, however, it appears that HIV positive people's actions were scrutinized and judged more severely than those of others would have been.

Experiencing support and acceptance

People's reactions to an HIV positive status are not always negative. Some of the respondents described very positive experiences following disclosure or suspicions people aired of their HIV seropositivity. One woman, for instance, explained how she had received the full support of her family (*vuvale*) and had never been lectured for having contracted the virus. A man reported feeling that his friends had doubled their demonstrations of love towards him since knowing about his HIV status. Another woman explained that the news of her HIV seropositivity and the period of illness that followed was a bonding moment for her and her brothers who were constantly at her side. A man who had felt left out by his family before diagnosis said that the news of his HIV status and the attention he had got from his public disclosure had brought him respect and improved relations with his family. Other women and men who had publicly revealed their condition reported having been frequently stopped by people on the street, given money (*solì*) and thanked for their awareness-raising work. The following extracts from interviews echo the support and acceptance experienced by some people living with HIV in Fiji:

And yes, I've been so fortunate in the sense that I've got the support... One thing about me is... The support that I have is one of the main reasons I've managed to recover. *The support from your family and relatives?* Yeah. [...] That is something that is really important. That is the main reason why I've made it out, to be where I am today. (Woman living with HIV, November 2008)

I always assumed that my relatives will reject me, but the moment I disclosed my status to them, they were very respectful and very lovely. (Man living with HIV, December 2007)

Surprisingly, I... In Fiji, I've heard that some people were treated very badly when they [disclosed their HIV status]... [...] But I was one of those people who were very lucky in the sense that I've never been treated in any different way than people noticed me before. It's still being normal. People acknowledge me in the street, people actually I don't even know, strangers, total strangers, come up and say "Good morning [X]. How are you today?" So they come to me with genuine concern, trying to find out whether... how you're doing, how is everything at home. So yes, it's been very good. (Woman living with HIV, April 2008)

And you may ask what is the response [referring to his public disclosure of his HIV status and to his awareness-raising work]? I've gained more respect than discrimination from people that I've talked to. More respect. There are people that you see on the street and say "Hey! Hey!", but now they come and shake hand with you and say "Hey! Thank you very much. Thank you for talking to my children." (Man living with HIV, April 2008)

Two main elements seem to have played a part in the support and acceptance experienced by the women and men interviewed. Information about the infection was crucial in all cases. Knowing about the modes of HIV transmission attenuates people's fears for their personal safety and makes them more likely to show support towards people living with the virus. This clearly transpires from the life stories of some of the interviewees who were initially rejected but were later accepted after those close to them had learned the basics about the virus and its transmission. This was the case, for instance, for one woman who was told by her mother not to call her mommy again, that she was no longer her mother and did not want to see her anymore. The woman eventually apologized to her daughter, saying she did not know at the time that HIV could not be transmitted by hugging and kissing. This was also the case for a woman who related how her father had told her that she would always be his daughter but that she could no longer live with them. After attending an information session organized for people living with HIV and their families, her father's fears were allayed and the woman was not asked to leave, though her children were sent to a relative so as to prevent any "risk" of transmission. One man also explained how a workshop organized by the village nurse and the testimonies of two HIV positive people who had visited the district had made relations with his fellow villagers easier. Accurate information about HIV clearly constitutes a key determinant of positive reactions to HIV disclosure.

Being perceived as "not deserving" their condition seems also to have played a role in the support and acceptance experienced by some of the people interviewed. Those, especially women, who were perceived as not having "sought" the infection, either because they did not have many sexual partners, "muck around", drink or go to nightclubs, tended to be more easily accepted by family and community. Similarly, women who had contracted the virus from their husbands or from long time *de facto* partners attracted more sympathy than women who had contracted HIV after having been in a short-term

relationship. To be at the “right end” of the morality spectrum contributes to being supported and accepted.

***Tauvi AIDS* or being labelled**

One aspect about living with HIV which all the people interviewed mentioned as being particularly difficult, irrespective of the context of their HIV acquisition and of the support or rejection experienced with those close to them, was the fact of being labelled and regarded as “someone with AIDS” or *tauvi AIDS*. One woman, for example, revealed how she felt ashamed when walking on the street or when in public places because she could hear people saying “Oh! She’s positive” (*Okoya sa HIV*). Another woman reported how she could feel people staring and looking askance at her. A woman, who had revealed her HIV status to only a few, carefully chosen people, recounted how she had once seen people massed at the entrance of a supermarket to scrutinize two HIV positive people who were passing by. This experience had reinforced her decision to never disclose her status publicly. As many of this study participants emphasized, being labelled and perceived only through the prism of their HIV seropositivity not only reminded them of their condition but also contributed to the feeling of being different, a feeling common among people living with HIV. Being stared at and referred to as “HIV or AIDS people” also accentuated the feeling of shame (*madua*) experienced by several women and men living with HIV. The following excerpt from an interview clearly illustrates the impact of being labelled:

The most difficult thing is that... to be known, to be labelled. See? Here goes the HIV positive person. Because even when I go on the street, they say “Oh! There goes the woman. *Tauvi AIDS*. That woman has AIDS.” See? For me, I don't have AIDS, I've got HIV but when you hear that... it sort of triggers something in me and I say “Man. I'm labelled.” See? Even though I'm not openly discriminated... but they are uttering... their utterances are just that... you know, it's so... it leaves an impact on me knowing that I'm this person who's going around with this label: HIV or AIDS. And that's how people see me: the AIDS woman. That's how I'm perceived, that's how people see me. When the name [X] is mentioned obviously “Oh! AIDS” or “HIV.” (Woman living with HIV, April 2008)

However, life with HIV is not just a question of people’s attitudes towards one’s status. Living with HIV, as the term suggests, means adapting to the condition and having a life despite the virus. The 28 women and men interviewed for this research were asked what it was like to live with HIV in Fiji. Their answers are examined below.

Living with HIV

Receiving an HIV diagnosis unquestionably changes one’s life. For HIV positive people, there is often a life *before* and a life *after* HIV. But what is it like to live with HIV? How do people in Fiji talk about living with the virus? What are the changes they report in their life due to the infection?

What it is like to live with HIV

For some of the interviewees, most of them men, the experience of HIV was anything but positive. These individuals emphasized how much they had lost because of the infection (partners, children, employment, etc.) and how HIV had prevented them from attaining their objectives in life. They said they preferred not to think about the virus and wished they could forget about it completely:

I just put it out of my mind, eh? I don't want to think about it. (Man living with HIV, February 2008)

They've ruined my future, they've ruined everything because of the information they said [referring to an inexcusable breach of confidentiality on the part of medical personnel]. Because I was having a good job and I've lost everything, even my family, my house. Yeah. (Man living with HIV, February 2008)

The way I look at HIV [...] it's taken me out of my work, of my job, of my financial means and it's stopped me from doing... from moving for... for what I was supposed to be, for what I was supposed to achieve. [...] This disease kind of cut me off. (Man living with HIV, February 2008)

Although they considered HIV an extremely negative event in their life, a few, probably echoing what doctors had told them at the time of diagnosis, said that things could have been worse because at least HIV, when medically controlled, is not as debilitating as some other conditions:

But the good thing about this disease, the thing that I'd learned about this disease a few months ago, it's much better than diabetes. You know, like diabetes, they're dealing with body that had been cut, you know, no legs, no... dealing with pain things.⁵³ But having this disease is just a blood thing. You do as normal things as you always do, you know? The most important thing for you is to take your pills. Yeah. Which I like about that disease. I don't like it, but... (Woman living with HIV, October 2008)

Several of the respondents, despite having been through a whole range of difficulties, spoke of their life with HIV in fairly positive terms. Some, especially those who had publicly disclosed their status, were far from believing that the virus had been a limitation in their life. They said being HIV positive had actually opened up new opportunities for them in the form of employment, education, and travel and allowed them to meet new people. Some interviewees said that having HIV had opened up their minds and changed the way they looked at people and at life. Some also mentioned that having HIV had enabled them to find an inner strength they had not realized they possessed. Another fact frequently mentioned as something profoundly positive about the infection was that having HIV did not prevent one from leading a "normal life." Two elements were implied in this assertion: that the condition did not require health care and a follow-up

⁵³ This woman is referring to complications of uncontrolled Type II diabetes, which include sepsis, ulceration and gangrene which, in turn, may result in lower limb amputation. Approximately 300 diabetes patients undergo amputations every year in Fiji (World Diabetes Foundation, 25th January 2011).

that disrupted everyday life and that HIV, when controlled, did not affect a person's capabilities – they could carry on normal activities. Many of the women and men who took part in this study found it satisfying to still be able to accomplish daily tasks associated with running a household and subsistence farming. A few young men mentioned they still enjoyed playing rugby, a sport that requires very good physical condition. Several commented positively on the fact that their life was still the same. As the following excerpts show, life can be good despite HIV:

Being infected with HIV opened up my mind. Yeah. And I've met new friends and I've been to places that I hadn't been to. Yes. It's like... I see a new future for me, eh? Yes. (Man living with HIV, December 2007)

[...] I'm realizing my inner strength. If I can go through that, I can go through a lot more. (Woman living with HIV, December 2007)

I'm staying on a farm, eh? I can take a bag of *dalo*⁵⁴ or cassava, put it on my back and bring it home. I can and a lot of people, they can't do that. After, I take my big bucket and I do the washing. Finish with the hand washing? I start to peel the *dalo*. People can't believe I can do all those things. *You have a lot of energy*. Yeah! (Woman living with HIV, December 2007)

I can feel it's a new beginning. I see the difference, before HIV and after HIV. Before, I used to be skinny. Now, I have HIV and I'm fat. I'm fat and I can go from that place to that place, do a lot of work, more than before, you know? And my mind too. Before, I used to put myself down... People can't believe that I have HIV. I'm fat, fat, fat.⁵⁵ (Woman living with HIV, October 2008)

I always say to myself that the sky is the limit, you know? Not because I'm HIV positive that I will have conditions and limitations [...]. (Woman living with HIV, February 2008)

My everyday life is still the same! I can go to the garden: weeding, planting... (Woman living with HIV, October 2008)

Biographical disruptions associated with HIV

Though the physical capabilities of people living with HIV may remain the same and their everyday life may on the whole sometimes stay unchanged, HIV nevertheless causes what some researchers have called “biographical disruptions” (Bury 1982). HIV often interferes with the career path of those affected. As already mentioned, two respondents stated they had lost their job because of their HIV status (see p.44). Seven

⁵⁴ *Dalo*: taro.

⁵⁵ It has been noted previously that body size is considered by indigenous Fijians as a reflection of an individual's physical, psychological and relational health (pp.27-28). In this extract, this woman talks of changes in her body as signifying an overall improvement of her state. From “skinny”, she became “fat”, by which she means that her life with HIV has been more fulfilling than her life before diagnosis. It should be noted that this woman was not under antiretroviral therapy at the time of interview. Therefore, the change she reported in physical appearance was not linked to the effects of HIV treatments.

had to leave employment or abandon studies due to episodes of illness caused by the infection. Among these individuals, two were still too unwell at the time of interview to resume their activities, three considered they no longer had the physical capabilities to go back to their former job and had made a career change and two, although they said work had been a fundamental part of their life, thought that having a regular job was not compatible with being “sick” and had decided to stay home.⁵⁶ For six people, HIV also meant a new career. As noted at the beginning of this report (p.10), six interviewees worked for organizations involved in HIV prevention activities and in providing services to HIV positive people. For at least three of these individuals, working in the field of HIV represented their first stable, salaried job.

HIV also strongly affects the life of couples. For one man, being diagnosed with HIV meant never seeing his wife and child again, the former having filed a petition for divorce after hearing of his condition. For six women and one man, HIV meant having to look after a sick partner. This included giving them medication and taking them to hospital but also frequently bathing and feeding them. Six women and one man had also seen their partner die from the condition. Conversely, two people were brought together by their condition as they met each other in the context of HIV advocacy.⁵⁷

The impact of HIV can also be seen in the reproductive life and desire for children of people living with the virus. Among the research participants, four had lost a child due to complications from the infection. At least three others had had to terminate a pregnancy (theirs or their partner’s) for fear the baby might be affected by the virus. Five people had also chosen not to have any more children after being diagnosed with HIV, at least three women having even put a premature end to their capacity to reproduce by undergoing tubal ligation. As mentioned in the first pages of this report (see p.9), the people living with HIV interviewed in this study had a mean of 1.5 children (with no difference between women and men), which seems considerably less than the average number of children observed in the indigenous Fijian population as a whole.⁵⁸ Medical follow-up during pregnancy and the observance of guidelines for the prevention of HIV transmission from mother to child nevertheless enabled six people to have HIV negative children despite their status (three had one child and three had two children).⁵⁹ It also made it possible for at least four women and men to plan to have children in the near future.⁶⁰

⁵⁶ Though many of the people who took part in this study considered that HIV was not a limitation and emphasized, in interviews, the contribution that HIV positive people could still make to society, a few clearly considered that having HIV meant being a “sick person” and thought working was detrimental to their condition.

⁵⁷ For a very interesting and important account of the impact of HIV on intimate relationships see PIAF (2011).

⁵⁸ Walsh (2006) cited data from the Fiji Islands Bureau of Statistics according to which the number of children ever born to women aged 15-49 years in the indigenous Fijian community in 1996 stood at 4.19. The United Nations Children’s Fund (UNICEF), in its *State of the World’s Children 2011*, indicates Fiji’s total fertility rate in 2009 was of 2.7 children per woman.

⁵⁹ Three more people were waiting for the final results regarding the HIV status of their child.

⁶⁰ On Pacific women’s experiences and views of motherhood and HIV see PIAF (2011).

Changing lifestyle habits

Confronted with a virus that both causes and benefits from a weakened immune system, people living with HIV often report altering their lifestyle to boost their body's defences. In this perspective, the people who participated in the study frequently reported⁶¹ having made changes in their diet, which, as the following extracts from interviews illustrate, consisted essentially in making an effort to reduce their intake of meat and "junk food" and to eat more fruit and vegetables:

I've changed my diet. I hardly ate vegetables before. Now, I'm forcing myself to eat vegetables. [...] I'm trying to boost my... my immune system. (Man living with HIV, September 2008)

That's something that I'm really working on, eh, my diet. Because I *loved* eating, you know, just snacks and sweets and take-away and all that. I loved that, eh? And now, I'm working hard on my diet, eh: eating more fruit, drinking water. (Woman living with HIV, November 2008)

I've changed my diet. Eating, eh? I used to eat fatty food like meat and all that. Now, I just have greens. Like today, you know what I had today? Just cassava, boiled cassava, and *roro*⁶², plain *roro*. I just eat meat once a week, two times a week, like that. Before I was diagnosed, ouh! I could have two chickens. Now I eat vegetables, fruit. (Woman living with HIV, October 2008)

Several interviewees stated that they tried to sleep more and to do some physical exercise. The respondents also often said they had stopped smoking and had reduced their consumption of kava (*yaqona*). The latter, though it has a fundamental place in indigenous Fijian culture, was considered detrimental to health by people living with HIV when taken too frequently or in large quantities:

The sleeping pattern had to change because I'm a person who loved to... like stayed awake. I had... I had a lot of work to do and I could stay up late and slept at 2:00 or 3:00 o'clock in the morning only to wake up at 6:00. That had to change. The diet had to change. Exercise had to be emphasized and I put a lot of emphasis on exercise because I need to keep fit. So those are the things that have changed. (Woman living with HIV, April 2008)

Sleeping. I've changed my sleeping habits. I sleep early like 7:00 o'clock. I do my little bit of exercise. (Woman living with HIV, October 2008)

[...] I've stopped abusing my life: I quitted cigarettes, beer and, like, I've put myself some curfews and... You know, I've programmed my life, eh? (Man living with HIV, February 2008)

⁶¹ These are *reported* changes, of course. While the respondents certainly tried their best to adopt routines and life habits beneficial to their health, it is very probable that they did not always succeed in maintaining them, if only because of social requirements and obligations and financial constraints.

⁶² *Roro*: dish made of taro leaves.

[...] before, I used to drink: drink *yaqona*, drink alcohol and when I got sick, I left all that. (Woman living with HIV, October 2008)

As the last excerpts show, many of the study participants also said they had stopped drinking alcohol and going to nightclubs. Not only were these habits considered unhealthy by people living with HIV but drinking and going to nightclubs, as explained earlier in this report (pp.15-17), were thought to be directly associated with having sex, a “risk” which many of the people interviewed implicitly said they did not want to take:

I used to enjoy, like... at the end of the week... going out and drink. But that has hardly ever happened for the past two years. Since I was diagnosed, yesterday was the first time for me to drink. So just imagine the things that I had to sacrifice for my health. (Woman living with HIV, April 2008)

Before, I used to go out and dance in nightclubs. (She laughs) Those things? Finished. (Woman living with HIV, December 2007)

I've put a stop on all that: going out, partying, drinking, nightclubbing. All stopped now. So now I'm more, like... I can say more religious, eh? (Woman living with HIV, November 2008)

It should be noted that the changes in life habits reported by people living with HIV were not always linked to their diagnosis *per se*. For some, it was more the new medicalization of their condition (i.e. having to start taking ARVs), episodes of illness or the death of their partner from HIV which initiated these changes. In many cases, these transformations in terms of lifestyle were also associated with another change that almost all the women and men interviewed reported: that in their relationship with God. This element is examined below.

Renewing one's relationship with God

One of the main life transformations reported by the research participants was the prominent place spirituality took in their life after their diagnosis. In interviews, people talked of having converted to Christ, of a new relationship linking them with God and of their faith reaching a new level. Considered as the result of the discovery of their HIV positive status, this renewed relationship with God was said to be their main source of strength in dealing with the virus:

[...] when I became HIV positive, something that became prominent in my life was my trust and belief in God. (Woman living with HIV, November 2008)

Like before, you know, I was not that much spiritual. I was... you know, I just went to church but I didn't think about going. Because it was Sunday I had to go to church. But after [HIV diagnosis], I had to attend Monday, Wednesday, Friday, Sunday. *You needed it. Yeah. You wanted to be...* Close to God. (Woman living with HIV, March 2008)

What keeps you going on? What helps you to cope with the fact that you're HIV positive? Just my faith. Just my faith. My personal relationship with God. That's it. The Holy Ghost. Holy Ghost. Just to be filled with the Holy Ghost, to live and walk with Him. (Woman living with HIV, October 2008)

For a good number of women and men, this transformation in their relationship with God coincided with conversion to an evangelical, charismatic or Pentecostal church. Among the people who participated in this study, nine (9/25) belonged to the main Christian churches of Fiji, that is to say to the Roman Catholic (1/25) or the Methodist church (8/25, based on 25 people because of unknown religious affiliation for the others). Sixteen people – a proportion considerably higher than that given for the indigenous Fijian population in general (*Population by religion and by race – 1996 Census of population, Fiji Islands Bureau of Statistics; see also Walsh 2006*)⁶³ – stated they were members of “new” churches. To be more specific, five said they belonged to the All Nations Christian Fellowship, three to the Seventh Day Adventists, two to the Assemblies of God, two to the United Pentecostal Church and four to other groups and denominations (Galilee Church, Lion of Judah, Church of Christ, New Methodist Christian Fellowship). At least five of these people (5/16) reported having adopted these new faiths as a result of their HIV diagnosis or following events connected with their condition (illness, hospitalization, death of a partner from the infection, etc.).

The people who took part in this research explained they had deserted the mainstream churches for various reasons. Commonly expressed was the feeling that the conventional Christian churches in Fiji – and particularly the Methodist Church to which almost all the respondents had belonged before conversion – did not really care about their followers. They saw proof of this in the fact that none of these churches had visited HIV positive people during periods of illnesses. Conversely, according to the women and men interviewed, the new churches attached importance to visiting patients in hospital, to sharing the words of God with them and to praying for their recovery. This is clearly how some of the churches mentioned above, especially the All Nations Christian Fellowship, had succeeded in making the participants in this study members of their church. The following extracts from interviews illustrate these points:

[...] all the time I was in bed, and I was sick for fifteen months after diagnosis, the Wesleyan church, the Methodist church didn't even turn up at my door. And this other denomination came to me. (Woman living with HIV, November 2008)

Like, in the Methodist church... When I was... I don't think people had heard that I'd contracted... And one time I got sick. You know, even... they didn't even come, like, they neglected, you know, they ignored me. Even though we prayed and everything. Like... I mean, this prayer group, like, they care, they care about me a lot. (Woman living with HIV, March 2008)

⁶³ According to the 1996 census, of the 389 752 indigenous Fijians who declared a Christian religious affiliation, 81% (316 748) were followers of the “old” churches (Anglican, Catholic, Methodist, Presbyterian and Salvation Army) while 19% (73 004) were members of “new” churches (Apostolic, Assemblies of God, Baptist, Christian Mission Fellowship (Every Home), Gospel, Jehovah's Witness, Church of Jesus Christ of Latter-Day Saints (the Mormon church), Seventh-Day Adventists and other Christian denominations).

Other people reported they had decided to convert to new church denominations after having been through spiritual experiences of great intensity (speaking in tongues, trances, visions, etc.) or after having been miraculously “cured” of various symptoms (see also pp.31-32). These individuals considered such experiences as invitations to join denominations which proposed more vibrant and experiential forms of worship:

I converted. I converted after diagnosis. Yeah. [...] *Before that you were a Methodist?* Methodist. (She laughs) Methodist. It's probably one of the experiences that I had when I was very, very sick and I knew that, realistically, it was coming... my life was coming to an end. [...] And at that time, I... on the day that I was... I knew that I was preparing myself spiritually, I had this kind of experience. I still can't explain it. Suddenly, I began speaking in tongues. It's something that I hadn't experienced before as a Methodist [...] [a]nd nobody else was there to help me in the process. It was just me reading my Bible, praying. And in the process of praying and reading the Bible, I was crying all along. Even though I was shedding tears, it was happiness I was feeling, so much happiness and peace I never knew before. It was quite an experience. [...] When I asked mom about it “What is that? What did I just go through, speaking and walking as if I was floating and not feeling my feet on the ground?”, she told me “You’re actually filled with the Holy Spirit.” And I said “What is that?”, because we'd been... I'd been a Methodist ever since I was born and baptised. I'd never felt anything like this. And that's something that has changed. [...] So that is something that really... was a turning point [...]. (Woman living with HIV, November 2008)

When my husband was at the hospital, the pastor of the All Nations came in... at the time... when the doctor told me to pack my husband's things, just to take him back home and wait for death there. He couldn't do anything for my husband. [...] At the same time, a pastor came in. [...] So the pastor came and said “Peace in this room.” Peace in this room, eh? “Peace in this room.” I felt a peace right at the same time. And he came inside and shook hands with him, shook hands with me and again “Peace in this room.” *Oi!* I just sat down. I just sat down and took my Bible. [...] At the same time, a noise came out of my husband's stomach: a growl inside because of diarrhoea. “Show me your stomach.” The pastor put his hand on his stomach and the noise stopped. The pastor prayed. After five minutes, it was finished. Because, you know, he used to run to the toilet every two minutes. After five minutes of praying [...] the thing stopped and he never stood up again to go to the toilets. It stopped. The vomiting stopped. At that time, I looked up and praised the Lord. [...] *So it's after that that you decided to go to the All Nations. Because he was a pastor from the All Nations.* At that very time. (Woman living with HIV, October 2008)

The people living with HIV who participated in this study also stated that their conversion to new churches afforded them a more intimate and personal experience of God. They said that worshipping in evangelical, charismatic or Pentecostal church denominations enabled them to feel the presence of the Lord in their everyday lives. They also reported that being a follower of these new churches gave them a sense of belonging, a sense which some were clearly in need of after having been rejected by families and communities.

Joining FJN+

Joining organizations or networks of people living with HIV is another way for many HIV positive people to create a sense of bonding and belonging after diagnosis. In 2007 and 2008, when the fieldwork for this research was conducted, the Fiji Network for People living with HIV and AIDS, or FJN+, was the only organization dedicated to providing services to people living with HIV in Fiji. The present section is concerned with these individuals' experiences with this organization.⁶⁴

FJN+: mission, aims and activities

Set up in 2003, but officially registered under the Charitable Trusts Act of Fiji in September 2004, FJN+ is an organization whose mission is “to promote the improvement and overall quality of lives of people living with HIV [and] AIDS in Fiji” (Constitution of the Fiji Network for People Living with HIV and AIDS, unpublished). The aims of the network include providing a discussion forum for people living with HIV, giving its members opportunities to develop employment-related skills, lobbying for the protection and promotion of the basic human rights and needs of people living with HIV, lobbying for access to highly effective antiretroviral drugs and treatments of opportunistic infections and pressing for the full participation of people living with HIV in decision making on issues affecting them. FJN+ also aims to raise awareness, disseminate information and educate the general public about HIV (Constitution of the Fiji Network for People Living with HIV and AIDS, unpublished). The organization uses different activities to work towards these objectives; in particular, it holds monthly meetings where people living with HIV can socialize and participate in information sessions regarding different aspects of the infection. It also coordinates income-generating activities and housing assistance, offers psychological and spiritual support and manages an emergency fund for people living with HIV who are in extraordinary need. The network is also deeply involved in the prevention of HIV through the organization of awareness-raising sessions around the country. At the end of 2008, FJN+ stated it had 28 members (39 minus 11 deceased)⁶⁵, though active membership seemed more to oscillate between 15 and 20 people. Among the women and men interviewed for this study, 20 said they were members of the network; four of them specified their involvement in the group was very irregular.

⁶⁴ The Pacific Islands AIDS Foundation, or PIAF, has since opened an office in Lautoka where it provides services and support to people living with HIV from around the country. AIDS Task Force of Fiji was also a leading figure in terms of networking of HIV positive people and advocacy for their rights. However, when this research was conducted, both people living with HIV and key informants said that the organization had ceased its activities. Moreover, attempts to meet staff or volunteers from the organization proved unsuccessful.

⁶⁵ This information was publicly revealed during a fund-raising dinner organized to finance the network's emergency fund in December 2008.

The benefits of being a FJN+ member

All the members interviewed stated there were benefits to joining FJN+. The first was the opportunity to be among people like themselves and to share information and personal experiences. Several of them spoke of the difficulty of talking about their lives with non-HIV positive people. Some also mentioned a sense of isolation and loneliness following diagnosis. Joining FJN+ was therefore a way to relieve their mind of the worries caused by the infection and to restore a sense of connectedness:

I decided to join 'cos I knew that people were the same as myself: they'd been isolated. I knew we could come off, share our difficulties, our problems, share stories. (Man living with HIV, February 2008)

The thing is because, like, at home, you can't share with your family what really touches your life. But in the organization, when you come here, you can throw any message around. There's no problem because we are in the same boat, eh? You can share. [...] It's like when you are with positives, like, you are empowered. (Man living with HIV, February 2008)

Joining FJN+ was also a means for many people living with HIV to learn about the health issues affecting them. Several respondents reported they knew very little about their condition after diagnosis. Some said that the medical personnel at the clinics and hospitals where they were diagnosed had explained nothing to them when they had learned about their infection. Some stated that the technical terms and language employed by medical staff had prevented them from understanding the information given. There is no doubt that the socially required behaviour when in the presence of people of higher status or in a position of authority – behaviour showing respect, deference and humility⁶⁶ – or the expectations of what a doctor/patient relationship should be had deterred many people from questioning their general practitioner and, thus, from seeking information on their condition. It should also be borne in mind that the shock of the HIV diagnosis may have had such a strong emotional affect on the women and men interviewed that they were incapable of assimilating any information, particularly at the very moment they learned of their infection. As the following excerpt from an interview shows, a self-help group was therefore a favourable environment for them to learn more about their condition:

He said that the doctor explained to him. It was a long explanation which... he didn't understand what he was trying to explain. I think it's the technical terms. And then he finally got to know, got to understand when he said... the doctor said "You are HIV positive. There's no cure. You will die." [...] The next time around he came and had his check up with Dr. [X]. Then she told him "There's an organization here that looks after positive people. Your life will be long if you join this organization." Which he joined and now he's learned about HIV and it's changed all his life, how he sees life and how he lives with HIV. (Translation, man living with HIV, February 2008)

⁶⁶ On this subject see, among others, Ravuvu (1983), Toren (1990) and Nabobo-Baba (2006).

Several of the people living with HIV interviewed for the purpose of this study had also joined FJN+ in the hope of improving their living conditions. As mentioned before, the organization coordinates income-generating activities for its members, including the making of *sulu* (Fijian sarong or pareo) and jewellery that are sold at public events. It also supports the employment of HIV positive people. Members of the organization are hired for most of the office's maintenance work. In addition, in accordance with its objective of promoting greater involvement of people living with HIV in all issues concerning the infection, FJN+ prioritizes the employment of people living with HIV to run awareness-raising sessions in communities around the country. All these activities are opportunities for HIV positive people to earn a salary and, consequently, to make a living for their family. This was greatly appreciated by the women and men interviewed. The respondents also talked of FJN+ as a very "supportive" organization. This support almost always referred to financial support and many explained how the organization had helped them to pay their bus fare to visit the clinic, to buy milk for their babies or to pay for their children's school fees or necessities. As is generally the case in indigenous Fijian society, this help in the form of money, gifts or food was considered a material expression of the love, care and compassion the organization had for them. The following extracts from interviews illustrate how joining FJN+ was considered financially helpful:

They're good! They helped us, like, with food, with money during the time we [she and her partner] didn't have any place to... anyone that could help us... like, the family, family support... lack of family support. (Woman living with HIV, October 2008)

What are the benefits, according to you, of being a member of FJN+? How does being a member of this organization benefit you? [...] He said what benefits him from being in this organization... the help that he's come across is that, before, he knew that HIV had no cure and when he came to FJN+, he heard there were drugs that could help him and now he's planning... they told him to take... to be on [ARV] treatment. And through the organization he came to work and through that he feels that he can help his family financially. (Translation, man living with HIV, February 2008)

[...] you didn't feel like going [to FJN+]? No, because, you know, my husband was there all the time supporting me, eh? I had no reason to go there. Now I have the reason. I need support financially, and everything... yeah... to talk... *So it's not that you didn't want to be part of the organization. It's just that you didn't see the need at that moment.* Yeah. Yeah. I... I want to be part of that organization. Now, I'll go and take part in full time. (Woman living with HIV, September 2008)

Finally, it should be noted that some of the people living with HIV also reported a simpler motive for joining FJN+. Some interviewees said they had come to the organization primarily because their partner had wanted them to do so. It was only men that gave this as a reason for joining FJN+, showing once again the greater tendency of women to seek support appropriate to their condition (see also p.9).

Reasons for not joining

As already mentioned, not all the research participants had joined FJN+. A comparison of the membership of the organization (28 members) with the number of patients seen at the Reproductive Health Clinic of Suva for follow-up due to their HIV status (61 patients in May 2008) (see p.9) indicates in fact that more than half the people living with HIV residing in the capital area were not part of this support group. The women and men interviewed gave several reasons to explain this situation. According to them, it was first and foremost the fear of being seen near the network's office or with HIV positive people who had disclosed their status publicly that prevented people from joining the organization. Many of the members of FJN+ interviewed reported they had shared these concerns at first. The fear of being identified as a person living with HIV was also echoed in what most of the women and men interviewed who were not members of FJN+ said when asked about their personal motives for not joining the organization:

Do you have an idea why some people don't want to become members of FJN+?
'Cos they don't want to be seen by someone who could tell their family about it, eh?
(Man living with HIV, February 2008)

He says maybe because they're afraid. The family doesn't know, the peers don't know and if they start coming to the office... that's a well known place... people might know that they're HIV positive. (Translation, man living with HIV, February 2008)

Because they just don't want anyone to know about their status. (Man living with HIV, February 2008)

It was difficult the first time [to go to FJN+'s office]. I was scared that people could see me. (Man living with HIV, February 2008)

I'll be honest to you. I thought about that. Yeah. I thought of that. I was thinking like that too the first time. I was saying "Man, maybe...." Because [X] is known, eh? "Maybe someone gonna see you with this one, you know? [...] People gonna put two and two together and then they'll just... Even though they don't know, they'll just come to the conclusion that I'm HIV as well." (Woman living with HIV, September 2008)

Another potential reason identified by the interviewees as to why some may not join FJN+ is that the organization encourages its members to disclose their status publicly. As noted previously (p.40), FJN+ supports the public disclosure of HIV positive people both as a way of raising awareness about the virus and preventing new infections and as a means of fostering acceptance of people living with HIV in the population. While very few people interviewed questioned the value of the testimonies of people living with HIV for the prevention of the infection and while all hailed the courage of those who had decided to publicly reveal their HIV seropositivity, some did not want to take on the role of advocate and reported feeling the organization had tried to force the idea onto them. One woman, as the following excerpt indicates, even thought that publicly disclosing

one's HIV status was a prerequisite to becoming a member of FJN+. As she did not yet feel ready to do so, she had decided to seek support only from medical personnel:

Fabienne, in fact... I mean, I don't know. I've just been told there's FJN+ and I don't know exactly what happens there and what it is about, what do they do and all that. All I know is that all those people who are there, they all go out public, they have gone out public. *Some of them, yeah, not all them.* Not all them? *Not all them. Some are not public.* Oh! What I thought was that all those... People that I'd heard about, they have all gone public and I'm not ready yet to go public. *So that's one reason why...* Yeah. (Woman living with HIV, November 2008)

As this last quotation shows, some people living with HIV were also clearly unaware of the aims and services of FJN+.

The research participants also talked of concern about issues of confidentiality which kept HIV positive people away from organizations and support groups. Networks of people living with HIV are not exempt from information leakages and breaches of privacy. Staff, volunteers or fellow members, intentionally or not, may sometimes divulge information that people living with HIV would prefer remain undisclosed. A few of the women and men interviewed complained of personal details and experiences that had been related to people both inside and outside the organization (to medical personnel or the staff of NGOs involved in HIV prevention, for example) and that had led to gossip about them. Some also mentioned specific situations in which the disclosure of personal information about members (for example age, place of origin or first name), in the media or elsewhere, had increased suspicion about these people's HIV status.

Finally, the interviewees mentioned personal stories and conflicts between members of FJN+ as a reason why some people living with HIV might not want to join the group. According to them, the image of both HIV positive people and of the organization had been damaged by internal affairs and anecdotes that had come to the public's attention. For this reason, some people might not want to be associated with the group. It should be kept in mind here that tension, quarrels and animosity are fairly common in social milieus such as community organizations. So too is the development of feelings of friendship or love in these environments. Comments on the personal repute of FJN+ members thus seem to indicate two facts: first, as already suggested (see p.47), that HIV positive people's actions are scrutinized more severely than those of others; second, that as HIV is still regarded as an illness resulting from immorality (see pp.42-43), people living with HIV are expected – both by non-HIV positive people and by their peers – to act according to higher moral standards than everyone else.

Conclusion

The aim of this research was to document the experience of people living with HIV in Fiji and to make their voices heard by the Fijian population. This report, I hope, has made a step in this direction possible by examining different aspects of these people's situation: their experience of learning about their HIV status; the social realities that impact their

contraction of the virus; the way they make sense of their condition and look for health care and treatments; their experience of disclosing their HIV status or, conversely, of keeping it secret; the population's attitudes towards them, including stigma and discrimination; their experience of living with the virus and the biographical disruptions and changes in lifestyles it involves; and their experience of joining organizations for people living with HIV, specifically the Fiji Network for People Living with HIV and AIDS.

By studying the biographies of those affected, this research also aimed to contribute to more effective responses to HIV in Fiji. Therefore, this report concludes with recommendations for better HIV prevention, control and care practices. These recommendations are made bearing in mind the excellent initiatives that already exist in Fiji and the dedicated work of numerous people in the field. They are also made knowing that the social realities which impact the risk of the infection (the *tabu* on talking about sexuality, gender norms of behaviour, women's access to economic resources, domestic violence, etc.) are profoundly entrenched and cannot be changed overnight. I am also conscious that the development of HIV programmes and policies is more often than not a question of funding rather than good will. Nevertheless, it is hoped that these recommendations will be acted upon and that they will help to prevent further infections and to improve the life of those already living with HIV.

Recommendations

- This research has focused on the experience of indigenous Fijians living with HIV. Despite attempts made, I was unsuccessful in recruiting people of Indian descent living with HIV to participate in this study (p.9). It is recommended that research be conducted on the specificity of the experience of Indo-Fijians with HIV and sexually transmitted infections so that socially and culturally appropriate action can be developed for this community.
- More women than men were interviewed for the purpose of this study. This trend in the sample corresponds to the sex distribution of patients in reproductive health clinics, where more women than men – though the latter seem more affected by HIV infection – seek health care appropriate to their condition (p.9). It is recommended that research be conducted into the reasons that lead people living with HIV, and especially men, to desert the health care system. Accordingly, measures should be taken to try to retain them so that they receive good follow-up care after diagnosis.
- This research has shown that very few of the people living with HIV interviewed received their diagnosis following self-initiated testing for the infection (p.10). This was the case although several of them reported having heard rumours concerning their partners' HIV status (p.11). More should be done to sensitize the population to the benefits of HIV testing. Opportunities for voluntary testing should also be increased. Sports competitions and festivals have proved to be

good ways of encouraging testing for the infection on a sporadic basis. However, more permanent initiatives are needed. The systematic offering of HIV testing to women in the antenatal care setting in Fiji has become one of the most important sources of testing for the infection in the country and it might be appropriate to extend it to these women's male partners. Offering HIV testing on a systematic basis in other medical services could also be envisaged.

- It has been noted that more than one third of the people living with HIV who took part in this research received their diagnosis after they had experienced HIV-related symptoms. This was particularly the case for the men, half of whom had learned of their HIV status because of episodes of illness (p.10). Late diagnosis is a cause for concern and strategies to prevent it should be developed. Information on the symptoms of HIV-associated diseases and infections should first be part of any awareness activity on the virus so that people are able to identify potential symptoms in their partners and themselves and, thus, avoid late presentation. All medical personnel should be trained in the clinical manifestations of HIV so as to be capable of recognizing possible symptoms in patients and avoid delayed diagnosis and treatment. A partnership with Fijian medicine specialists (*vuniwai vakaviti*) should also be envisaged. As this study has shown, Fijian medicines (*wainimate vakaviti*) were the first means sought by people living with HIV who had experienced periods of illness before diagnosis (p.29). In many cases, HIV-related symptoms were mistaken for signs of *kalou ni draki* (p.24). Fijian medicine specialists trained in HIV-related symptoms could be prepared to refer patients suspected to be living with HIV to HIV specialists.
- Information delivered during awareness campaigns should be clear, accurate and complete. Without minimizing the risk of HIV contraction associated with unprotected sex, people should be told that having sex once with a person living with HIV does not *necessarily* result in contraction of the virus. Some of the interviewees reported they had stayed with someone they suspected was HIV positive because they had had sex once and thought they had inevitably contracted the virus. Similarly, one serodiscordant couple had stopped using condoms after having failed to use one on a night the man had drunk a lot of alcohol. As they were sure the “damage” had already been done, they thought it was no longer worth taking preventive measures. The population should also be made aware of the existence of post-exposure prophylaxis that reduces the likelihood of HIV infection after potential exposure.
- More than one third of the people living with HIV interviewed for the purpose of this study were seamen or the sexual partners of men working at sea when they contracted HIV (pp.17-18). This shows the importance of making particular awareness-raising efforts in the fishing and maritime transport industry.
- The biographies of people living with HIV have shown that nightclubs had been a dating place for many of them and that several women and men had had sex, and contracted HIV, while under the influence of alcohol (pp.15-17). Considering

their place in the dating and courting landscape, nightclubs should become “hubs” of HIV awareness and prevention. Partnerships with bars and nightclubs should be developed so as to make information materials and condoms accessible at all times. With the owners’ support, posters containing HIV prevention messages could be installed in toilet cubicles. Training nightclub’ staff to become HIV educators should also be considered.

- The promotion of condoms as an effective means to prevent unwanted pregnancies, sexually transmitted infections and HIV needs to be vigorously stepped up. In the course of this study, people living with HIV mentioned several reasons as to why they or people known to them either seldom or not systematically used condoms (pp.22-23). It should be added that the Christian churches in Fiji have been quite vocal in their opposition to condom use for prevention purposes and that public health messages have been rather cautious in their promotion of this means of protection. In the light of the evidences showing that religious and cultural norms are not successful in protecting people from HIV in Fiji, it is recommended that the Ministry of Health take the lead and adopt a pragmatic and humanistic approach to the infection by promoting condoms as an appropriate and efficient way to prevent HIV acquisition and transmission.
- Research should be conducted on the way HIV positive people are treated within the health care system. As noted in this report, the study participants were satisfied with the health care and follow-up received at the Reproductive Health Clinics of Suva, Lautoka and Labasa. However, their experience with other medical centres and hospitals did not seem as positive, many people reporting having encountered stigma and discrimination (p.27). Breaches of confidentiality on the part of medical personnel are also of great concern (pp.34-35). Though the *HIV/AIDS Decree 2011* now makes unauthorized disclosure of HIV status by people in the course of their duties an offence (p.35), research into this issue is a necessity. Participatory action research in which cases of breaches of confidentiality are documented and people living with HIV intervene to sensitize (through the use of sketches, drama, dance or any other means) medical personnel to the impact breaches of confidentiality have on their lives should be promoted and implemented.
- As this study has shown, many people living with HIV resort to Fijian medicines (*wainimate vakaviti*) for preventive purposes or to treat minor symptoms and illnesses (pp.29-30). Similarly, some of them are prepared to try local treatments that claim to be capable of curing HIV and AIDS (*wai ni AIDS*) (p.30). Research on the effects, *both positive and negative*, of these treatments should be conducted so as to allow people living with HIV to make informed decisions about their health. In particular, investigations into potential interactions with ARV treatments should be carried out.

- This research has shown that women and men living with HIV in Fiji commonly look to God for support in their pursuit of well-being and health. Though the majority of the people interviewed said they hoped to be healed through faith and prayer, some also revealed that they had sought the help of churches which practice healing through the imposition of hands or other methods (pp.31-32). It is reported that some of these churches recommend people living with HIV to stop taking ARVs. Further study into this subject is needed. It is also recommended that Christian churches, and particularly the “new” denominations to which people living with HIV frequently convert after diagnosis (pp.55-56), be sensitized on the biology of HIV and on the rationale of antiretroviral therapy.
- The narratives of women and men collected for this study attest to the fundamental role of antiretroviral therapy in the quality of life of HIV positive people. Not only do ARV treatments make it possible to control the quantity of the virus in their body and, consequently, to preserve their immune system, but they also contribute to their self-image and esteem by allowing them to maintain a normal weight and physical appearance (pp.27-28). This normal physical appearance, in turn, seems associated with an increased likelihood of social acceptance and support (p.45). These benefits militate in favour of more efforts towards universal access to HIV treatment in Fiji.
- Professional psychosocial support should be offered to any person who receives an HIV diagnosis. The *HIV/AIDS Decree 2011* already provides for post-test counselling to be offered to anyone who tests positive for HIV (section 27 (3)). However, counselling should not be a one-time event nor should it consist only in the transmission of information about the infection. As this research has shown, several people living with HIV reported having been through periods of sorrow and depression and having had suicidal thoughts after learning about their HIV status (p.11). Some also revealed they had experienced conjugal and family crises, which, in turn, had made adherence to ARV therapy difficult (p.28). Many of the women and men interviewed had not been able to disclose their HIV status to their partners or had contracted the virus after someone had failed to do so (pp.37-38). Disclosure of HIV status to people close to them was also mentioned by all the interviewees as something they had been profoundly anxious about. Professional psychosocial support on a regular basis following diagnosis would clearly help people living with HIV to come to terms with their serologic status and deal with the issues associated with their new condition.⁶⁷
- As this research has shown, an HIV diagnosis involves many more people than just the individuals themselves. In the indigenous Fijian community, the shame said to be associated with the infection is borne not only by the person living with HIV but also by their family and community, that are thought to be accountable for their members’ actions (pp.45-47). Neglect and rejection of people living with HIV sometimes also affect the people close to them. It is recommended that

⁶⁷ For further evidence of the importance of counselling services for people living with HIV see PIAF (2009; 2011).

professional psychosocial support be offered to family members and the partners of people living with HIV. Extending care services to those close to HIV positive people could help these individuals accept their family member's or partner's condition and facilitate HIV positive people's relationship with them. This could, in turn, attenuate the reproach and criticism commonly meted out to people living with HIV by family members and decrease their experiences of neglect and rejection.

- More initiatives should be developed in order to make the voices of people living with HIV heard by the Fijian population and deconstruct the discourses that portray them as “malevolent”, “dangerous” and “immoral” people (pp.40-43). The booklet of 16 life stories of HIV positive people published by FJN+ in 2008 has made important contributions to this aim (Fiji Network for People Living with HIV and AIDS, 2008). So too have the *Positive Lives Series*' videos (*Maire, Peati, Irene, Maiinga* and *Faces and Voices of Pacific HIV*) produced by the Pacific Islands AIDS Foundation. Drama, which has been used elsewhere in the Pacific – for example in New Caledonia with the production of a play based on the collection of testimonies of people living with HIV compiled in the booklet “*Sida, je vis... j'écris*” (AIDS, I live... I write) (Association Solidarité SIDA-NC, 2002) – could be envisaged as an effective way to increase awareness about the lives and experiences of HIV positive people.
- It is recommended that funding for organizations by and for people living with HIV in Fiji be maintained or increased. As this research has shown, organizations or networks of people living with HIV, such as FJN+, play a crucial role in the life of those living with the virus. They do so by giving them the opportunity to be among themselves and to share information and personal experiences, by allowing them to learn about their health, by offering them jobs and the possibility to develop employment-related skills and by providing them with financial support in times of extraordinary need (pp.57-59). Organizations for people living with HIV are clearly a much needed supplement to government and family support.
- Finally, people living with HIV should be given a more central role in the planning and delivery of HIV education, prevention and care services in Fiji. The different elements examined in this report attest to their first-hand experience of the infection and to their expertise for the development of appropriate responses to HIV in Fiji.

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ⁱ As almost three years have passed since I completed fieldwork data collection for this study, I feel the need to mention the reasons which have led to the delay in the completion of this report. In-depth interview is a research method that presents many advantages. However, demanding tasks are linked to it. Transcribing and analysing the 44 interviews conducted with people living with HIV as well as other research material without help or support has been time-consuming. Writing an extensive research report in English, which is not my first language, has also been a challenge, albeit a very good experience. Unfortunately, I have not been able to devote myself entirely to the preparation of this report. The doctoral scholarship which had permitted me to collect data in Fiji having come to an end, I have had to find work to earn my living. Other responsibilities, particularly my collaboration in a participatory action research on HIV with commercial street sex workers who inject drugs in Quebec City, Canada, have also diverted me from the task. Nevertheless, I believe that the findings of this study are still topical and that the voices of the people I interviewed deserve to be heard.

ⁱⁱ Attempts at getting feedback from people living with HIV and from collaborators in this study met with little success. At the time of submitting this report to the Fiji Health Research Committee, only four people have formulated comments. All were succinct but very positive. Examples of feedback received include: "Great report. Well written. Just competent", "You capture some of the things that may have been missed out by other reports", "I think you did a great job [...] even with the use of the Fijian words." Only one person, a representative from an organization by and for people living with HIV, commented on the consultation process used in the preparation of this report. This person said it was only the second research report, among the many that have been done about HIV, on which their opinions had been sought before release. They thought it was the way to proceed.