

**“Treatment is My Life Now”:  
Experiences of treatments among People  
Living with HIV in the Pacific Islands**



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Printed in the Fiji.

Cover photograph: K. McMillan 2013

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ISBN: 978-982-9157-01-0.

Layout and design by Joey Tau

Gorman, H. (2013). *“Treatment is My Life Now”: Experiences of treatments among people living with HIV in the Pacific Islands*. Cook Islands National HIV, STI & TB Committee, Rarotonga.

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**This report is dedicated to**

**Eti and Te**

**our peer researchers who passed away and were not able to  
complete this journey with us.**

## Acknowledgements

This study was born of the vision of Maire Bopp, who played a pivotal role in ensuring that antiretroviral therapy became a key part of the Pacific HIV response. She also wanted to know how people living with HIV were doing on treatment and encouraged this study to be completed.

The research team would like to express sincere gratitude to the numerous individuals and organisations who have supported this study. The funds that have enabled this study to be completed have been provided by the Pacific Islands HIV and STI Response Fund 2009-13. The majority of activities for this project were completed under the oversight of the Pacific Islands AIDS Foundation (PIAF), and in April 2013 the Cook Islands National HIV, STI & TB Committee (CI NHSTC) generously agreed to provide oversight to allow this project to be completed.

In Fiji, this study was completed in partnership with the Fiji Network of People Living with HIV (FJN+); we would like to thank their staff and members for their support. We would like to thank many individuals in Fiji who also offered support, including Dr Frances Bingwor, Dr Rachel Devi, Dr Rahena Meinaz, Dr Atinesh Prakash, Dr Pablo Romakin, Asivorosi Tora and Mere Delai of the Fiji Ministry of Health; Dr Alan Garvez, Dr Nin Sophaganine Ali of the Secretariat of the Pacific Community; Dr Jason Mitchell of the Oceania Society for Sexual Health and HIV Medicine; Alita Waqabaca and Mereoni Radio of Empower Pacific; Laitia Tamata, Temo Sasau, Frances Namoumou and Titiana Wara; Dr Kamal Kishore and Sharan Ram of the Fiji National University. Thanks are also extended to Fiji National University for providing a training venue. In Guam, we would like to thank Cherisse Santiago, Bernadette Schumann and Jessica Cate of the Department of Public Health and Social Services. In Kiribati, we would like to thank Dr Kenneth Tabutoa, Dr Teatoa Tiira, Baurina Kaburoro and Mareta Tito of the Kiribati Ministry of Health, and Mauea Wilson. In Samoa, we would like to sincerely thank Palanitina Tupuimatagi Toelupe of the Ministry of Health; Andrew Peteru of UNESCO, and Treena Atoa. In Solomon Islands, we offer gratitude to Dr Nemias Bainivalu and the staff of the HIV and STI Unit, Joyce Gumi and Marilyn Iro of the Ministry of Health. In the Cook Islands, we wish to thank Frances Topa-Fariu and Polly Tongia of Cook Islands National HIV, STI & TB Committee. Thanks are also extended to Emi Chutaro, Mary Enciso and Semenson Ephel of the Grant Management Unit, Secretariat of the Pacific Community, North Pacific office. Thank you also to Vere Turagaiviu and Rusiate Mataika for their translation and transcription services.

Appreciation is also extended to the following organisations for their general support: Secretariat of the Pacific Community; International HIV Research Group, University of New South Wales, Australia.

A number of individuals also generously reviewed the report and provided feedback, for this thanks are extended to Fabienne Labbé, Dr Kamal Kishore, Lawrence Hammar, Leslie Butt, Dr Nin Sophagaine Ali, Heather Worth and Temo Sasau.

Last and most importantly profound thanks are extended to the people living with HIV who generously and courageously shared their stories and made this study possible.

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## Executive Summary

Antiretroviral therapy (ART) has prolonged and saved the lives of millions of HIV-positive people. It has transformed the condition from being fatal to a chronic manageable illness. With the availability of ART, considerable challenges have emerged, including the growth of health infrastructures in developing countries and the challenge of ensuring that people living with HIV (PLHIV) adhere to their treatment. As well, there is the challenge of dealing with the paradoxical or inconsistent effects of treatment. These paradoxical effects include the way in which: in many developing countries ART increases hunger within a context of poverty and food insecurity; ART prolongs life but also produces negative side effects; and ART is available yet many people who are HIV-positive remain socially marginalised. The provision of ART is only part of the treatment, care and support required to sustain the lives of HIV-positive people. Treatment uptake and adherence is also affected by social factors such as poverty and stigma.

In the Pacific, ART became available to PLHIV in the early-2000s and several years earlier for those living in Pacific Island territories. Within the Pacific Island countries and territories (excluding Papua New Guinea) there are a total 1,736 reported HIV cases, an estimated 692 HIV-positive people with 429 people on ART. There has been no research on the experiences of treatments among PLHIV in the Pacific Islands outside of Papua New Guinea. This study aims to document and describe the treatment experiences of HIV-positive people from Fiji, Guam, Kiribati, Samoa and Solomon Islands. This study has also aimed to meaningfully involve and collaborate with PLHIV as peer researchers in carrying out this study.

This report summarises the results of qualitative research that was conducted to better understand reasons for initiating, continuing and ceasing treatment among PLHIV in the Pacific Islands. In total, 49 PLHIV were interviewed, including 23 HIV-positive people in Fiji, 11 HIV-positive people in Guam, 2 HIV-positive people in Kiribati, 5 HIV-positive people in Samoa and 8 HIV-positive people in Solomon Islands. A training workshop was held in November 2011 where the team of 10 PLHIV peer researchers, 2 training support facilitators and the team leader worked in collaboration to develop the method for the study. In-depth interviews were selected as the research method to gain a detailed understanding of the participants' treatment experiences. Research participants were recruited through PLHIV support networks where they exist and through health clinics that provide treatment to PLHIV. When possible, the participants had the choice of being interviewed by a peer researcher or the team leader. When given the choice, approximately half of the participants opted to be interviewed by their peers. Research ethics approval was granted in each country either through the national research ethics committee or the Ministry of Health.

## Results

The participants included people who had been diagnosed between 1989 and 2012; the median year of diagnosis was 2005. The participants' ages ranged from 19 to 58 years old, 30 were female and 19 were male. Of the 49 participants 27 people were connected to a network of PLHIV. At the time of the interview 40 respondents were on ART, and over half of these had ceased treatment at least once, 7 people had ceased treatment, 1 was refusing treatment and 1 was not yet in need of treatment.

### Diagnosis and Medications

- Participants who were diagnosed before the mid-2000s (when ART was not available) received limited information about HIV and treatment. Those who were diagnosed more recently were generally told about treatment upon diagnosis. The main sources of information about HIV treatment were health workers and to a lesser extent non-government organisations (NGO) and the internet.
- Most people said that ART had an immensely positive impact on their lives because it increased their strength and helped them to regain their health. Improvements in their health were noted to enable the participants to resume their daily activities and return to work.
- Some respondents also experienced side effects and felt that they should have received more information about these effects that were sometimes temporary but sometimes ongoing. The participants said the side effects included: anaemia, diarrhoea, dizziness, loss of balance, sleepiness, swelling, body rash, itchiness, ach-



- ing bones and joints, lipodystrophy (uneven distribution of body fat), increased hunger, severe nausea and vomiting, short-term memory loss, forgetfulness, feeling “stoned,” and having vivid dreams or nightmares.
- Some of the respondents who had not disclosed their HIV status to their families hid or lied about their HIV medications. For those who were not open about their HIV status, HIV medications helped to improve their physical appearance but were also a concern as they were also evidence of being HIV-positive.

### **Meanings and Attitudes to Treatment**

- In describing the meaning of treatment, respondents said that it prolonged life and gave them hope. It also meant that they could resume their normal daily activities and felt “normal”. When asked what was good about treatment, many of the participants noted the improvement to their health, the positive physical effects and the availability of health services.
- When asked what was bad about treatment, a number of participants stated that they did not feel that there was anything bad about treatment but others mentioned side effects, issues with accessing health services and concerns with adherence.
- Ambivalence towards treatment was expressed in a number of cases as many respondents felt uncertain and noted both the positive and negative effects of ART. For some people there were more negative aspects, yet these were downplayed by health workers even though they had a profound impact on their lives.
- Attitudes to ART focused on the idea that ART was necessary to survive, and many participants expressed gratitude for having access to this life-saving medication.
- Respondents were hesitant to discuss the issue of treatment and sex. Some people felt that they no longer wanted to have a sex life, while others were confused, and a few had reconciled being HIV-positive and having a sex life. In a few cases, women were told by health workers that they should not have children and were not informed of the use of treatment to prevent mother-to-child transmission.
- Some participants conveyed a sense of hope but at the same time worried about the future of treatment in the Pacific. Their concerns were mainly about whether the costs of ART would continue to be covered by international donors and governments in the future.
- More than half of the respondents had views about the links between their religious faith and treatment. Some of them felt that their faith had increased after being diagnosed and receiving treatment. Some also viewed faith and treatment as being complementary in supporting them to live.

### **Health Services**

- Barriers to accessing health services included: having to travel long distances; clinics being closed or unattended; not having money to pay the bus fare; long waiting times; and being afraid to access HIV-related health services.
- Counselling was generally described as being offered to participants who were diagnosed after the mid-2000s. It was noted as being important in helping to deal with being diagnosed HIV-positive and understanding the importance of treatment.
- Issues with ART being out of stock were noted by participants from all of the countries. CD4 and viral load testing were noted to have become more widely available, but many participants did not understand the test results and some mentioned delays in receiving results and infrequent testing.
- Health workers’ attitudes towards the participants were in some cases described as unsympathetic and strict, sometimes that was thought to encourage treatment adherence but in other cases it discouraged people. Some respondents felt that they had faced stigmatisation and discrimination from health workers which was often subtle and took the form of being unsympathetic or unnecessarily mean, and there were a few cases where discrimination was described as overt.
- More than half of the participants did not feel that they could trust health workers with their personal information. Breaches of confidentiality occurred through gossiping with other health workers or other patients. There were also instances noted that had generally taken place several years ago where health workers disclosed the patient’s status to a member of their family or village community without the patients permission.

- Many participants also described health workers as being supportive like family and they noted the great lengths they went to in order to support their patients and ensure they receive their treatment.

### **ART Adherence**

- Starting treatment is an important decision and a lifetime commitment. A few participants were reluctant to take treatment. But most described how taking medication twice daily had become a habit that was associated with meals or prayers and supported by alarm clocks and people reminding them.
- A lack of money, distance to health centres, bad weather, limited understanding of treatment and difficulties in dealing with side effects were mentioned as reasons for stopping ART. Life events such as the death of a family member or learning of a partner's infidelity also acted as a trigger to cease treatment.
- Support from their immediate family, partners and children by reminding PLHIV to take their medication and providing food, comfort and emotional support greatly enabled people to adhere to their treatment. For many participants this demonstrated unconditional love and support. Although some participants appeared to be supported, for example by being reminded to take their medication, in some cases this support was limited and consequently led them to lose hope and reduced their adherence to treatment.

### **Alternative Therapies**

- Respondents described using alternative therapies in the hope of being healed or cured because they felt that a cure would enable them to live a normal life again. More than half of the participants had tried alternative therapies, in a couple of cases before needing ART, in other cases they used it at the same time as taking ART and about half of the participants who used alternative therapies used them instead of ART. Some people tried using alternative therapies on more than one occasion and each time ceased ART.
- Participants in many cases used alternative therapies because their family wanted them to or because people approached them and promised a cure. But many people interviewed refused them because they wanted to follow the doctor's advice, because they believed in biomedicine and because they thought these therapies could be harmful to their health.
- Herbal therapies, faith healing and traditional medicine were used as alternative therapies in different ways. These three types of alternative therapies were often used in combination. Some people described using traditional medicine to treat skin rashes or diarrhoea while continuing ART. Others stated how they ceased ART and focused solely on a herbal therapy that had elements of faith healing.
- Many participants who had tried alternative therapies, particularly those who stopped ART, noted that these therapies ended up causing health problems for them. None of them felt that they had been cured and they cautioned other PLHIV against using them.

## Recommendations

- Decrease fears around testing by providing more information that addresses fears of dying so that people understand that medication is available to treat HIV, but it is a lifetime commitment that should not be taken lightly. This approach should be employed by health promotion units and NGOs that provide information about HIV. Media should also use this approach and should refrain from using scare tactics and stigmatising language.
- Continue to educate PLHIV about HIV treatment to understand the benefits of ART, how to cope with side effects, the purpose of CD4 and viral load testing and support available to them. Information about treatments should be provided in simple terms and when possible communicated in local languages. Health workers can play a key role in this education, positive support networks and other NGOs that support PLHIV should also play a role in improving knowledge and understanding of treatment by conducting workshops and providing accessible information.
- Continue to train and build the capacities of Pacific health workers on the importance of offering confidential, non-judgemental care and support to PLHIV. Encourage health workers to continue to warn clients about alternative therapies and promises of cures, and to promote ART as the only proven way of reducing viral load.
- Improve access to ART and CD4 and viral load testing. Increase the accessibility of ART by expanding the dispensing of ART beyond urban health centres. Increase the range of ART available to Pacific PLHIV. Continue to increase the efficiency of CD4 and viral load testing services for PLHIV.
- Ensure that families of PLHIV are educated about how HIV is and is not transmitted, the role and importance of ART for PLHIV and the significance of family support in treatment adherence. Health workers have a vital role to play in providing this information, and positive support networks where they exist can also provide this support to PLHIV and their families.
- Fund and support PLHIV network organisations so that they are able to continue to offer support to PLHIV, to the families of PLHIV and educate communities and the general public on the HIV treatments and importance of care and compassion towards PLHIV.
- Ensure that Ministries of Health slowly integrate the cost of ART into health budgets to decrease reliance on funding from international donors which are not likely to be indefinitely available.
- Future research should be conducted on HIV treatment adherence more broadly to explore experiences of PLHIV, doctor-patient relationships and the views of health workers as well as the constraints that they work under.

# 1. Introduction

*Treatment means that I can live a healthy life and I was thinking before that I'm gonna die probably next year or something. I guess I can live longer life now, because of this treatment that is being provided to us.*

(Vincent from Fiji, aged 26) <sup>1</sup>

Globally, antiretroviral therapy (ART) has dramatically extended and saved the lives of millions of HIV-positive people (Hirsch, Parker & Aggleton, 2007). ART, the medication that is used to treat HIV, has meant that HIV is no longer a death sentence for those who have access to treatment. ART has helped to transform HIV from being fatal to being a chronic, manageable condition.

With the roll-out of HIV treatment programs in developing countries, new challenges have emerged, including the need to develop new health infrastructures to support HIV treatment programs. There is also the challenge of ensuring that people adhere to treatment. In addition, there is the challenge of dealing with the paradoxical or inconsistent effects of treatment. One of these paradoxical effects is that in many developing countries ART increases hunger within a context of poverty and food insecurity (Kalafonos, 2010). ART prolongs life but also produces negative side effects, and viewing the negative physical effects of ART as “side effects” downplays the impact that these effects have on patients’ lives. This perspective also tends to criticise and blame some patients as “defaulters” or treatment “failures” (Hammar, Gucake & Strobel, 2013). A further paradoxical effect is that although ART is available many people who are HIV-positive remain socially and economically marginalised (Biehl, 2007; Davis & Squire, 2010; Nguyen, 2010).

ART is only part of the treatment, care and support that is required to enable people living with HIV (PLHIV) to live long and healthy lives. In other words, HIV medications are only supplementary to the full treatment of the condition. “Healing, after all, is a multifaceted concept, and ‘healing’ is no more synonymous with ‘treatment’ than ‘treatment’ is with ‘drugs.’” (Biehl, 2007, p. 386). ART is a biomedical treatment that is taken by people who are HIV-positive and the social context of people’s lives affects treatment uptake and adherence (Biehl, 2007; Butt et al.,

2010; Hammar, 2010; Kalafonos, 2010; Kelly et al., 2009; Labbé, 2011; Mukherjee et al., 2006; Nguyen, 2010).

Poverty, stigma, access to health services and family obligations are social factors that influence initiation and adherence to ART. As Hirsch, Parker and Aggleton (2007) note in discussing the social aspects of ART, there are important social research questions that need to be examined at the individual, community and societal levels. At the individual level they note the importance of exploring “the experience of being HIV-positive and, more conceptually, people’s life projects and therapeutic itineraries” (p. S2). Understanding the social experience of HIV treatments can help to inform clinical practice and HIV policy and support programs for PLHIV.

Little is known about the social experience of treatment among PLHIV in the Pacific Islands outside of Papua New Guinea (PNG). Research has been conducted on experiences of HIV-positive people in PNG that focuses on the social experience of ART (Kelly et al., 2009) and the issue of food insecurity and increased hunger among HIV-positive Papua New Guineans on treatment which highlights how a lack of food was noted to affect treatment adherence, particularly among those living in the urban capital, Port Moresby (Kelly et al., 2013). A qualitative study on HIV, pregnancy and parenthood by Kelly et al., (2013) explores how most of the HIV-positive women and men interviewed noted the positive impacts of treatment on their lives, including being healthy and enabling them to have an HIV-negative baby and that almost all participants mentioned the undesirable side effects of ART.

Research focused on the experiences of PLHIV in Fiji has explored treatment as an aspect of living with HIV. The insightful work of Labbé (2011) is based upon fieldwork in Fiji and semi-structured interviews among 28 PLHIV in Fiji and notes the benefits and challenges of ART as a biomedical aspect of living with HIV. This study describes how PLHIV in Fiji tend to first turn to Fijian medicines to regain their health, some HIV-positive Fijians use local treatments in hopes of being cured and many also believe in the healing power of God (Labbé, 2011). A study of Fijian self-assessment of transmission and risks of HIV notes that some health

<sup>1</sup> Pseudonyms are used throughout this report to protect the identities of the participants. In some cases identifying factors have also been altered or omitted.

workers believe that HIV infection can be cured through faith and prayer (Hammar et. al., 2011; Hammar et. al., 2013). A study conducted by PIAF (2011) based on 25 in-depth interviews with HIV-positive women in Fiji and PNG also briefly notes the benefits and challenges of ART, including issues with adherence, use of traditional medicines and access to health services. Yet, no research has yet been conducted specifically focused on experiences of HIV treatments in the Pacific Islands. This study aims to explore people's experiences of HIV treatments in five Pacific Island Countries and includes people on ART, people refusing ART, people who have ceased treatment and people with different adherence levels.

ART became available in most Pacific Island countries starting from the early-2000s. In Pacific Island territories it has been available since the mid-1990s. Funds to cover the cost of the provision of ART in most of the Pacific Island countries have mainly been provided by international donor organizations particularly the Global Fund to Fight HIV, Tuberculosis and Malaria.<sup>2</sup> According to the Secretariat of the Pacific Community (SPC), from July 2013 to December 2014 funds to cover the costs of ART will be provided by the Public Health Division of SPC in partnership with the Pacific Islands HIV and STI Response Fund (SPC, 2013a).

## **Aims**

Understanding the treatment experiences of Pacific PLHIV can help to provide a basis for improving treatment services and supporting PLHIV to adhere to their treatments. This report is based on a project titled *Experiences of Treatment among PLHIV in the Pacific Islands: A Qualitative Participatory Study*. This project has two key aims. First, it aims to understand and document the experiences of PLHIV in Fiji, Guam, Kiribati, Samoa and Solomon Islands, through an identification of factors affecting uptake, continuance and cessation of treatment. Second, this project aims to meaningfully involve PLHIV in HIV social research by training them and having them collaborate in designing, conducting and presenting the research results. This study was funded by the Pacific Islands HIV and STI Response Fund.

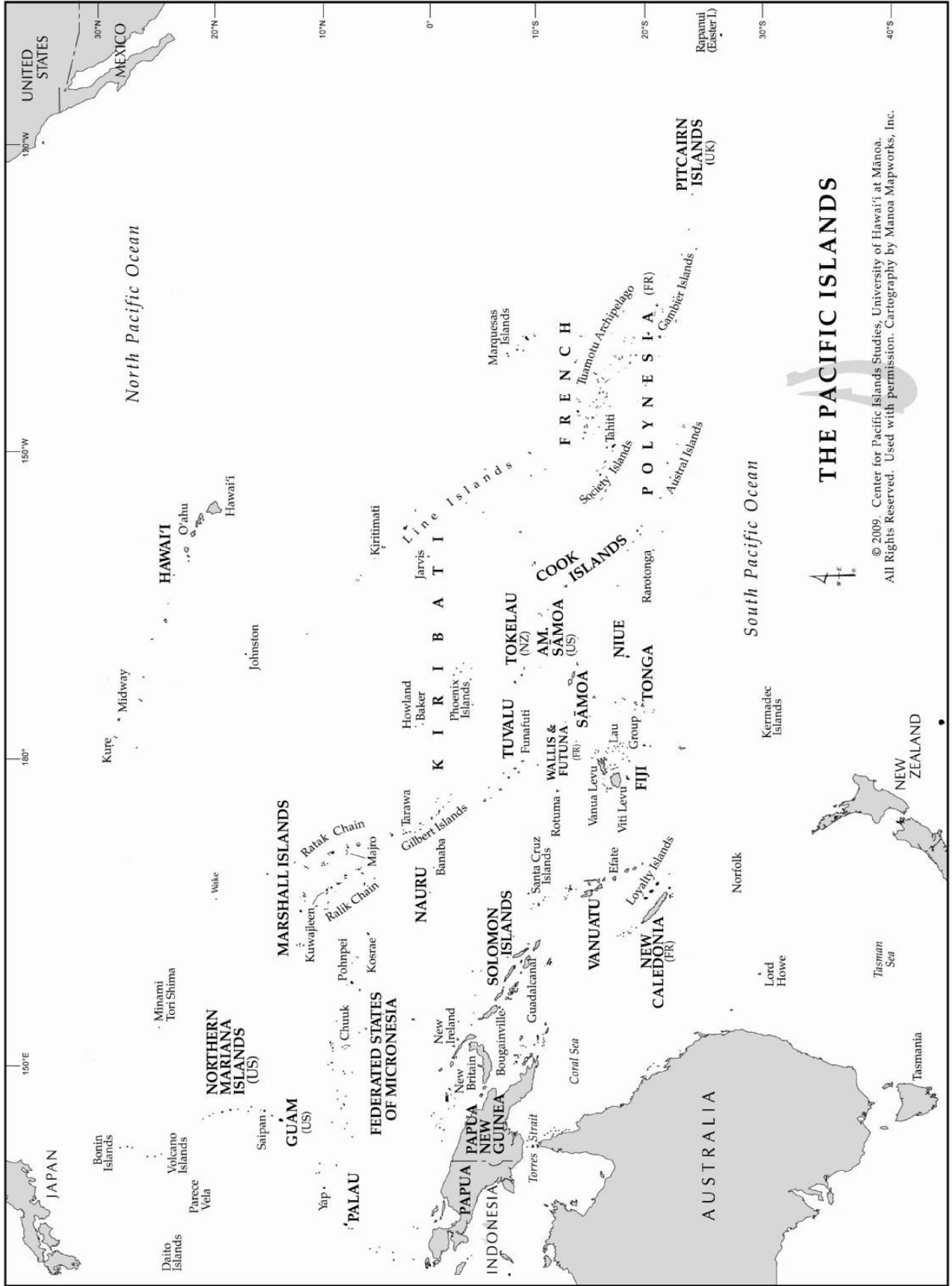
This report documents the findings of a qualitative study conducted by the research team of 8 PLHIV peer

researchers and a team leader in five countries which focused on understanding experiences of treatment among PLHIV through in-depth interviews. A total of 49 interviews took place. This report demonstrates the immensely positive impact of ART but also describes the challenges in adhering to ART as depicted by the participants when they shared their treatment stories. The challenges include the distances required to travel to clinics, not having money for bus fares or food, suffering from side effects and especially not receiving support to enable PLHIV to deal with these issues. It is hoped that understanding the realities of treatment for PLHIV will help to improve treatment and support services in the future. This report is aimed at policy makers, civil society, health workers and organisations working with PLHIV and in the area of HIV prevention and sexual health. It is also aimed at PLHIV as a way of helping to decrease the isolation they may feel upon diagnosis, initiating treatment or struggling to adhere to treatment – understanding the experiences of others may help them to know that they are not alone.

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<sup>2</sup> Fiji was not part of the funding application for Global Fund round 7 and hence the Fiji government has been paying for ART for PLHIV who are eligible in Fiji.

# Map of the Pacific Islands



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## 2. Methodology

The methodology employed for this study has aimed to be participatory and meaningfully involve PLHIV by collaborating with Pacific PLHIV to develop knowledge and understanding of HIV treatments based on the perspectives of PLHIV. Several steps were involved in developing the participatory approach to this study. First, in early 2011 PLHIV from selected Pacific Island countries and territories were invited through the positive networks of PIAF and Fiji Network of People Living with HIV/AIDS (FJN+) to complete an application to become part of the research team. Following the application process, 10 participants from Fiji, Kiribati, Samoa and Solomon Islands participated in an eight-day workshop in Suva, Fiji in October 2011. This workshop was conducted with training support from the International HIV Research Group of the University of New South Wales, Australia. At this workshop the participants learned first about different aspects of HIV treatment and then five days were devoted to introducing the peer researchers to social research and methods. The peer researchers, training support facilitators and team leader then collaboratively mapped out the project by clarifying the aims of the project, deciding upon a method, developing interview themes and identifying and discussing ethical issues. The peer researchers were trained and practised conducting in-depth interviews using the interview guide that had been developed through these discussions and activities. The additional ways in which the peer researchers contributed as members of the research team are discussed in the sections that follow.

### Country Locations

The Pacific Islands include a total of 22 countries and territories. There is considerable variation in terms of culture, language, geography, level of economic development and health service infrastructure between the different countries and territories. There is also variation in terms of the incidence of HIV and other sexually transmitted infections (STI). Of the Pacific Island countries and territories excluding PNG, there are 1,736 reported HIV cases, an estimated 692 PLHIV and 456 on ART (SPC, 2013b). The countries or territories with the highest number of HIV cases include: Fiji with 482 cumulative HIV cases, an estimated 230 PLHIV and 124 on treatment; New Caledonia with 402 cumulative HIV cases, an estimated 188 PLHIV and 156 on ART; French Polynesia with 355 cumulative HIV cases, an estimated

123 PLHIV and 106 on ART; and Guam with 244 cumulative HIV cases, an estimated 64 PLHIV and 23 on ART (SPC, 2013b). The remaining 18 countries and territories have a cumulative number of cases that ranges from 0 to 55. In the remaining countries the number of people on ART ranges from 0 to 9 people (SPC, 2013b).

Fiji, Guam, Kiribati, Samoa and Solomon Islands were selected for several reasons. First, there was a desire to include different countries to get a regional perspective.<sup>3</sup> Second, they were selected in order to include countries with significant and smaller numbers of HIV-positive people including those on treatment. Third, for practical purposes the countries with a very small number of PLHIV were not included; for example those with only one or two HIV-positive people living in the country.

The interviews took place between February and December 2012. In total, 49 PLHIV were interviewed from 5 countries: Fiji, Guam, Kiribati, Samoa and Solomon Islands.



*The research team of peer researchers, training support facilitators and team leader.*

<sup>3</sup> It was also intended that interviews would be conducted in French Polynesia; however, the interviews did not eventuate there.

Table 1. Summary of HIV cases, PLHIV on treatment and interview data by country

Country	Total HIV cases <sup>4</sup>	Total PLHIV	Total on ART <sup>5</sup>	Total interviewed	Interview locations	Comments
Fiji	482	230	121	23	5 interviews took place in Lautoka, 3 in Labasa and 15 in Suva.	Of the 23 participants, 19 were indigenous (iTaukei), 3 were Indo-Fijians and 1 was from another Pacific Island country.
Guam	244	64	23	11	Interviews took place at 2 hospitals on the island of Guam.	Of the 11 participants, 5 were Chamorro <sup>6</sup> , 5 were originally from other Pacific Island countries of Micronesia and 1 was of Asian descent.
Kiribati	55	28	6	2	Two interviews took place in South Tarawa.	Three other potential participants were contacted but refused the invitation to be interviewed. Of the 2 participants both were i-Kiribati.
Samoa	23	13	9	5	4 interviews took place on the island of Upolu, and 1 on the island of Savai'i.	Of the 5 participants, 3 were indigenous Samoans and 2 were originally from another Pacific Island country.
Solomon Islands	19	10	9	8	3 interviews took place in Honiara, and the remaining 5 in 2 provinces.	All 8 participants were indigenous Solomon Islanders.

The statistics from each country provide an idea of the number of HIV-positive people in each country, yet they must be viewed with caution for several reasons. First, there are likely a number of cases of HIV that for various reasons are not recorded in public health recording systems. Second, many people who are diagnosed HIV-positive are lost to follow-up and may pass away and may not be recorded as having died of AIDS. Third, these statistics do not provide any insight into the lives of those who are living with HIV.

### In-depth Interviews

During the research training workshop the research team planned the methodology for this project, the

team agreed that a qualitative approach, using in-depth interviews would be the most appropriate method for learning about the social experience of treatment among PLHIV. In-depth interviews allow the meanings behind people's decisions and experiences of HIV treatments to be explored and better understood (Liamputtong, 2007). The interview guide was developed and piloted by the research team who practised interviewing each other during the research training workshop. The interview guide listed questions around several themes including: family background, history of diagnosis, health services, history of treatment, attitude to treatment and knowledge and information sources.

<sup>4</sup> The data on the total number of HIV cases and total number of PLHIV comes from SPC produced table Summary HIV cases by Pacific Island countries and territories, as of 31st December 2012 (SPC, 2013b, p. 14).

<sup>5</sup> The data on the total number of PLHIV on ART were the total number recorded at the time when fieldwork was conducted in country.

<sup>6</sup> Chamorro refers to indigenous people of the Mariana Islands.



Potential participants were given the choice of being interviewed by a peer researcher or the research team leader (who is not a Pacific Islander). When given the choice, approximately half opted to be interviewed by a peer researcher. In Guam, all interviews were conducted by the team leader as there was no PLHIV peer researcher applicant from there. In Samoa, the trained peer researcher was not available to conduct the interviews hence some interviews were conducted by the team leader and some by a Samoan in the Samoan language.

### **Recruitment**

Participants were recruited through PLHIV support networks where they exist and through health clinics that provide treatment for HIV. Information about the research was shared with potential participants through health workers and through the support network staff. Potential participants were then asked to register their interest in the project. In a few cases, participants were informed of the research and then interviewed shortly after being told of the research. In Fiji and Guam, efforts were made to include participants of different ethnicities, ages, genders as well as those who were not part of PLHIV networks. In Kiribati, Samoa and Solomon Islands due to the limited number of PLHIV, invitations to participate in an interview were extended to all the people who could be contacted. The criteria for participation were that the individual had been diagnosed HIV-positive more than four months ago and were over the age of 18 years old. The participants were provided with a small sum of money as an honorarium and to cover their travel expenses. In all of the countries there were people who refused to be interviewed and potential participants who did not show up for interviews.

### **Procedure**

The study received ethics approval for all five countries in which the research was conducted. In countries where an official ethics review board does not exist approval was granted by the Ministry of Health. In Fiji, approval was granted by both the Fiji National Research Ethics Review Committee and the National Health Research Committee. In Guam, approval was granted by the University of Guam, Committee on Human Research Subjects. In Kiribati, approval was granted by Ministry of Health and Medical Services. In Samoa, approval was granted by the Ministry of Health, Strategic Planning and Policy Division. In Solomon Is-

lands, approval was granted by the National Health Research & Ethics Committee, Solomon Islands Ministry of Health & Medical Services.

### **Data Analysis**

The digitally recorded interviews were transcribed and translated from the local language to English when necessary. The transcripts were manually coded by the research team leader through use of NVivo 7 qualitative data software. The topics generated from the coding of data were then categorised into themes that form the basis of each of the results sections of this report. After the first round of coding was completed a research analysis workshop was held with 6 of the peer researchers to introduce the participants to research analysis. During this workshop the participants each coded one interview which helped to verify the categories and themes of the report.<sup>7</sup> The report was written up by the research team leader and was reviewed, revised and edited.

### **Study Limitations**

Limitations should be considered in reviewing the findings of this study. First, this study does not include the PLHIV who are lost to follow-up. A few of the respondents that took part in this study noted that after being diagnosed HIV-positive they waited months or years before returning to a clinic to receive health services. It was not possible to reach people who had not had contact with support or medical services for a prolonged period. Second, this study does not include people who are only accessing private care or treatment services outside of their country of residence. Third, the regional focus of this report prevented an analysis in relation to local cultural and structural factors and may mask the differences between countries. Last, this study is not representative of all Pacific Island countries and territories but the experiences of the respondents are likely similar to PLHIV from countries and territories that were not included in the study.

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<sup>7</sup> During the workshop the research team discussed and agreed upon the dissemination strategies for this report.

### 3. Results

#### Study Participants

Interviews were conducted with 23 people in Fiji, 11 in Guam, 2 in Kiribati, 5 in Samoa and 8 in Solomon Islands. A total of 30 females and 19 males were interviewed. The ages of the participants ranged from 19 to 58 years old and the average age was 34. The year in which the participants were diagnosed HIV-positive ranged from 1989 to 2012 and the median year of diagnosis was 2005. 40 people were currently on ART, more than half of these had started and ceased treatment at least once, 7 people had been on ART but were currently not taking it and 2 had never been on ART either because they did not yet need it or because they were refusing it. The participants ranged from those who could easily access transport to get to a clinic to those who lived far from health services and, for example, had to hire a private boat to reach health services. When it was possible, efforts were also made to include people of different socio-economic backgrounds including those who were unemployed with no source of income and those who had incomes. Of the 49 participants, 27 were in some way connected to a PLHIV support network either within their country or as part of a Pacific regional PLHIV network. The level of involvement and level of development of these peer support networks varied significantly. FJN+ in Fiji is an established PLHIV network. In Guam and Samoa there are small networks that are slowly developing. In Kiribati and Solomon Islands no peer networks are established but there are individuals who are part of a regional network.

#### 3.1 Diagnosis and Medications

##### Diagnosis and Information about Treatment

Of the countries where participants were interviewed for this study ART generally became available to PLHIV in 2004, except in Guam where treatment was available from the mid-1990s. Before treatment became widely available throughout the Pacific, the information about HIV treatments and HIV in general provided to people who were newly diagnosed HIV-positive was limited and often vague. People who were diagnosed HIV-positive in the 1990s and early 2000s were generally told that there was no cure or treatment available. They were advised to look after themselves, eat healthily, not to drink or smoke and not to lose hope. In some cases these patients were given

antibiotics to take for protection against opportunistic infections. Many were also told to have faith and to serve God. In Guam, treatment was available in the early 1990s but the pill burden and toxicity of ART were very high. As a man from Guam who took HIV treatment in the mid-1990s stated:

*Like I said when I was taking those pills, I was literally almost throwing up because of the amount that I had to take.*  
(Warren from Guam, aged 51)

Participants who were diagnosed more recently stated that they were generally told that ART was a medication that treated HIV by inhibiting viral replication and thus supported their immune system at the time they were diagnosed HIV-positive. They were informed of treatment to reduce their fears about the association of HIV and early death, and in some cases they were advised to start treatment if they were late being diagnosed.

Although many participants who were diagnosed after the mid-2000s received information about treatment when they were diagnosed, a number of them noted that it was difficult to take in the information as they were in a state of shock. As one participant who was recently diagnosed said:

*For me actually at that time I don't want to receive anything about treatment, like I can't receive that information that I was sick. Yeah, I was shocked and I was doubting whether this treatment would .... (work). Cause I had little information about it. The only thing I knew before (about HIV) is oh death will be.*  
(Sarah from Fiji, aged 34)

While another participant who was diagnosed in the early 2000s did not receive any information about medication, even including the antibiotics he was prescribed to treat opportunistic infections. Over a three-year period he was admitted several times to the hospital and he said it was because he did not understand how and why he was to take the medication. He said:

*The only thing I could know is that the doctor told me is that we will all die, and for me not to be afraid and lose hope but I wasn't told anything about the tablets or treatment.... At first when I heard about this disease I was shocked and scared and I wasn't bold enough to go and ask for advice and I don't even know who to ask advice from. Because I didn't know much about this disease and the only thing I knew was AIDS because I didn't know about HIV. Just AIDS and death, that's the only thing I know and I don't know any other information about it, that's why I was scared because I know that since I have HIV the next thing is death.*  
(Josh from Fiji, aged 39)

The quotes above from Sarah and Josh underline the lasting impact of early HIV prevention campaigns that used scare tactics and associated HIV with death. Their reactions convey that HIV remains associated with death and is not widely associated with treatment. Another participant made an important point about current prevention campaigns, this man said:

*The advertisement on the TV, they mostly probably talking about using condoms, that's it. They don't air on TV that there's a treatment for HIV, they should tell people that there is a treatment for HIV, they make people so scared that the first thing a person does if they, you know if they find about HIV is they want to commit suicide. So the media should help the people who are HIV- positive to get the message across.*  
(Vincent from Fiji, aged 26)

A few participants from other countries similarly felt that prevention campaigns should include more information about treatment, especially when they aim to encourage testing for HIV.

Participants said that their main source of information about HIV treatment was from health centres and was provided by doctors, nurses and counsellors at hospitals and clinics. Some of the participants received information from organisations such as the FJN+ and PIAF, either through meetings, workshops or from staff members. Some participants noted that the internet was also a source of information for them.

## Impact of ART

Most of the participants described ART as having an immensely positive impact on their lives. Many participants described how initiating ART meant that they felt stronger and put on weight after having lost a significant amount of weight and being very ill. Many also said they no longer suffered from conditions such as asthma, anaemia and shortness of breath, but many of them also continued to struggle with health issues. As these participants stated:

*It's like I don't wanna live, I just wanna die. Yeah, but when uh, when that time Max [a counsellor] still worked with Public Health. So he always told me "you know you just have to be strong" and he always encouraged me. So he told me to keep on drinking<sup>8</sup> the medicine that will help me and it's true when I start on the medicine, I feel, I feel strong.*  
(Wendy from Guam, aged 34)

*I've got my strength back because of the treatment that I'm taking – because, before I'd lost weight when I first got the sickness, but when I started drinking the tablets, I felt better, the sores on my body cleared up, I no longer have other sicknesses like headaches which I used to get and low energy.*  
(Elizabeth from Samoa, aged 32)

*I was very happy when I was told that there is a medication, I am very happy to take it, in this way I can carry on with life again with my family.... It's good, it is healing me slowly. Sometimes we face common sickness, but now that we have got the pills, we are okay.*  
(Caroline from Kiribati, aged 29)

The physical impact of increased strength and health gained after initiating ART translated into a positive social impact and participants felt they could resume their daily activities and return to work. Many said they felt they no longer looked HIV-positive which often helped to increase their sense of self-esteem.

However, some PLHIV experienced side effects or toxicity associated with ART. Generally the participants stated that they were informed of the potential side effects before initiating ART. However, for some peo-

<sup>8</sup> Participants from several of the countries in this study referred to "drinking" their medicine, which means the same thing as taking their medicine, pills or tablets.

ple the side effects were often more severe than anticipated and some participants felt that they should have received more information about side effects and how to deal with them. The side effects described included: anaemia, diarrhoea, dizziness, loss of balance, feeling sleepy, swelling of the body, body rash with itchiness, aching bones and joints, lipodystrophy (uneven distribution of body fat), increased hunger, severe nausea and vomiting, short-term memory loss, forgetfulness, feeling “stoned”, and having vivid dreams or nightmares. For some participants the side effects were short term and lasted only a few days; for others some of the side effects were ongoing.

Different types of HIV medications cause different side effects so for some participants it came down to choosing between having vivid nightmares or an itchy rash that covered their body. The following quotes illustrate the impact of ART in producing side effects:

*I hate getting fat in all the wrong places.... And, you forget easily and sometimes it's a real, it's a real uh how do you say? It's a real drawback you know, cause you can't remember everything like you used to. Sometimes you like, what's that, what's that and it was really simple but then you just forget it just like that, that's not normal for me I know. It's not surprising for me but I know that's part of the treatment that it's one of the side effects, but I guess if I didn't know that I would be really freaking out.*

(Nicole from Fiji, aged 32)

*The first time I took ARV, they used to say about the side effects. I didn't experience any side effects, like being itchy or diarrhoea. The only thing is that my stomach used to be empty, like it used to make my stomach empty. When I come to the hospital the doctor used to ask me and I always tell her that I always want to eat and the doctor used to tell me that is also one of the side effects.*

(Kylie from Fiji, aged 34)

The side effects described had many different impacts on the participants' lives. For some it meant constant hunger, trouble sleeping, for others it meant undesirable changes in their appearance and for many it meant worry, stress and feeling unsettled.

Some of the participants, particularly those who had not disclosed to their families, said that they took efforts to hide and sometimes had to lie about their HIV medications. The participants told their family members or relatives that the medication was for headaches, diabetes, epilepsy, mental illness or depression. As well as hiding their medications some of them also said they hid that they were going to the health clinic or would lie about their reason for going there. As one man said:

*I always say I am diabetic, they always ask questions like "why you are you always going to Public Health?" I said "No I have to go and check something." They always ask questions and I have to lie. (Henry from Guam, aged 45)*

When asked why they wanted to hide their HIV medications the participants said they felt embarrassed and were ashamed of being HIV-positive and thought that disclosing their status may lead to rejection from their family members. As one participant stated:

*Maybe they will swear at me and they will dislike me or.... Yeah that's one, maybe yeah dislike (me). Yeah, I am afraid they will reject me. (Evan from Fiji, aged 24)*

Participants who had not disclosed their HIV status and feared being rejected by their families went to great lengths to secretly take their medication when no one was around. Sometimes they would miss or be late taking their medication because, as one woman said, she could not “find the right time where you can put your hand inside that big bottle without anyone noticing.”

A couple of participants told how they were unable to continue hiding their HIV medication. For example, one woman whose sister was a nurse described how her sister found her medication and then confronted her and asked if she was HIV-positive. Other participants who hid their medications noted that it was a constant source of worry for them. One woman described the impact of having to lie about her medication all the time and said:

*Like you know when you lie (it's like) you carrying a burden right, it's like you have it all in a backpack like you are carrying it and I feel I get more sick and sick and sick cause I know my mind is still not okay. I'm not free because I lie to that person so I'm going, and I'm carrying it. So, I get, I get boils on my back and I get stressed out and I know I was lying, yeah but now when I disclose my status I feel like I feel good, yeah.*

(Brooke from Fiji, aged 32)



The case study below profiles the narrative of Zach who speaks about the positive effect of ART along with side effects and how he is still not confident to stop hiding his medication.

#### **Zach: A Healthy Life with Serious Side effects**

Zach is a 42-year-old Fijian man who was diagnosed HIV-positive in the mid-1990s. He began taking ART in 2005 but took it only for a few months and had resumed treatment six years later in 2011 after he became ill. He spoke of the positive impact of medication and said, *“What I’m happy about is when I visit the hospital when they tell me that my CD4 has increased and I can witness that while taking treatment I can now do some of the things that I couldn’t do before. Those are some of the things that I was told, my CD4 has increased, my weight increased and I am healthy.”*

Zach also spoke of how being on ART he felt that people in his community no longer seemed afraid of him and would come and speak to him. But he also said of being on ART, *“I feel like I’m high, I can’t even, like I’m flying, yeah. And also I’m hungry and I can’t have that tablet because the food that, you know I was supposed to have it, I don’t have it so it was like I feel, I scared of it, like I’m scared to use it.”*

Zach is scared to use ART, despite the positive effects and is also still coming to terms with not hiding his treatment. He described a recent experience where he had people visiting his home when it was time to take his medicine. *“They just look at the packet but they didn’t really know about the treatment and they asked me “this tablet is protecting you’ and I told them ‘yes it’s just like the Panadol’ then I took it. That was in the afternoon and that was also the first time for me to take my treatment while people are there with me.”*

When asked why he said it was Panadol, he said it was just easier to answer their questions that way.

It was indicated that health services to support HIV diagnosis and initiation of treatment have developed and improved. The impact of ART on people’s lives was described as positive in that it prolonged their lives, supported them to regain strength and helped to change the view that HIV was a death sentence. Yet, there are side effects and some patients feel the need to hide their medications and their use of HIV-related health services.

In sum, inconsistencies emerged with HIV diagnosis and initiation of ART as it supports the immune system but also produces negative effects. Another inconsistency described by the participants was that although ART led to improved health and physical appearance, thus reducing the visible effects of HIV infection, possessing the medication posed a personal risk as it was evidence of being HIV-positive.

## 3.2 Meanings and Attitudes to Treatment

### Meanings of Treatment

The participants were asked what treatment meant to them, and they described the significance, value and consequences of treatment. The most common response was that treatment first and foremost meant prolonged life, improved quality of life and for some people they no longer felt that death was imminent. Treatment also meant being able to resume their normal daily activities and feeling and looking “normal” as opposed to being HIV-positive. Many of the participants made statements like this:

*To me treatment means, treatment is my life that's what treatment is to me. To me treatment is like, yeah it's a part of me now, I can say that it's, it's something that I cannot live without.*  
(Natalie from Fiji, aged 34)

*This treatment, especially the ARV treatment, is important because we have to take it and it's for our lifetime and this treatment can help us to build our immune system. It helps our soldiers to function well and make us strong and so that we can do our things, and we can help our children.*  
(Zoe from Solomon Islands, aged 30)

*Treatment means for me to stay healthy and it reduces the, the HIV in my body so, I can feel strong, healthy and it's very important to take care of myself. I know the medication is very useful for me. I feel that, it's like I'm not HIV-positive but I'm a person like anyone else.*  
(Earl from Kiribati, aged 41)

Treatment was also described by some as accessing health services and medication. As this respondent said:

*What does treatment mean to me, getting the right and proper medication. And anything simple as following up on how you're doing. You can't, to me you can't get treatment unless there is something wrong. So if they don't know if there's anything wrong, how you gonna get treated? You know unless you say something.*  
(Warren from Guam, aged 53)

As Warren notes, treatment also means acknowledging that you are HIV-positive and need medication and

health services. A few participants mentioned that treatment also meant side effects and having to adhere to medication. In sum, for the participants treatment means prolonging life, regaining health and normalcy. Yet, as the participants shared their stories, they elaborated on what treatment means to them and more complex issues emerged.

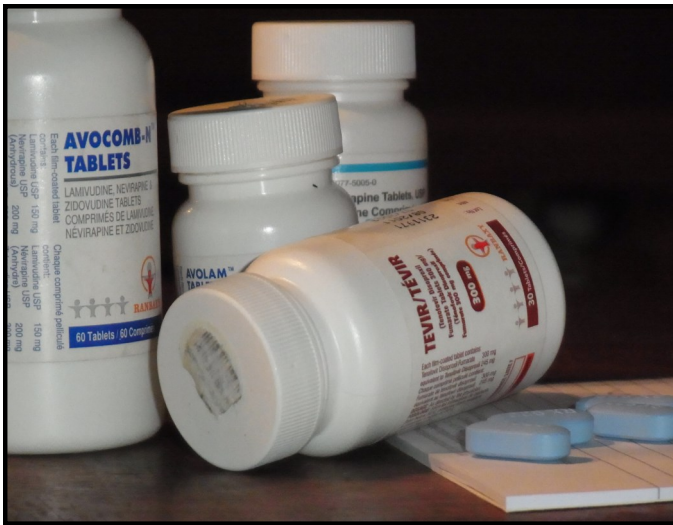
### What was Good about Treatment

The respondents were asked what they felt was good about treatment. Many of them repeated that it prolonged life and improved their health and wellbeing. They also referred to the positive physical effects and the benefits of health services. They said:

*Treatment is very good, it helps us a lot uh when I was not taking drugs I was very weak, I can't walk, I can't do the job and when I'm taking drugs I can do everything. I can go and cut firewood and fishing, everything, it's very good the HIV treatment.*  
(Judy from Fiji, aged 37)

*I always feel happy when they call us, "hey you guys come over here and have your treatment, like a blood test, CD4." I'm happy because and also when I stand on the scale at that time I know my weight. I know my, CD4, I'm happy I know everything what's happen to my body.*  
(Howard from Samoa, aged 36)

Judy says ART enabled her to return to her daily activities, Howard states the reassurance he gets from his health being monitored. When mentioning health services a number of respondents also noted that it was important that they did not have to pay for treatment. A number of participants said that treatment helped them to be able to take care of their children and watch them grow up. Only one person mentioned that it helped to prevent the spread of the virus.



Henry described the waiting times he faced accessing health services; other participants also complained about always having to go for check-ups and for others the main issue was feeling embarrassed to access services. Other participants noted another bad aspect was having to change their drug combinations and worrying about the consequences when they were unable to adhere.

### Ambivalence towards Treatment

Many of the participants expressed ambivalence towards treatment. They stated that they felt treatment had many positive effects but at the same time noted the negative effects, particularly the intense side effects produced by the toxicities of ART. As respondents said:

*Sometimes I thought it might cause something like another sick in my body if I take the treatment, because it's too strong for me and it might cause some damage or if I take the ART, I might overdo it, it might damage some organs in my body that's why I'm a bit scared.... There are no side effects, sometimes only dream at night I got nightmares at night, that's all.... Yeah, it helps me because when I take ART I feel strong and I can do something to earn money.*

(Penelope from Solomon Islands, aged 38)

*I do feel worry about the tablets, that I will continue taking them on the one hand, but then, on the other hand, they might give me other problems, like they might affect different organs of my body and also my eyesight. This is because I'm taking the tablets every day.*

(Mavis from Samoa, aged 38)

### What was Bad about Treatment

When the participants were asked what was bad about treatment, a number said that they did not feel there was anything bad about treatment. Some of these people were perhaps reluctant to complain as they later went on to describe issues they faced in terms of difficulties accessing treatment and side effects. When participants did mention what they felt was bad about treatment they noted first and foremost the side effects, issues accessing health services and concerns with adherence. The statements below convey the participants' general feelings about what is bad about treatment:

*The bad aspects about it, is the side effects. The thing is, you know the memory eh. For a while I'm very good up here with my memory. Yeah I'm very good, I have a short memory now, but before I was very good with my memory. I said "oh, oh evidence side effects of drugs."*

(Helen from Fiji, aged 38)

*The only thing is it takes so long, waiting. If I go there to see the doctor I have to sign in three times, so sign in and wait for them to call. And call again, go back there and then they check how many pound I weight. And check my blood, after that go back again wait and after that that's the time I go and see the doctor. If I go like 9 o'clock in the morning I'll be finished like 5 o'clock. All day and then so why can't they make it fast?*

(Henry from Guam, aged 45)

The case study below profiles the situation of one woman who also experienced ambivalence.

#### **Emily: Rejecting Treatment**

Emily is a 26-year-old woman who lives on an island far from the capital Honiara. She says *“My life at home is very good, my family loves me and I live happily with them, although they heard of my HIV status, however, they seem to love and care about me.”* She first started on treatment when giving birth to her second child. She feels that *“treatment is good because it helps to give strength to my body, (and) stay happily with my children.”* She had not taken her treatment for the past six months because she said it made her weak, but then later repeated that treatment was “good” for her. As the interview came to a close, she wanted to say one more thing, *“Okay, the thing about treatment is, it causes hair loss, weakness, itching, makes me feel tired and nauseous and sometimes I feel that the treatment would easily cause death too. As I take it I feel like committing suicide, killing myself, that’s what I think about the treatment.”*

Emily clearly expressed that for her the negative aspects of treatment outweighed the positive ones, yet still at times she spoke about ART in a positive manner. Like Emily, other participants felt the need to reiterate the benefits that they were told treatment would have on their lives. Yet at the same time, they felt compelled to share the other less commonly discussed effects. Some participants stated that these negative aspects were downplayed by health workers but had a profound effect on their lives.

#### **Attitude to Treatment: Gratitude and Trust**

Attitudes to ART related to the outlook, feelings and mindset of PLHIV. It was felt that ART was important, necessary to survive and supported their will to live. A number of participants also mentioned that being on ART made them want to take care of themselves by eating healthily, exercising, working in their garden, refraining from smoking, consuming alcohol and drinking kava (*yaqona*). Many described how they were grateful for having access to ART, both in general and also towards the governments, Ministries of Health and health workers who made it available and as well as to the scientists who invented it. As these participants said:

*It’s when I found out about this disease that I have HIV, I felt like committing suicide. And I went on the net to look for the treatments and all. So, it says in the internet that there’s treatments available and I was thinking why should I commit suicide, I got life to enjoy. I like to live a happy life and don’t care about my HIV status. So I have this disease but it’s not affecting me that bad. It’s just like I’m feeling normal. It’s just that I have to take the tablet to keep me good, that’s it. I have to combat those negative thoughts.*

(Vincent from Fiji, aged 26)

*My attitude towards treatment is that I trust treatment, I trust ART like nothing else and I’ve been on the other side as well. I left treatment and I went herbal and that just made ART even more important for me, I see, I know the significance of taking ART I’ve experienced it first hand. So yes my attitude towards treatment is like, it’s really strong support for treatment and I wish every other PLHIV will really see it like that as well.*

(Nicole from Fiji, aged 32)

*Firstly as for me I have been living for a long time with my other friends who also have HIV before the treatment exists, I have seen them passed away. That’s why I said that they are not lucky because they didn’t come across the treatment and they went in late for a check at the hospital. I could say that I am lucky that I was treated at the right time and my blood was able to be tested at the hospital and now I have come across the tablet. I am taking the tablet and it has helped me to gain weight again, do my work and look after my family.*

(Josh from Fiji, aged 39)

Gratitude was the strongest sentiment expressed when it came to general attitudes to treatment. Yet, in discussing different aspects of treatment more complex features of their outlook on treatment were revealed.



## Treatment, Sex and Reproduction

The participants were asked whether their treatment decisions had affected their sexual relationships and plans for pregnancy and parenthood. Generally the participants were reluctant to discuss this subject. Some participants did not understand the link between treatment and sex, for example that treatment could have a positive or negative impact on their sex life, or that treatment could support them to have an HIV-negative baby. Some other participants simply preferred not to answer the question. A few people felt that they no longer wanted to have a sex life, while others had come to terms with it. For example these participants said:

*One thing that came to my mind was that I don't want to have a sexual relationship and because my wife passed away I will not have another partner. For I don't want anybody else to get infected with this disease as I know the things that I went through. I was thinking like that but when I came to know more about the tablets it changed my view and I realised that we are all human and we will have feelings for this kind of things in our body.*

(Josh from Fiji, aged 39)

*I know the treatment and would like to have sex but sometimes I do not like to. I guess it's the side effects of the treatment, sometimes I do like have but sometimes I do not.*

(Emily from Solomon Islands, aged 26)

*Being on treatment gives me the courage to have babies since I am on treatment and I could live to support and look after my children. Secondly for me my sexual relationship has been improved again because I feel that my body is in good shape or I am healthy, not like when I wasn't on treatment as I used to feel weak most of the time.*

(Tim from Fiji, aged 35)

Josh indicates how at first he did not want to have a sexual relationship but later like Tim he accepted it. Also, as was the case with many of the participants, condoms were rarely mentioned when it came to discussing sex and relationships.

Other participants similarly spoke of how they wanted to and were having sex, but had a lot of anxiety related to using condoms. One woman spoke about the issue of condom use and related it to having children, she said:

*[F]or me I look at it this way treatment helps me, it buys me time right but all those other things like having a sexual relationship and all that is something that I have to live with and I have to like understand that I will never have a normal sexual relationship. I can't have babies the normal way but treatment has nothing to do with that, maybe because, for me if you're cured then you can have a normal life but when you are on treatment, I know they say there's less risk and all that but .... I don't buy that. I want a normal pregnancy. But we've had our problems with the condoms as well. Burst, blasted condoms.*

(Rachel from Fiji, aged 28)

Rachel feels that using condoms consistently and the possibility of having a baby are complicated for her. Other women were told by health workers that they should not have children because they were HIV-positive, sometimes with the explanation that it would be difficult to take care of more than one child if both parents were HIV-positive. The women who were told they could not have more or any children were distressed by this. This indicates that they were not informed of the effectiveness of ART in greatly reducing mother-to-child transmission of HIV. As one woman said:

*I assumed that the treatment would affect my ovulation process and that made me feel hopeless because I can't have kids anymore.*

(Lily from Solomon Islands, aged 29)

Respondents also did not understand how ART reduces the viral load and thus also greatly reduces the risk of HIV transmission in sexual relationships. Perhaps this was because some health workers were not comfortable discussing sex with their patients, some health workers also may not understand how ART reduces the risk of transmission or as was indicated by some participants some health workers may hold the belief that PLHIV should not be having children or sexual relationships.

## Treatments and the Future

Participants not only portrayed a sense of hope but also some worry about the future and their treatment. The main worry was if international donor and government funding would continue to cover the costs of treatment. As one woman said:

*Future for the treatment, I want it to be free, because I heard the rumours going around that sometime we gonna pay for the treatment. We pray very hard for it to be free because we heard it's expensive. We (PLHIV) can't afford for that but in Fiji we are lucky.*  
(Rosie from Fiji, aged 37)

*Yes, my fear is what if the tablets will finish or there's shortage of medicine or what if we will have to pay for the tablets, then we won't know what to do for the patients in the future or even for us who are now on treatment.*  
(Bella from Fiji, aged 20)

Some participants conveyed a sense of hope and commitment, as indicated by the words of a single mother with three children who said:

*I have, I have committed and made a promise to myself that I will adhere to my treatment ever since what happen the last time when I went off of treatment. I am going to adhere to my treatment for as long as I live because this is a vital importance as it, treatment is my life now and it's just like my children, you know I have linked them together whereby I cannot live without my treatment just like I cannot live without my children, that's what treatment is to me right now.*  
(Natalie from Fiji, aged 34)



Treatment in this sense was seen as vitally important to the future of the participants. Some participants also expressed hope that treatment and health services would improve in the future and that more people would come to know about treatment and that a vaccine or cure would become available.

## Faith and Treatment

More than half of the participants expressed their views about the relationship between their religious faith and treatment. Some of them felt that their faith had increased after they had received treatment. As these participants said:

*Before I never used to be serious about religious rituals but now while taking treatment I can see that I have grown and improved in my religious ritual and I am praying for my life.*  
(Zach from Fiji, aged 42)

*Before ART I was having faith. Well ART increased my faith from before and I feel stronger when I believe it, everyday in my life. Everyday with Jesus is sweeter than the day before. And I think that is one of the main things that carries me.*  
(Sarah from Fiji, aged 34)

As Sarah indicated, faith was an important factor in sustaining her and, as other participants noted, it helped to maintain their sense of hope and helped them to get on with their lives.

Many of them viewed treatment as a gift from God or as part of God's plan. A number of respondents made statements like this:

*I praise God for ARV, yeah I praise God for ARV, all I can say, I'm thankful that ARV is there for us HIV-positive, treatment is there and that's life, so just I praise God. Yes cause that's biblical, the bible says the doctors not here for the, for the healthy people, they here for the sick.*  
(Helen from Fiji, aged 38)

*I think God gave us doctors, you know and so the doctors they come up with this medication and the scientist. It's all part of God's plan I guess. But I don't think God will want me to leave medication, something that's helping me.*

(Nicole from Fiji, aged 32)

The participants who viewed treatment as a gift from God made sense of the relationship between faith and treatment by viewing the two as being complementary. A few participants spoke specifically about the complementarity of the two and said:

*I see both at the same time, yeah so I mean yeah faith is strong but then you still need the, you know the manmade thing.*

(Barry from Guam, aged 58)

*Baha'i<sup>9</sup> [her religion] think that physical sickness, physical medicine can cure it and you can support it with prayer and spiritual sickness, spiritual healing can cure it.*

(Libby from Solomon Islands, aged 36)

*I don't agree with herbal medicine but for the faith healing I believe that if I take my medicine and go to church then I would be healthy.*

(Bella from Fiji, aged 20)

A few participants did not see faith and treatment as being complementary. One participant stated:

*For Indians we believe like the next God apart from God is the doctors, so the doctors can help you, it's not medicines, it's not the herbal medicine and all. It's the doctors who give you the real thing. I believe in professional doctors. There is no influence of religion in my treatment.*

(Samuel from Fiji, aged 26)

Samuel's view was not the norm, it was more common for people to view religious faith and treatment as somehow being connected.

The case study of Warren shows the attitude that many participants had when it comes to treatment.

#### **Warren: "It Keeps You Alive"**

Warren is a fifty-something-year-old man who has been living with HIV and on treatment for over 18 years. After being diagnosed and starting treatment he said "Okay I have been given a second chance, I will have a positive outlook in life and through help both medication, faith and support, that's how I'm gonna live." He feels that treatment is good because "it keeps you alive. And treatment is necessary and I mean there's no other way about it, you don't get treatment, and you're good as dead. You know um now affording treatment is a different problem. You know people that can't afford it, I'm just I feel like I'm blessed that Public Health is there because if, if it wasn't for Public Health, I don't think I'd be alive today."

Warren has not experienced many side effects and says that it would "be suicidal for someone to refuse treatment. So, you know why would anybody not want treatment and you know I'm not gonna say this is fate, this is what's suppose to happen to me cause it's not, we all have choices, you know to me it's not a mistake it's I think to me it's an experience in life, that happened. Make the best of it you know if you wanna survive. Don't drag anybody down because of what happened... And I wanna see the sun shine, I wanna feel the rain, you know and again with me I think the best treatment other than medicine is laughter." When asked what his thoughts were about treatment and the future he said, "Well for me at this age I don't know if there's any other treatment that's gonna come about to say, we found a cure. I hope that they find it for somebody else if they can't find it for me but I'm gonna do everything I can to see if I can reach that."

<sup>9</sup>Baha'i is a monotheistic religion that has spread throughout many of the Pacific Islands.

For the participants treatment meant prolonged life, improved health and normalcy. The negative impacts were not discussed as openly but noted to include side effects, issues with accessing health services and adherence challenges. The meanings and the attitudes to ART expressed by the participants often revealed uncertainty in that for some treatment simultaneously produces positive and negative effects. In other words, ART is not a cure-all and for some the effects are overwhelmingly negative. Although the future offered both hope for a cure or vaccine at the same time there were worries about the supplies. Participants were hesitant to discuss the issue of treatment and sex, and those who did discuss it mentioned ambiguity and confusion related to treatment and their sex lives, having children and the use of ART to prevent mother-to-child transmission. Discussions on treatment and religious faith revealed some participants viewed faith and treatment as being complementary. Importantly, the meanings indicated that the participants' treatment experiences are not uniform and that many factors play a role in determining people's attitude to treatment.

### 3.3 Health Services

The infrastructure of HIV-related health services varied significantly between countries. In countries such as Fiji and Guam where there were more than twenty people receiving treatment the services were more developed than the other countries with only a small number of people on treatment. In Fiji, there are sexual health clinics in Suva, Lautoka and Labasa, and information and treatment support are available through FJN+. In Guam there is a small budding support group of PLHIV and there is also the advantage of being a territory and having access to a wider range of ART and health services. In Kiribati, Samoa and Solomon Islands the number of PLHIV is small. Samoa is the only one of these countries to have a developing peer-support network. In Kiribati, Samoa and Solomon Islands because the number of HIV cases are small HIV treatment and support services are more limited and the health services are also burdened with other health issues including tuberculosis, malaria and non-communicable diseases such as diabetes and obesity amongst a large proportion of the population.

#### Accessing Health Services

Some of the issues that arose when discussing the participants' experiences of accessing health services included the distance to the clinic and the clinic being closed or unattended. Some participants had to travel several hours by boat or bus, which was often expensive and therefore not possible for them to do every three months, and sometimes resulted in them failing to pick up their medication for several weeks, months or even years. At the same time, other participants living in or close to urban centres still described the bus fare as being an impediment to accessing health services and treatment. As this woman who had to travel by ferry and bus to reach the clinic said:

*The only trouble is when I'm short of money for fares to travel to the hospital. It's only my father that gives me money for my fares to go for my check-ups at the hospital, otherwise I borrow money from someone.*  
(Elizabeth from Samoa, aged 32)

Another cost that was mentioned was having to buy antibiotics because the free supply was out of stock.<sup>10</sup> Waiting times were also noted as a factor that discouraged people from accessing health services. Another

barrier mentioned was feeling ashamed and embarrassed to access services. One woman who was recently diagnosed and started treatment said:

*The first time when I come for my medicine like I just don't want to see other people. I don't want to see anybody that knows me coming here, but now it's ok because I know it's my life.*  
(Sarah from Fiji, aged 34)

This woman describes the fear that she was able to overcome to access treatment, while other participants who were diagnosed several years ago described how after diagnosis they waited as long as four years before returning to access health services.

A number of participants also mentioned that they wanted to better understand their condition, medication, CD4 and viral tests and would like to spend more time with the doctor. As one man said:

*I need time with my doctor to talk about my virus about treatment and that stuff, why I'm... you know the questions I have to ask my doctor. Why I have to change my medication cause I have a little while with her cause she has more patients waiting outside.*  
(Zach from Fiji, aged 43)

Other participants also mentioned how they had trouble understanding the doctors. Only a few respondents reported using private health services occasionally, some said they would prefer to use private services but could not afford them.

#### Counselling as Part of HIV Treatment

Counselling is an important aspect of health services that helps people to deal with an HIV diagnosis, understand that treatment is available and to support them in taking ART. Whether or not respondents received counselling depended largely on where and when they were accessing health services. As one participant said:

<sup>10</sup>In Fiji financial support is something offered from the PLHIV network to assist in purchasing treatments for opportunistic infections.

*Yes, that time at the hospital there wasn't good counselling done like I have said for I wasn't even counselled on the tablets [antibiotics] that I was taking. Counselling regarding HIV was not even available until 2003 when I met the doctor that was looking after the HIV cases.*  
(Josh from Fiji, aged 39)

As Josh notes, HIV counselling became more widely available in Fiji and other Pacific Island countries after 2003 and a few years later in some countries. Some participants reflected on the positive impact of counselling and said:

*It was very helpful, it was helpful in the sense that it, it allowed me to prepare myself mentally and physically as well for, for the great step, the big step that I was going to take, I was told all that I would be facing or all that I had to encounter in terms of the side effects and all that. And I prepared myself mentally and physically to make sure that I could, that I could stand up to this, just overcome this because eventually I was told in the end that once my body gets used to the drugs and all then you know it all be normal.*  
(Natalie from Fiji, aged 34)

Counselling in numerous cases was depicted as providing emotional support and valuable information about treatment that supported people to deal with HIV and treatment.

### **ART, Viral Load and CD4 Services**

When it came to the provision of ART and the discussion of supply issues, in all of the countries there were people who reported not receiving their medication, including ART and antibiotics, because it was out of stock. This resulted in them going off ART for up to a month or two. A few respondents said it was sometimes their fault for leaving it to the last minute to pick up their medication. Some participants consequently expressed worry about the supply of ART as well as concern about the possibility of needing to switch to second-line ART. On the other hand, when it came to supply issues a number of participants noted the great lengths that doctors and other health workers went to by making arrangements and sending the medication by plane, bus or boat or arranging to meet outside of the clinic and outside of working hours to ensure that

their patients received their medication.

Having to change ART combinations was another issue. The reasons for changing combination included first and foremost side effects that were difficult to cope with, and a few mentioned they changed combinations because their previous combination was out of stock. As one participant said:

*I keep on changing my tablets, right now, I've changed now I am taking two in the morning then taking three tablets in the afternoon. Before I was taking cotri [cotrimoxazole] and now I'm taking three in one but one, one, one, [separately] not in combination. I was taking zedovudine, nevirapine and lamivudine [each separately] and then after that I was taking two in one and then after that they gave me three in one.... I think this year it was the worst thing in my life, I have so many [complications] yeah, cause I was changing my medication cause I was taking efavirenz and I was admitted, I was.... I don't know maybe I was not committed on my, cause....*  
(Zach from Fiji, aged 42)

Zach describes the complications of his treatment regimes that included many different medications in different forms at different times. Changing of drug combinations often brought about stress and worry of having to manage the pills and also deal with a new set of side effects.

CD4 and viral load tests are important in monitoring the health of PLHIV. Participants from all the countries stated that they had access to CD4 testing, but only in some countries was viral load testing available. Many people did not understand well what the CD4 and viral load numbers meant in terms of their health. A number of participants spoke cautiously about the delays in receiving results and the infrequency of testing. However, many noted that these testing services were improving. Those who lived far from the capital or one of the main health centres had these tests done more sporadically. One participant who lived in an urban centre had this to say about getting blood tests done:

*Before we used to get our CD4 test after one year because they would send it overseas but, now just after three months we can know the result of our viral load, we can know whether it has increased or decreased and you can know whether the tablets you're taking are working or not. That's why I said that the service regarding the CD4 and viral load is now good.*

(Josh from Fiji, aged 39)

In addition to improvements of the testing some participants mentioned the effect of having these tests done:

*Most of the time when I go for blood test my viral load is undetected and sometimes when it is undetected then I go and smoke, drink I don't watch my diet and then it will get worse again to 200 or below 200 for my CD4 and then I'll try to recover again by changing my diet.*

(Tim from Fiji, aged 35)

*When the time comes for me to know how many counts my CD4 if I was not told I would be happy, if I knew the result I feel bad. I mean it's good for me like I know now I feel bad but I, I have to manage it, I have to be strong.*

(Brooke from Fiji, aged 32)

Tim, on the one hand, has his viral and CD4 tests done, and then adjusts his health behaviour depending on the result. While Brooke would rather not know the result of her tests but also feels that she has to manage the results. Although these participants mention drawbacks of getting their testing done, many other participants were happy to have their CD4 and viral load monitored.

### Health Workers

The participants were asked what they felt the health workers' attitudes were towards them with regards to treatment. In some cases it was felt that the health workers were unsympathetic, strict and acted in an angry fashion. As these participants said:

*Some doctors they, they don't make me more strong, they make me more weak because they kind of scare me away. They don't try to make me fight for my life, they say "you wanna die, you really wanna die?" You are supposed to do this and that, if you don't do it you gonna die. Not like the other doctor, they don't say "do you wanna say die?" They say after this you'll be strong, and they make me strong. When they say that I'm gonna die it makes me weak.*

(Henry from Guam, aged 45)

*I think they are very strict in telling us to adhere to the medicine and their attitude will be like, they try real hard to make us see the importance of this treatment. So I guess they, they really want us to continue with this and not like drop it and take up the medicine again and drop it and take it up again.*

(Nicole from Fiji, aged 32)



Nicole explained that the health workers act in a strict manner to encourage patients to adhere to their medication. Many others similarly stated that when they were scolded they felt it was the health workers' role to do that. As this respondent said:

*The doctor usually tells us that our life depends on the tablets that we are taking. The doctor's job is just to counsel us but it's up to us to take care of our lives and our tablets.*

(Simon from Fiji, aged 35)

One participant initially refused to take treatment, and explained how the health workers helped her to understand:

*Yes, first when they told me I'm like I don't want to but then they really like scold and, you know like explain it to me. If you wanna live longer with your children you have to take treatment no matter what.*

(Pamela from Guam, aged 32)

Some participants also noted the supportive role of health workers and described them as good, kind and stated they “act like family”. A few people also described how health workers provided support by educating their families and also village communities about HIV, which enabled them to understand that HIV was not easily transmitted and that PLHIV should not be isolated or discriminated against. This was another instance where health workers were described as going far beyond the call of duty in providing treatment and support to their patients.

## Stigma

Stigmatisation and discrimination from health workers was something experienced by some of the participants. However, many of them said they had experienced it in the past, but not recently. Discrimination was mainly subtle, but still greatly affected those who experienced it. It was described as health workers being unnecessarily mean, unsympathetic, scolding them, looking down on the patients, and in a few cases as having the health worker not want to touch them. In other instances it was overt: some participants said they were separated from other patients. A number of respondents from Fiji had similar stories; they reported that their hospital bed sheets were collected and kept separate from others before being taken to the laundry. One participant described what she felt was discrimination:

*They [the health workers] heard that I am HIV but they were just like, they put me aside like you know they don't wanna take my folder. I was the first person to come to the hospital cause you need to get a number then get seen by the doctor but I was waiting there for long time.*

(Brooke from Fiji, aged 32)

People in other countries and in other health care contexts also felt that they were served last even if they arrived early at the clinic.

Some participants felt that they had not faced any discrimination and that health workers had treated them well, were supportive and kind and treated them “in a normal way as a normal person”. These respondents said:

*I used to (experience discrimination)...but those nurses when they see me now they come and hug me because they have gone through training as well, like they have finished with, you know discriminating against us.*

(Kylie from Fiji, aged 34)

*I was treated highly with a lot of respect, with a lot of love compassion towards my situation. So I think my situation is just ultimately different from other women and other positive people who have experienced stigma and discrimination because, I don't see any level of stigma or discrimination but I feel that one thing that we should check is the internal stigma because sometimes it's just the perception of positive people.*

(Polly from Fiji, aged 33)

Other PLHIV who had also publicly shared their status felt that they did not confront discrimination and this was perhaps due to being well known as an HIV advocate.

## Confidentiality

Confidentiality is an aspect of health services that is of the utmost importance for HIV-related and sexual health services in general. More than half of the participants felt that health services were not confidential and did not trust health workers with their personal information. The nature of breaches of confidentiality varied. Participants from different countries described how several years ago health workers contacted either people in their village or family without their permission and informed them of the patient being HIV-positive. For most of these people these breaches had a severe impact on their lives as they were not ready to disclose their status and had to either deny their HIV status or deal with questions and stigma and discrimination for which they were unprepared.



There were other circumstances where people either feared their confidentiality could be breached or was breached when accessing health services. Participants, especially those had not publicly disclosed their HIV status and were not part of PLHIV networks were very anxious about how their patient files were handled. When they were able to see the names on the files of other patients they worried that other patients could similarly see their names. Others described how they did not like receiving counselling or having contact with health workers in an area of minimal or no privacy, for example when there was only a curtain between them and other patients and the health worker either referred to or openly spoke about them being HIV-positive when they did not want others to hear. There is a perception that confidentiality and support practices had improved over the years, but that there are still contexts where it seems to be routinely breached.

Gossip among health workers and between health workers and other PLHIV patients was another context where confidentiality was breached. As this participant noted:

*Because we go to the clinic and we hear stories about others [other PLHIV], you know that are supposed to be confidential. It's not confidential enough so sometimes there are things that I wanna tell them but you know at the back of my mind it's going, oh they gonna talk about this after this, straight after I leave this room they gonna talk. (Natalie from Fiji, aged 32)*

As Natalie notes, the lack of trust she has in health workers who she perceives gossip about different cases means that she feels she cannot confide in them. As well, sometimes there was a misconception that because a person was public with their HIV-positive status different aspects of their health and treatment could be discussed openly between health workers and PLHIV who are part of the network. A number of people also shared their concerns about gossiping within the PLHIV network. The effect of breaches of confidentiality and anxiety about others knowing their status caused worry and stress.

#### **Rose: Controlling ART Access**

Rose is a 24-year-old woman. She lives with her mother, her brothers and their wives and children. She says that when she was diagnosed, *"The doctor counselled me and told me not to lose hope because there is a tablet that I can take to weaken the virus and secondly it will help the soldiers of my body to help me live longer and be strong."* She felt happy and reassured to receive this advice. Shortly after being diagnosed she told her mother, but they kept it between them as a secret for over two years. She says that she has not experienced discrimination while accessing health services and the services are good, but she also mentioned the experience of having a nurse from the health clinic talk about her in the neighbouring village where Rose's husband is from. This was how Rose's brother first heard rumours of her being HIV-positive and she then decided to disclose her status to them. She says of revealing her status to her family, *"It was really hard and I didn't know how to disclose my status to them, then one day we all sat and my mum told them about my status. When my mum disclosed my status to my family, like they didn't talk or say anything, I can feel that life at home has begun to change."* She repeatedly said that she is stigmatised and discriminated against at home.

Rose began taking ART in 2009 and said she was doing well on it. But then stopped treatment, *"because my brother had seen that I am healthy and he told me that I don't need to be taking my tablet again because I am healthy and there's no more sickness in me."* When asked why she listened to him she said, *"because I was staying with him and secondly because he used to pay for my fare to the hospital."* She was concerned because, *"I know that if I'll leave the tablet the virus will be strong again and there won't be any tablet to defend the virus, after that then I went back to take my tablet."*

Last year, Rose travelled to the village to visit relatives. While she was visiting there was a bad storm and she was one month late returning to the city. When she returned to the clinic to collect her medication, she was told that she would have to be counselled before starting treatment again and health workers refused to provide her with medication. Several months later she says *“Even now I’m off my tablet and I really want to start taking my tablets again and if I’m going to start taking it, I won’t drop it again because I have known the importance of taking the tablets.”* Rose clearly understands and wants to take ART again, she says *“It’s part of my life even now when I’m not taking my tablet I still think of it when it comes to the time I used to take it when I was on my tablets.”*

Rose had stopped taking ART twice for reasons over which she had little control. Her brother, as a man in her family who is older than her, was able to override her desire to continue treatment. Another woman from Samoa similarly was forced by her husband to stop treatment and other women stated that their husbands tried to influence their treatment decisions. For Rose, after overcoming her brother’s control, she was temporarily stopped from taking treatment due to not being able to reach the clinic and then was dictated to by a health worker who felt that she would not adhere. Despite wanting to take ART, understanding the importance of ART and even saying that she still thinks about her ART when it is time to take it she was not able to resume treatment.

In sum, transportation costs and distance associated with travelling to clinics sometimes delayed or stopped people from accessing health services. A number of issues were noted such as a lack of counselling, ART stock-outs, infrequent or delays with receiving CD4 and viral load test results but it was also felt that these services were improving. Some participants observed that some health workers were unsympathetic, acted in a stigmatising manner and they cited instances of discrimination. Breaches of confidentiality by health workers through gossiping and disclosing patient information were also described. However, health workers were also noted as being immensely supportive and going to great lengths to provide treatment to PLHIV.

## 3.4 ART Adherence

### Initiating Treatment

Initiating treatment is an important decision. Most of the participants were on treatment or had started it at some point, but a few had stopped or were refusing treatment and one was not yet in need of treatment as their CD4 level was above the recommended level for initiating treatment. Before starting treatment the patient is told that treatment is a lifetime commitment, that adherence is very important and that they may experience side effects. One participant who was diagnosed several months ago and was advised to start treatment was refusing treatment, he said:

*I'm kind of scared but I'm trying not to show it. My life, I'm only young. But today I'm gonna live... I would love to [go on treatment], I would love to take it, I am going to go on treatment but sometimes I'm scared to go to treatment, I don't know how those medications will make me after because I have never take any pills or even gone to care service.... I'm just scared. I have an idea it's just me, I'm in a closet that's why I'm not going to treatment, why basically I am in this pretty little shell.... I'm okay. I just blame myself.*  
(Matt from Guam, aged 23)

This young man seemed to be afraid of HIV in general as his health had quickly deteriorated. Although his family were supportive, they also were misinformed and were worried that HIV would be transmitted easily, as he conveyed when he shared that his family had been kind and bought him his own set of dishes.

Fear of the effect of ART on the body was also noted by other respondents. The statement below is from a young man from Solomon Islands, who had an allergic reaction to antibiotics in the past and now refused treatment. He said:

*I am scared of the treatment because they told me that the side effects of the treatment will be strong against the body that may cause loss of hair and is too strong. When my wife was taking it her head went dizzy and she felt really weak about 30 minutes or so, then the dizziness slowly improved and she recovered.*

*The treatment will help to make me strong to work and make money. Oh yes, I feel it in my body that I should start my treatment*  
(Dale from Solomon Islands, aged 25)

This man was scared of the side effects, but also felt he needed treatment to support his health. People experienced the benefits and challenges of ART unevenly. Some of the respondents had many benefits and few side-effects, while others had some benefits but severe side effects. As well, they also have varying levels of knowledge of treatments and different levels of support from family and health workers thus their adherence to treatment varied.

Adherence to treatment means taking treatment at approximately the same time everyday without missing a dose. Many participants described how for them treatment became part of their daily routine. It was often described as a habit that was associated with having breakfast and dinner or rising in the morning and going to bed in the evenings or praying in the morning and evening. They noted practices that reminded them to take their treatment, for example having an alarm on their mobile phone, remembering to take their pills with them when they go out and people reminding them to take their treatment. When it came to discussing adherence, some participants said they missed doses sometimes, while others choose to leave their treatment for prolonged periods ranging from weeks, to months, to years.

### Reasons for Stopping or Refusing Treatment

There were a range of reasons why the participants did not adhere to their treatment. Some of the practical barriers included a lack of money to travel to the health centre as well as the distance, while others also mentioned bad weather or natural disaster. Side effects also affected adherence, as one participant said:

*Sometimes I complain about the food if I don't eat well I don't have good food I won't have taken my medication. Because in a family right, if we eat at home I'll say if I don't have any good food I won't eat, I won't have my medication. Like I feel like scared to use the medication like you know I need to eat well and then I have my medication.*

(Brooke from Fiji, aged 32)

Brooke lives with her family and is unemployed and receives social welfare that amounts to about \$80 FJD a month.<sup>11</sup> She says when she takes ART she feels like she becomes “choosy” with her food and wants to eat “expensive foods and not just drink tea” but she can't afford it. She feels it is not appropriate for her to only buy food for herself, so she buys for her family as well, which means for most of the month when her social welfare money is spent she is hungry when she takes or does not take her medication. Other participants said:

*I left it a bit because when we take treatment it has to go with food we take and I was facing hardships and also I haven't known the importance of the treatment then but now I have known its importance to me.*

(Zach from Fiji, aged 42)

*Yes just last month I didn't take it because I, myself go to work I can't take it and go to work eh. When I go to work I feel dizzy in my workplace.... I'll just sit for some time then I do my work again. But during weekend when I stay home I take my tablet, during weekend because I just take it and have some rest and then I do my work at home.*

(Vasa from Fiji, aged 32)

Zach states that he did not understand the importance of taking treatment daily, because when he was first prescribed ART he did not understand the instructions as well as not having money for food. While Vasa indicates she did not fully comprehend or was unable to adhere to taking the medication every day and twice a day because the side effects of hunger and dizziness were incompatible with her job. Brooke sometimes missed doses, Vasa took it on the weekends and Zach had ceased treatment altogether for several months. The following case study describes a man's anguish as he struggles to deal with side effects and adhere treatment.

### **Rufus: Nightmares and the Struggle to Adhere**

Rufus lives in Guam, but is from another Micronesian country. He was diagnosed HIV-positive in 2009 and has disclosed his HIV status to two people – one friend and his cousin who is a nurse. In talking about his struggle with treatment, he says, “*Sometimes I don't even finish the other bottle is coming up. I hate when my pill bottles are piling up because it's like I'm not drinking it, but I do drink it. You know?*” The pill bottles that pile up by the time that Rufus has his next appointment indicate that he has not been taking his ART and serve as a reminder of not adhering to his medication. He says, “*It's very hard sometimes, you know, I am always taking all these pills, it's just like sometimes I just tell myself I can't do it anymore but I still have to do it. Yeah, but you know because I do want to take the pills but sometimes I don't really like to take the pills when I want to go to sleep cause that's when I have more side effects - nightmares. Sometimes I dream this dream and I'm supposed to be dreaming about my family's funeral, yeah those sorts of things. I got into car accident, all that sort of stuff. But I don't, you know I'm not scared because I'm gonna forget about it and wake up. But still sometimes it goes bad like you know like it replays. For me I don't have problems taking the pills but it's just that ... Yeah, it's not because of the dream you know, it's because the pills are controlling me.*” Rufus has not shared his HIV status with many family members or friends, consequently the struggle to adhere is something he mainly deals with on his own.

Rufus truly grapples with side effects to the point of feeling that he is controlled by his medication. In addition to side effects other types of barriers to adherence were described.

Another reason for leaving treatment was because family members tried to influence people to go off of their treatment. One woman told of how her parents-in-law told her to cease ART, she said:

*They have no knowledge of the tablets. If we drink our tablets, they try and stop us from taking them. I say to them that there is no trouble with the tablets, they only help to stop the virus.*

(Elizabeth from Samoa, aged 32)

<sup>11</sup> Social welfare assistance in Fiji includes \$60 FJD and \$20 FJD worth of food vouchers per month.

This woman's husband stopped her taking treatment because like his parents he did not believe that they were HIV-positive or that they should be taking ART. They instead sought a cure through traditional medicine.

Other reasons for stopping treatment were because participants said they simply forgot, were busy or felt tired, but in some cases there were underlying reasons behind the initially stated reasons. One participant described how she had recently lost a close family member that led her to go off treatment for over three months. She said:

*I never told anyone that I had stopped treatment and yeah I just refused to take treatment, as much as I tried I didn't even go for counselling. I think I was grieving, I don't know whether it was grieving or whatever it was but I just refused to continue with treatment, my whole body just shut down.*  
(Sally from Fiji, aged 35)

She later confided in a friend and went for counselling and this support she said enabled her to return to her treatment. Other participants also told of life events that acted as a trigger for them to cease treatment. Since starting treatment in 2006 this woman had gone off treatment once, she said:

*We [her and her newborn baby] were discharged from the hospital and then my husband was not coming and after that I heard that he's going with another woman then I stop the treatment for one year. I don't like (to take treatment), I said leave it. Just because I'm angry with him because I'm thinking that because he's the one who infected me and then he should support me but then he knows everything but then he just left me there, so I don't wanna take the treatment.*  
(Zoe from Solomon Islands, aged 30)

Another woman similarly described how she also stopped treatment after learning of her husband's infidelity. In sum, life events such as the death of a close family member or an argument with family or partner were portrayed as triggers for not adhering to treatment as well as the side effects and access issues.

## The Role of Support in Treatment Adherence

Treatment adherence was noted to be helped by alarm clock reminders and establishing routines, but the most critical factor was support from other people. Support from other people came first and foremost from family members and partners and to a lesser extent from friends, peers and people from NGOs. Support from family was noted to include being reminded by their children, partner, and immediate family to take their medication; being taken care of when sick; making sure they received healthy food and love and providing emotional support. As one participant said:

*My little girl used to tell me, "Mummy you have to drink medicine." If I don't drink in the morning she'll come and wake me, "Mummy, Mummy go and get your medicine." I always forgot that's why I always tell her, if not she will get the medicine, "Mummy here's your medicine. Drink it."*  
(Barbara from Solomon Islands, aged 25)

For many participants the act of being reminded to take their medication was just one of the many ways in which family members expressed their support. In many cases the gesture of reminding people to take their medication was symbolic of the unconditional love and support that they received. As this man said when speaking of his wife:

*Yes you know like my wife remembers because she wants to see me in a different way. She wants to see me healthy, she wants me to, probably she wants me to live longer. That's why she remembers about the tablets.*  
(Vincent from Fiji, aged 26)

For Vincent the gesture of being reminded is one of many acts of support that he receives from his wife and his immediate family. Yet, as the following case studies illustrate, being reminded to take up medication does not always symbolise unconditional love and support.

**Sophie: "Forget Me"**

Sophie is a 30-year-old woman. She was born in Federated States of Micronesia but grew up in Guam. She lives with her partner's extended family and has children of her own. She was diagnosed HIV-positive a few years ago. Her family found out about her status as they were curious about her doctor visits and her father went searching for her medical papers. She said *"And then I came home and he said, he called me into his room and he judged me (he said), 'I know you have HIV, I know you got it'. I said 'How did you know?' and then he said, 'I went into your room and I took all the paper and I start reading it for your medicine and those medicine the one that you taking it's for that.'" Although her family tell her she should be on medication, she is refusing ART. Previously, she took it for one month but says that it made her stomach burn and that the pills were too big. She says her family was angry with her and they were worried that they would catch it from her, despite being told by health workers that HIV cannot be transmitted through casual contact. Her family tells her not to touch things at their house. She says "I was you know, mad and sad and I wanted to kill myself, that's why I stop taking the medicine."*

Her mother belittles her in front of people, she says *"when I went to my family house, my mum will be like 'how come you getting, you losing a lot of weight?', and I just stop right there because I know that she knows."* When she visits the hospital she also feels that the nurses are afraid to touch her and that they do not offer any support. Sophie was still pondering taking ART, she said *"Yeah because when I'm looking at my daughter. So you know I wanna live, I wanna you know I wanna stay, I wanna be with her. For the rest of her life but, I don't know. That's why I'm getting her treatment. Yeah continue with her but me I said forget me I'm just gonna..."* Her family continues to tell her to get treatment but she says *"It's okay I'll just die. Because if they didn't tell me that too, like encourage me to do that, maybe if they didn't tell me to do that every day, then I would already be taking the medicine but them telling me in front of our people and other things that's what making me stop."*

Although Sophie's family tell her to take treatment they do not offer her the love and support that she needs. The underlying reasons for her refusing treatment seem to be due to the repeated blows she experiences which have diminished her will to live. Similarly the lack of support received by Boyd also affects his treatment adherence.

**Boyd: "Why Do I Have to Hide This?"**

Boyd is 40 years old and was born and raised on Guam. He lives with his extended family, but has his own room and own space. The adults in his family are aware that he is HIV-positive but he says they are in denial. His nieces and nephews do not know about his HIV status because their parents want to keep it hidden from them. He says his siblings are ashamed and that is why the nieces and nephews do not know, even though some of them are already adults. Boyd suspected that he was HIV-positive for about two years before getting tested and has had to deal with many medical issues. When it comes to treatment, he says his family *"do tell me to, they ask if I've taken my meds, they ask if I'm gonna see the doctor again. The only thing is none of them wants to accompany me because they don't wanna be seen."*

When asked if he ever misses his medication he said *"Once in a while I hesitate to take my medication but I still take it."* But at times he takes it late or misses a dose but will resume the next day. He says the reasons for this vary *"sometimes it's family issue sometimes I just wanna, I just sometimes give up. I think I don't wanna be around anymore but that's only for, not for long, it's only for just a few minutes, just a few hours."* Taking treatment is an established habit for him, it is because of family issues that he sometimes does not adhere and has to hide his medication. He said that lying about his treatment *"makes my nerves go. So at the same time they ask, it just makes me leave them, makes me go on to my room. It's not that I'm not accepted it's because they are too young. They don't understand, but why do I have to hide this?"*



In sum, the reasons for not adhering to treatment included: a lack of money to travel to the clinic or to buy food to take with medication, and limited understanding of the importance of treatment. Life events sometimes acted as a trigger for ceasing treatment. But most of all, receiving support from other people helped people to adhere to treatment. PLHIV who default on treatment or fail to adhere are perhaps not actually “bad patients” or treatment “failures” but in many cases they are actually the ones who are not loved or accepted by their families, partners, community members and even their peers within PLHIV support networks.

For Boyd the lack of unconditional support at times causes him to temporarily lose hope. Similarly, one participant from Samoa describes her family as supportive yet notes that she struggles to get transport to the clinic despite her family owning a car that is available for them to take her. People were not always forthcoming when it came to describing non-support, they sometimes described it in subtle ways. Perhaps they did not want to criticise their families, they were ashamed of their family or perhaps it was too painful to directly speak of. One participant who was originally from the Republic of Marshall Islands spoke about his fears of returning home to his country, not only in terms of his worry about accessing health services and treatment but also his perception that he would be shunned by the community there. This hurt him deeply and he wanted people there to know that he had this fear. He also had not disclosed to his family and said:

*I keep thinking about it, I really want everybody to know so I can relax. Because I cannot relax when this is like bothering me.... Maybe they gonna help me be stronger.*

(Henry from Guam, aged 45)

Having partners and families understand the importance of treatment for PLHIV was helpful in enabling people to be supported to adhere to their treatment. But, there were instances where people adhered to their treatment despite their partner or family putting pressure on them to try other treatment options.

### 3.5 Alternative Therapies

Alternative therapies were used in every country where participants were interviewed for this study. More than half of the respondents had tried an alternative therapy at some point since being diagnosed HIV-positive. Approximately half of those who tried alternative therapies ceased ART at the same time. The main types of alternative therapies used included natural or herbal remedies, faith healing and traditional medicine.<sup>12</sup> People mainly used alternative therapies because they wanted to or others felt that they could be healed or cured. The quote below explains the reasons why respondents took alternative therapies, the woman said:

*Because you know, you have to cope with this thing day in, day out, morning afternoon and when someone comes up and say they have a cure, "it's like okay maybe that's gonna stop, maybe well I'll just try it out." You know but then I had actually believed that it was a real cure.*

(Nicole from Fiji, aged 32)

Those who were seeking a cure felt that a cure would allow them to live a normal life. Specifically it was mentioned that a cure would enable them to not have to take medication daily and not have to deal with side effects anymore.

Some participants had left ART to try alternative therapies on more than one occasion. For example, one participant described how on three separate occasions she tried herbal medicines that also had a religious element and on a fourth occasion joined a church group to focus solely on faith healing. This person sometimes felt lost and had no family support, she seemed to find comfort in the support that came with the offers of a cure. People also try alternative therapies because they feel that the type of ailments they have can only be cured by a herbal or traditional medicine. As this man said:

*You know being in the village with our grandmothers they know all sorts of herbal medicine. They used to give me herbal medicine for chest pain, stomach-ache and other diseases but I never stopped taking my tablet when taking that herbal medicine.*

*I always take my tablet from the hospital at 8:00 in the morning and 8:00 in the evening, after taking my tablet then I can take the herbal medicine. The reason why I take herbal medicine is because of the bodra (severe stomach-ache), because at the hospital there's no tablet for this sickness. It's like something that's pumping from inside your stomach, when you have that you wouldn't want to eat and you will have diarrhoea. It's inside us and that's what they giving the herbal medicine for because when I went to the hospital they just gave me a tablet for it and I came and take that tablet but there was no change and then I came to the village. My mum then told me to take a herbal medicine for that sickness, then I drank it for four days, after that four days I didn't experience any pain again.*

(Simon from Fiji, aged 35)

While another woman from Samoa explained that when her husband was diagnosed HIV-positive in the 1990s his family did not have an in-depth understanding of HIV, and treatments were not widely available then. She explained how they did not believe that medications from the hospital would work. They believed that he had a local sickness and he should then use a traditional medicine. They brought in traditional healers who provided him with a traditional medicine. He died several months later. As well, some participants talked about how they had used alternative therapies in the past when they did not have a good understanding of ART.

A number of people used alternative therapies because their families wanted them to or because people approached them and promised them a cure. As these participants said:

*My mother used to tell me that this disease is from God, it's better for me to take herbal medicine and I used to tell her that I have taken herbal medicine but it's not like taking our tablets from the hospital. She used to tell me about the lemon (cure) but I never did it. But my in-laws they support me in both, if I come for clinic and if I want to take herbal medicine. But now I never take it, I just take herbal medicine if I have diarrhoea.*

(Kylie from Fiji, aged 34)

<sup>12</sup> In Solomon Islands traditional medicine was referred to as *kustom* medicine, in Fiji it was referred to as traditional or Fijian medicine, in Samoa it was referred to as *fofo* and in other countries as traditional or local medicine.



*Oh he [her husband] wanted to challenge my faith eh, "you shouldn't be on drugs, leave your drugs, just pray to God, faith healing eh" he advise not to take it. He asked me not to take my drugs, I said "You know just leave that alone please, you cannot come, I mean come in my treatment and medication (decisions)."*  
(Helen from Fiji, aged 38)

*Yeah they [her family] know about treatment but they don't want me to take ART, they want me to take herbal medicine. But the three years for my experience I mean two years of experience use taking medication [ART] it's ,I, I feel good about it.*  
(Brooke from Fiji, aged 32)

Brooke was then asked how she felt about her family seeing her take the ART, she said sometimes when she feels down her family tells her "see it is because of the medication." These participants were all compelled to try alternative therapies instead of ART, but only some of them chose to do so.

A number of participants opted not to try alternative therapies. The respondents explained why and provided these types of explanations:

*I don't believe in herbal medicine and all... it's like, most of the Fijian people believe in herbal. We Indians, we mostly believe in the pills that's what we have been taking for ages and I believe these pills are made in India as well.*  
(Samuel from Fiji, aged 26)



*Two men came to me with some herbal treatment but due to that ARV, I said "no" to them because my doctor advise me not to take herbal treatment and then counsellor said the same so I said "no, I do not take any other herbal treatment." Yeah it's in a weed form. Twice, they came but I told them I do not want it so they stopped coming again to me. They told me some rumours, oh we've tried to some other people and were cured but I didn't believe them.*  
(Stacey from Solomon Islands, aged 29)

*I don't believe (in alternative therapies), I just believe in medicine. I grew up with medicine.*  
(Sophie from Guam, aged 30)

*When I first disclosed my HIV status and I share my status my story on the television and on the radio announcement and for me and there's a lot of people coming and they, they want to give their local medicine for the treatment.*  
(Earl from Kiribati, aged 41)

Hence, the reasons for not choosing to try alternative therapies included: following the doctor's advice, a belief in biomedicine and the belief that alternative therapies are potentially harmful or even lethal.

### **Alternative Therapies: Herbal Therapies, Faith Healing and Traditional Medicine**

The alternative therapies were used in different ways. In some cases people, particularly those who were in search of a cure, ceased ART. In other cases, the alternative therapies were taken at the same time as ART. In this instance the treatments were taken for issues such as skin rashes, boils and diarrhoea and were used until the symptoms were gone. The type of alternative therapies used generally fall under three separate categories including natural or herbal therapies, faith healing and traditional medicine. At the same time, the alternative therapies cannot be easily divided into groups as they are interrelated and tend to be used in combination. For example, herbal therapies were often taken at the same time as doing special prayers. Sometimes traditional medicine also had religious elements. And sometimes herbal therapies have elements of traditional medicine and vice versa.

The type of alternative therapies and ways in which they were used varied significantly. Some participants, particularly in Fiji and Guam, mentioned taking different vitamins and supplements. Some also mentioned the use of other therapies such as acupuncture. People also mentioned eating certain fruits that were thought to have natural healing powers such as soursap, having a healthy diet, even having a vegetarian or vegan diet as a sort of alternative therapy. Often these therapies were used and viewed as complementary but in other cases they were used instead of ART and occasionally before needing to initiate ART. As this woman said of a therapy she tried with a group of PLHIV:

*I always used to tell myself, I will never go on ART and so while I was still healthy enough not to go on ART this was something I underwent, the natural therapy, and this is whereby it dealt a lot with our diet, our food, the type of food we ate, we became vegans and yeah and we learnt a lot about the types of food that will be suitable for us as positive people that will help us continue to maintain a healthy lifestyle and therefore not needing ever to go on treatment... We went for this camp and it was six weeks in a camp where we learnt about this. It was more like two sides spiritual and natural remedy focused or based approach.*  
(Natalie from Fiji, aged 34)

Natalie said this treatment was good for her as it helped her to be healthy and improve her eating habits, but later on she went on ART.

A range of therapies were used that had herbal or natural therapy aspects. A few participants described how along with a group of PLHIV they quit ART and took virgin coconut oil along with engaging with the One World Church in Fiji. *Kura* juice as it is known in Fiji, or *noni* juice as it is referred to in other parts of the Pacific, was drunk and in one instance was mentioned to be sold by a market vendor who sold the juice and claimed that it could cure many ailments including cancer, tuberculosis and HIV. He promoted this along with Seventh Day Adventist Church teachings. A few participants from Fiji also mentioned the Loloma Group<sup>13</sup> which combined herbal therapies with Seventh Day Adventist Church teachings as well as Fijian cultural traditions. In a number of cases traditional medicines of crushed-up plant leaves for example, were men-

tioned as being used for rashes and boils; these were applied externally and not ingested.

One participant from Fiji described one of the alternative therapies that he took, he said:

*Yes I started treatment in 2006, I left treatment because one man gave me a herbal medicine, I think he knew that I was sick he must have heard it. He just brought it (the herbal medicine), it is from the sea called the titi. He brought that and another one also from the sea, then he pound them and cook it then he brought it to me. I don't know whether he knows that I'm sick or what, he just brought it and give it to me and told me that that medicine will help me get well. That was just after two weeks from the time I started taking ART and when I heard that, I was really looking for help to make me better again. I wasn't well informed of what the ART could do my body and then I heard the information about that herbal medicine. I was told that that herbal medicine will clean my immune system that's why I took it and that was just after two weeks of taking ART.*  
(Zach from Fiji, aged 42)

Zach then went on to explain that after taking that treatment he had diarrhoea and the doctor was angry with him, he stated that he had learnt his lesson.

A number of participants described faith healing as increasing their religious faith by having religious leaders and congregations pray for them. Sometimes this included forgoing ART and sometimes this included maintaining their ART. In the latter case, people feel they are being healed by both faith and ART. One woman spoke of how she was approached by people who claimed that she could be cured through faith healing, she said:

*The Charismatic, they came home and they were brought by my sister and they prayed for me and they said that, the HIV is gone. So I came to have a blood test and they said that some of the HIV died, it killed it but my HIV blood cells is still there and it won't go away, nothing can take it away, no tablets, there's no cure for HIV.*  
(Shelley from Fiji, aged 43)

<sup>13</sup>This organisation was referred to by several names including the Loloma Group, Loloma Ministry and Loloma AIDS Foundation.

One of the sentiments that was associated with faith healing was that if you forgo ART you are demonstrating that your faith in God is stronger than your belief in ART. As one participant said:

*If you believe in God then you should stop the treatment, because if you believe that God can heal you, then why would you take the treatment?*  
(Rosie from Fiji, aged 37)

Rosie went on to say that in this case she had temporarily stopped ART, and felt that she was “*disobeying the rules of God*” by resuming ART but at the same time she reconciled that “*It’s better for me to go to the ART, never mind I still believe in Jesus.*”

The case study of Josh explains the reasons why he sought a cure.

#### **Josh: Seeking a Cure**

Josh is a Fijian man in his 40s who has been living with HIV for several years now. He has a wife and kids and says that he feels content with his life. He is currently on ART, but in the past he has gone off of treatment. When asked why he left treatment he said, “*I tried something out, for I was hoping and believing and I’m trying for the virus in me to go away. I was told that if I eat and drink these things it will help my body or my blood and I wanted to try it out. I didn’t tell anyone about it but I just left my treatment and try to see how this other treatment will work.*” When asked about the type of treatment he tried he said, “*First, one of the things I left it was because of the food and not herbal medicine. I thought that if I will eat healthy food I will get healthy and better and secondly it was through my faith. I believe that God can heal me but I don’t know God’s plan until when I was weak I went back to my treatment. It doesn’t mean that I didn’t go to the doctor. I just left my tablet but it was just for three to four weeks. The doctor didn’t know anything about this, it’s only me that know about it. Yes, I just want to experiment with things.*” After trying out these treatments he said he felt weak and he did not experience the benefits that he had hoped for. He wanted to share his experience with other PLHIV: “*I am advising others that it is good for us to follow what the doctor advises us to do, what we have to eat and drink, when to take our tablets and taking it at the right time.*”

Josh, like a number of other participants, ceased using ART as he was seeking a cure and he wanted to know if he could be healed by other means.

#### **Views and Reflections on Taking Alternative Therapies**

As the participants told their stories about alternative therapies, many of those who had tried them cautioned against them. Most of them noted that the other therapies caused diarrhoea, made them feel weak and led to decreasing CD4 count and increasing viral load levels. None of them felt that they had been cured and most of them eventually returned to their ART regime. When reflecting on their experiences, they said:

*I faced conflicts for about one year regarding that issue, the faith healing and those that give out juice, the juice therapist. Uh their beliefs, I believe that we should treat these people as our partners in intervention, we can recruit them in whatever areas they can be involved in so they can know their roles and their limits.*  
(Tim from Fiji, aged 35)

*I actually left my treatment and went herbal, I left my lifeline so I don’t know what happened but I just wanna add that, you know I wish my peers out there would see how treatment is very important and I hope they are not, they won’t do what I did.*  
(Nicole from Fiji, aged 32)

Many of the participants describe their use of alternative therapies as a sort of lesson learned.

In sum, alternative therapies in the form of herbal therapies, faith healing and traditional medicine or a combination of these therapies were used in many different ways sometimes with ART and sometimes instead of ART. Respondents either sought alternative therapies or decided to try them when offered to them as they wanted to be cured of HIV. People were often encouraged by their family members to try an alternative therapy or approached with the promise of a cure. A number of participants refused to use alternative therapies as they did not believe they would work. Many participants were influenced by health workers not to forego ART in search of a cure. The participants who tried cures which they felt failed, also strongly caution against forgoing ART and note the importance of ART in maintaining their health.



## 4. Conclusions and Recommendations

### Conclusion

In conclusion, the narratives of PLHIV that feature in this report demonstrate the power of ART in positively transforming the lives of Pacific PLHIV, but also illustrate the challenges and inconsistencies related to accessing treatment, adverse effects from treatment and the role of support and non-support from family, partners and communities. As ART became available throughout the Pacific as a medication to treat HIV, it has offered reassurance to PLHIV in coming to terms with their diagnosis. Experiences varied in terms of the impact, meaning and attitude of the participants towards treatment. Some people had mainly positive experiences, while others had negative experiences and many conveyed varying degrees of ambivalence. ART undeniably was noted as integral in prolonging the lives of the respondents, yet side effects were a genuine concern that some participants felt were downplayed by health workers. Respondents had worries about ART supplies for now and in the future. The experiences of HIV treatments were not uniform and are related to people's social condition and their bodily reactions to ART toxicities. With regards to health services the barriers included: transportation costs, ART supplies, waiting times and in some cases attitudes of health workers. Some participants experienced stigmatisation and discrimination and breaches of confidentiality occurred in numerous contexts, with the result that many participants did not trust health workers with their personal information. At the same time health workers were also noted as going to great lengths to support patients to receive and understand their treatment. Adherence was in some cases affected by practical barriers to health services, but severe side effects, life events and lack of family support were most crucial to non-adherence. Support from family and partners was most influential in enabling PLHIV to take their treatment on time and every day. Participants described how they tried alternative therapies in search of a cure for HIV, many were approached by people claiming to know of or offering cures. Many participants who had gone off ART advised PLHIV not to forgo ART to try these therapies.

ART was portrayed as supporting many PLHIV to live long and healthy lives. There are ways in which access to HIV treatment and health services could be improved which can better enable PLHIV to adhere to treatment. These factors relate to ensuring that quality ART and other medicines and health services are available free of charge, that clinics are open and staffed, that patients are able to receive information about treatment and that attitudes towards PLHIV become increasingly supportive. It is imperative that people, especially HIV-positive people in the Pacific, understand that treatment for HIV infection is available and that HIV is no longer a death sentence. It is also imperative that health workers, organisations working with PLHIV, the families of PLHIV and PLHIV themselves understand that there are challenges associated with treatment and that love and support are vital.

## Recommendations

- Decrease fears around testing by providing more information that addresses fears of dying so that people understand that medication is available to treat HIV, but it is a lifetime commitment that should not be taken lightly. This approach should be employed by health promotion units and NGOs that provide information about HIV. Media should also use this approach and should refrain from using scare tactics and stigmatising language.
- Continue to educate PLHIV about HIV treatment to understand the benefits of ART, how to cope with side effects, the purpose of CD4 and viral load testing and support available to them. Information about treatments should be provided in simple terms and when possible communicated in local languages. Health workers can play a key role in this education, positive support networks and other NGOs that support PLHIV should also play a role in improving knowledge and understanding of treatment by conducting workshops and providing accessible information.
- Continue to train and build the capacities of Pacific health workers on the importance of offering confidential, non-judgemental care and support to PLHIV. Encourage health workers to continue to warn clients about alternative therapies and promises of cures, and to promote ART as the only proven way of reducing viral load.
- Improve access to ART and CD4 and viral load testing. Increase the accessibility of ART by expanding the dispensing of ART beyond urban health centres. Increase the range of ART available to Pacific PLHIV. Continue to increase the efficiency of CD4 and viral load testing services for PLHIV.
- Ensure that families of PLHIV are educated about how HIV is and is not transmitted, the role and importance of ART for PLHIV and the significance of family support in treatment adherence. Health workers have a vital role to play in providing this information, and positive support networks where they exist can also provide this support to PLHIV and their families.
- Fund and support PLHIV network organisations so that they are able to continue to offer support to PLHIV, to the families of PLHIV and educate communities and the general public on the HIV treatments and importance of care and compassion towards PLHIV.
- Ensure that Ministries of Health slowly integrate the cost of ART into health budgets to decrease reliance on funding from international donors which are not likely to be indefinitely available.
- Future research should be conducted on HIV treatment adherence more broadly to explore experiences of PLHIV, doctor-patient relationships and the views of health workers as well as the constraints that they work under.

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