The art of living: the social experience of treatments for people living with HIV in Papua New Guinea

Before ART
I'm afraid of HIV
HIV make me weak

After ART
I'm fit
I'm strong

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Andrew Frankland
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Barbara Kepa
Brenda Cangah
Somu Nosi
Rebecca Emori
Lucy Walizopa
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University of New South Wales
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## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbreviations and acronyms</td>
<td>5</td>
</tr>
<tr>
<td>Foreword I</td>
<td>6</td>
</tr>
<tr>
<td>Foreword II</td>
<td>7</td>
</tr>
<tr>
<td>Acknowledgement</td>
<td>9</td>
</tr>
<tr>
<td>Executive summary</td>
<td>11</td>
</tr>
<tr>
<td>Introduction</td>
<td>14</td>
</tr>
<tr>
<td>Background</td>
<td>15</td>
</tr>
<tr>
<td>Methodology and methods</td>
<td>17</td>
</tr>
<tr>
<td>Sample demographics</td>
<td>19</td>
</tr>
<tr>
<td><strong>Key findings</strong></td>
<td>24</td>
</tr>
<tr>
<td>Knowledge and beliefs regarding HIV and ART</td>
<td>24</td>
</tr>
<tr>
<td>Access to services</td>
<td>29</td>
</tr>
<tr>
<td>Adherence</td>
<td>34</td>
</tr>
<tr>
<td>Food security and alcohol</td>
<td>39</td>
</tr>
<tr>
<td>Disclosure of HIV status</td>
<td>42</td>
</tr>
<tr>
<td>Health and well-being</td>
<td>46</td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>52</td>
</tr>
<tr>
<td>Sexual practices</td>
<td>56</td>
</tr>
<tr>
<td><strong>Recommendations</strong></td>
<td>64</td>
</tr>
<tr>
<td>References</td>
<td>65</td>
</tr>
</tbody>
</table>
Abbreviations and acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ART</td>
<td>antiretroviral therapy</td>
</tr>
<tr>
<td>HIV</td>
<td>human immunodeficiency virus</td>
</tr>
<tr>
<td>AIDS</td>
<td>acquired immunodeficiency virus</td>
</tr>
<tr>
<td>PLHIV</td>
<td>people living with HIV</td>
</tr>
<tr>
<td>PNG</td>
<td>Papua New Guinea</td>
</tr>
<tr>
<td>VCT</td>
<td>voluntary counselling and testing</td>
</tr>
</tbody>
</table>
Welcome everyone to this first research report on living with HIV in PNG: ‘THE ART OF LIVING’ covering people living with HIV (PLHIV) who are on ART and the issues they face with life on treatment.

This report contains data on the religious, sociocultural, emotional and health challenges and successes faced by PLHIV their partners, children and extended family as a whole. Some of the highlights of this report include the challenges posed by certain religious denominations with ART adherence, people with HIV complex negotiation of condoms, sex and sexuality, excellent adherence to ART, and the dramatic improvement ART makes on people’s mental health.

We hope the evidence presented in this research report will prompt you all to

• respond accordingly to the challenges faced by PLHIV,
• address emerging issues and
• build on the successes that have taken place.

As the national group representing PLHIV, Igat Hope Inc. ensures that all research about PLHIV in PNG is done in collaboration with us as these researchers have: Nothing for us without us. This successful collaboration reenforces the need for partnership between PLHIV groups and the wider community including researchers in the national and global response to HIV and AIDS.

Mr Peter Momo
President
Igat Hope

Ms Helen Samilo
Immediate Past President
Current Board Member
Igat Hope

Ms Maura Elaripe
GIPA Advocacy Officer
PNG-Australia HIV& AIDS Program (AusAID) and member Igat Hope
A major challenge facing Papua New Guinea is evidence on which to build policies and programs to prevent the spread of HIV and to provide treatment, care and support for those living with HIV. In order for PNG to scale up access to ART we not only need to gear up our clinical response but to understand the needs of HIV-positive people and the barriers and challenges to access and adherence to therapy.

The ART of Living: the social experience of treatments for people living with HIV in Papua New Guinea is extremely timely. It presents the results of a study carried out through a partnership between the PNG Institute for Medical Research and the University of New South Wales and funded by the National AIDS Council. It is the first large-scale study of people’s experiences of living with HIV in Papua New Guinea. Importantly the study was done using Papua New Guinean research trainees – the PNGIMR cadets – a group of ten early career HIV social researchers.

The project aimed to examine people’s social experiences of ART, to explore stigma and the barriers and enabling factors for adherence to antiretroviral therapies, to understand the sexual practices of those on ART, and to understand the role of health care workers and families in the roll-out of treatments.

One of the successes of this report is that it presents both qualitative and survey data. You can not only examine the graphs and tables, but you can read the narratives of HIV-positive people and see the ways they represent their experience of living with HIV before and after ART through their own drawings.

The results are too numerous to detail here – you must read the report. The study will be useful to numerous groups: funders, NGOs, international donors. But here I just want to highlight a few of the results and the recommendations that are most pertinent to the Government of PNG.

When ART began to be rolled out there was a feeling that those in developing countries would be unable to adhere to a pill-taking regime. This report clearly indicates that in PNG this is not the case. The rates of adherence are similar to those in Australia and elsewhere. However, while ART treatment in this country is provided free of charge one of the main barriers to access is the cost of transport to the clinic, particularly for those in more remote parts of the country. We need to think about the placement of new ART sites so that people do not have to travel such long distances to access their drugs.

The study plainly shows that because people living with HIV and on ART are feeling healthier they are returning to normal life. Some of the respondents felt that clinic staff were antagonistic to them resuming a normal sexual life. This is unfortunate -we must be sure to include safe sex counselling for people living with HIV rather than insisting on abstinence.

Feeling well is not just about sex – those on ART felt hungrier. Good nutrition is essential to successful treatments and yet the report shows that a number of people (particularly those in NCD where people do not have their own gardens) did not have enough to eat. We must examine the urgent need for food programs in Port Moresby for those on treatment.

As the complexity of issues around the rolling out of universal access to ART facing us increase, we need to think about ways to effectively communicate these results to those working in the field. This will ensure that research results are translated into action.
The ART of Living has not only produced data that is useful to the government and donors, but has shown a genuine commitment to the GIPA principle (a greater involvement of people living with AIDS). I appreciate the support of Igat Hope, people living with HIV and others who were centrally involved in the development of the reports recommendations and in the dissemination of the results.

Research provides important evidence for policymaking and programs. The National AIDS Council now has a Research Agenda and NACS has begun funding rounds for research grants which will continue this kind of work on other HIV topics. These projects will continue to provide high quality scientific evidence for the Government and other stakeholders to use to implement HIV policies and programs.

I commend this report as an example of the kind of research that is essential to the response to HIV in Papua New Guinea.

Mr Wep Kanawi CSM, OBE
Acting Director
National AIDS Council
Acknowledgements

Without the people living with HIV (PLHIV) on antiretroviral therapy (ART) who generously gave of their time for this research this project would not have been possible. Thank you for sharing with us your experiences of treatment so that we can learn something of your lives. We hope that this report reflects your lives in part or in whole. We also anticipate that these findings will help in advocating for better services for people on treatment and provide the evidence of the positive impacts of treatment. For those who provided feedback on the findings at the Igat Hope workshop in Port Moresby and to those who helped develop the report’s recommendations, thank you for your time and suggestions. We look forward to working together again in the future in this partnership model.

This project would not have been possible without the support of the staff and PLHIV at the recruitment sites in Mendi and Tari (Southern Highlands Province), Kainantu (Eastern Highlands Province), Mingendi (Chimbu Province), Mt Hagen (Western Highlands Province), Lae (Morobe) and Port Moresby (National Capital District). The recruitment sites we are indebted to are: Epe Anda and St Francis Care Centre (SHP); Poro Support Project Kainantu and Salvation Army Drop in Centre (EHP); St Joseph’s Rural Hospital (Chimbu Province); Rabiamul Clinic, Friends Club, Tininga Clinic at Mt Hagen Hospital, True Warriors and Baptist Union (WHP); Morobe Network of Positive Living and Anua Morere at Angau Memorial Hospital (Morobe); and Simon of Cyrene, Igat Hope, Hederu Clinic and Ward 4B at Port Moresby General Hospital, Anglicare StopAIDS, St Mary’s Medical Centre, Poro Support Project, House of Hope, and 9 Mile Clinic (NCD)

We would like to thank the key stakeholders involved in this project for their support, encouragement, advice, engagement and participation in developing the recommendations. They are Igat Hope, the peak body of PLHIV in PNG, particularly Rei Frank, Helen Samilo, Maura Mea and Peter Momo; the National Department of Health, particularly Dr Daoni Esorom and Dr John Millan; the National Catholic AIDS Office, particularly Sr Tarcisia Hunhoff; and Dr Agatha Lloyd of the WHO.

We would also like to thank Dr Patrick Rawstorne, (University of New South Wales) for his ongoing support with the design of the questionnaire and guidance in writing the report, Ms Llane Munau (Papua New Guinea Institute of Medical Research) for formatting the survey used in the study and for designing the report with Mr Douglas Diave (Papua New Guinea Institute of Medical Research) and to Ms Evelyn King (AusAID) for her support to do this study.

This project was carried out by early career researchers in Papua New Guinea. The researchers were employed in the Strengthening HIV Social Research Capacity Building Project funded by AHAPI (AusAID), a joint endeavour by the Papua New Guinea Institute of Medical Research (PNG IMR) and the University of New South Wales. The project was a two-year project which sought to build the capacity of Papua New Guineans in the area of HIV social research. We would like to thank the PNGIMR and UNSW for their ongoing intellectual and political commitment to this important piece of research.

Last but not least, this project would not have been possible without the National AIDS Council Secretariat (NACS) of Papua New Guinea with the financial support of the Government of Australia.
Map of Papua New Guinea showing the research sites used for the study.
The Art of Living is a comprehensive study of the lives of people in PNG who have been living on antiretroviral therapies (ART) for more than two weeks. As a study that recruited from ART clinics, drop in centres and support groups for people living with HIV in six provinces (National Capital District, Southern Highlands Province, Western Highlands Province, Chimbu Province, Eastern Highlands Province and Morobe Province), this report goes to the details of what it means to live with HIV and ART today in PNG. Designed to explore the social experiences of PLHIV on ART in Papua New Guinea, the project had seven key objectives:

1. Conceptualise and understand the way PLHIV think about ART in their lives;
2. Explore the relationship between stigma and the uptake of ART;
3. Determine the barriers and facilitators for PLHIV to adhere to ART;
4. Understand PLHIV’s beliefs and knowledge about ART;
5. Explore the impacts of ART on PLHIV;
6. Explore the gender differences in the impacts of ART on PLHIV;
7. Understand the role of health care workers and families in the experience of ART.

The study engaged a mixed-method research approach: survey, in-depth interviews and drawings. The quantitative component of the study involved a cross-sectional survey of 374 people with HIV who had been taking ART for more than two weeks. A non-probability, convenience sampling approach was used. The questionnaire gathered information about the following: demographics; knowledge and beliefs of HIV and ART; stigma and discrimination; health and well-being; disclosure; food security and alcohol use; adherence to treatment; sexual practices; and access to services. At the end of the questionnaire one qualitative question on the meaning of ART in people’s lives was asked. The survey was administered in English and Tok Pisin and analysed using SPSS (v. 15).

In-depth (semi-structured) interviews were conducted with 36 PLHIV and 15 key informants. The PLHIV were drawn from those who participated in the survey. The in-depth interviews provided people living with HIV an opportunity to tell their stories in more detail, in their own words and in ways that allowed the researchers to understand what was important in their lives. All data was transcribed, translated and analysed thematically.

The findings of this study are too numerous to report here in this Executive Summary, as are the reports recommendations which were developed in partnership with Igat Hope, representatives from the National Department of Health and the World Health Organization. However, let us reflect on just some of the critical findings for PLHIV, health care workers, government and non-government organisations and researchers interested in the lives of PLHIV.

**Knowledge of HIV and ART**

- Close to one fifth of the sample believed that ART could cure the virus.
- The majority of the men and women surveyed (90.6%) believed that ART worked or worked well.
- Some 77.3% correctly knew that HIV could not be transmitted by mosquitoes.

**Access to health care services for HIV**

- The majority of the respondents (65.2%) did not report experiencing any difficulties when accessing treatment.
- A higher proportion of those in the Highlands Region reported having had difficulties accessing treatment (39%) compared to those who lived in the Southern (27.6%) or Momase (21.7%) Regions.
- Insufficient money was the major obstacle to treatment access with 60.5% of those who reported difficulties accessing treatment identifying this as the primary cause.
- The aspect that the participants were least satisfied (38.5%) with was the amount of time that they had to wait to see a doctor or nurse at the clinic.
- The aspect of attending the clinic that the participants were most satisfied (95.7%) with was that the staff were friendly.
Adherence

- Slightly less than half of the participants (45.6%) reported having ever missed a dose of their medication.
- Those who lived in the Southern Region (59%) were most likely to have ever missed a dose while those living in the Highlands Region (39.1%) were the least likely to have ever missed a dose.
- Of all religious affiliations, those who identified as members of the Revival Church were significantly more likely than any other to have ever missed a dose of treatment (63.6%).
- The majority (79%) of the participants had been 100% adherent to treatment in the previous week.
- The majority (65.4%) of the sample reported that in the previous week they had taken their treatment at the correct time as told to them by their ART prescriber.
- The most common reason for not adhering to ART was forgetting (51.2%) followed by not having enough food to take with medication (15.3%).
- The most common reasons identified for adhering to treatment included wanting to look healthy (94.7%), not wanting to die (92.9%) and following doctors advice (92.9%).

Disclosure

- Almost all people (91.6%) had disclosed their HIV status to at least one person before they commenced ART.
- After ART, only 65.6% of people had disclosed their HIV status.
- Being on ART made it easier to disclose for 62.4% of participants. More men (68.9%) than women (58.3%) reported that being on treatment made it easier to disclose.
- Close to 90% of the participants reported being happy to very happy with the support they received following disclosure.

Health and well-being

- After treatment there was a 28.4% increase in the proportion of people who reported that their physical health was excellent and an increase of 28.3% of those who reported that their physical health was good.
- On ART there was a 72% reduction of participants reporting their mental health as bad to very bad.
- Approximately 90% of all participants who reported that in the year before ART their quality of life had been bad to very bad reported that in the last month on treatment their quality of life had improved.
- On treatment the majority of the sample rated their satisfaction with health as happy to very happy (74.9%) whereas before treatment this proportion was only 18.2%.
- There was a 33.7% reduction in the number of people spending every day in bed in the previous month on treatment compared to the month before treatment began.

Food security and alcohol

- Some 72.8% of the sample reported an increase in their appetite on ART and of these people 32.7% reported that they did not have enough food to satisfy their hunger.
- Those who lived in the Southern Region were most likely (52%) to report not having enough food to satisfy their hunger.
- Close to 80% of participants reported that they did not drink alcohol while 15% only drank once in a while.
- Amongst those who reported not drinking alcohol, the main reasons for not drinking were never having drunk alcohol (37.8%), while another 40.7% ceased as a result of having HIV and/or starting ART (HIV-related = 27.6% and ART-related = 13.1%).
Stigma and discrimination

- Some 47.3% of the sample reported having experienced some form of verbal abuse as a result of their HIV status.
- A higher proportion of females (53.4%) reported being verbally abused than males (37.9%) as a result of their HIV status.
- Of those who reported experiencing some form of verbal abuse as a result of their HIV status, 40.4% reported that since going on ART this experience of verbal abuse as a result of HIV had either stayed the same or had intensified.
- The majority (85.4%) of people in the study had not experienced physical abuse as a result of their HIV status.
- Close to double the proportion of females (17.7%) than males (9.7%) had experienced being physically abused as a result of their HIV status.
- Of these people who reported experiencing physical abuse, 63.5% said that it had improved since being on treatment while 36.5% said that their experience of abuse had either stayed the same or deteriorated on ART.

Sexual practices

- In the sample, 39.4% reported that they had had sex since being diagnosed with HIV while 60.6% had not.
- 37.9% had had sex in the previous 6 months.
- Of those with a regular partner, 94.4% had had vaginal sex in the previous six months.
- Fewer than half (46.2%) of the participants who had had vaginal sex with their regular partner in the previous 6 months reported that they always used condoms.
- There was high condom use (62.2%) the last time participants had had vaginal sex with their regular partner.
- The majority (91.2%) of participants with a regular partner had not had anal sex in the previous 6 months.
- Only two of the 11 people (18.8%) who had had anal sex reported that they had used a condom the last time they had anal sex with their regular partner.
- Nearly all of the participants (91.8%) had disclosed their HIV status to their regular partner.
- The majority of participants with regular partners who had had sex in the previous six months had a partner who was HIV-positive (64.7%), while 21% reported that their partner was HIV-negative. 14.3% reported that they do not know the HIV status of their regular partner.
- Only 22 people reported having had vaginal sex with a casual partner in the previous six months. Of these people, 63.6% (n=14) reported that they used a condom the last time they had vaginal sex with their casual partner.
- The majority of men had not paid for sex with a woman in the previous six months with only ten men (7.7%) in the sample reporting that they had done so.
- Only five (3.8%) of the total number of men reported having had male-to-male sex in the last six months.

This is the first extensive study into the social experience of ART for people with HIV in PNG and the primary recommendation from this study is that more research is needed into living with HIV and, in particular, the effects of treatments. There are also program-specific recommendations arising from this study: to address the issues of food security; stigma and violence against people living with HIV, especially women, and the issues of religion and adherence, in particular the influence of the Revival Church.

The research team and the stakeholders hope that this report will provide all people working in the field of HIV with more of the verification they need to create and argue for evidence-based programs, policies and practices which empower and support people living with HIV on ART in Papua New Guinea.
Papua New Guinea (PNG) is the focal country of the human immunodeficiency virus (HIV) in the Pacific region with a reported generalised epidemic and an estimated HIV prevalence in 2009 of 2.56% of adults over the age of 15 infected with HIV (Government of PNG, 2007). Like many developing countries, PNG is in a phase of scaling up access to antiretroviral therapy (ART). ART has been shown to reduce morbidity and mortality (Paella et al., 1998) and reduces the cost of care (Maisels et al., 2001). Furthermore, ART is one of a number of pillars of effective HIV prevention efforts.

It has long been argued that HIV is more than a biomedical issue. In fact, it is because HIV is transmitted by bodily fluids associated with sex and injecting drugs that it is inherently a socio-cultural illness. HIV is interpreted and shaped within sexual and drug injecting practices and, in turn, shapes those practices in local milieu and along grids of power. It is because of these aspects of HIV that taking ART is not akin to consuming other medications. That said, the availability of these treatments has transformed the social and illness (and indeed disease) experience of HIV in the developed world and, more recently, in the developing world (Mukherjee et al., 2003; Koeing et al., 2004 and Biehl, 2007).

The clinical picture does not tell us about the social world in which people with HIV live. As Hirsch et al. (2007:S1), like the authors of this study, argue that research must analyse the social impacts of the scale up of ART in resource-poor settings. However, and more importantly, such research, they suggest, will also ‘increase our ability to achieve our clinical and public health goals successfully’. Like this study, which has been undertaken as PNG scales up ART, these studies, writes Hirsch and colleagues, must study the social impacts of the scale up as the process unfold. If they do not:

we will lose vital opportunities for the mid-course corrections that could mean the difference between success and failure at multiple levels. Only by understanding the social aspects of scale-up can we maximize our opportunity to shape its outcome and lay the groundwork for ameliorating its unintended consequences (2007:S2).

Findings from other resource-poor countries are instructive in understanding the social aspects and impacts of treatment on people living with HIV (PLHIV) in PNG: the barriers and facilitators of treatment adherence; stigma; disclosure; how people conceptualise ART in their lives; the role of family and health care workers in the experience of ART; and PLHIV’s beliefs and knowledge of treatment. While findings from other regions of the world may provide insights for PNG they do not speak for or of PNG; therefore in this research we have sought to understand the lives of PLHIV on treatment in PNG. This report is based on data from the first multi-site study into the social impacts of ART for people on treatment in Papua New Guinea. Specifically, this report details the quantitative findings from a survey conducted using a convenience sample of 374 PLHIV on treatment for more than two weeks between February and July 2008. Removing ART from the sole sphere of medicine, this research places ART in the context of people’s social lives and aims to provide the evidence necessary for best practices in the care and support on people on ART in Papua New Guinea.
The physician-anthropologist Paul Farmer once wrote, ‘one can be impressed by the power of modern medicine and yet dejected by our failure to deliver it equitably’ (1991:264). Nowhere have we seen this more so than in the inequitable distribution of ART until very recently. Prior to 2002 the World Health Organization did not list antiretroviral therapies as ‘essential medicine’. However, the benefits of ART are at least twofold: people living with HIV are expected to have a better quality of life with less morbidity and mortality and ART can restore individuals to active participation in the social and economic activities of their families and communities.

Expanded access to ART is essential in mitigating increasing mortality rates, as ‘access to medical care is a more important predictor of survival than sex, race, and income level’ (Chaisson et al, 1995:755). With increased pressure from non-government organisations, and with people with HIV throughout the world demanding access to the treatments reserved for the comparatively rich people in the developed world, a new dialogue of ‘universal access’ to combination therapy emerged.

While AIDS treatment activism is not new the development of more sophisticated ART and then the continuing denial of these essential drugs to those from resource-poor settings triggered a new era of treatment activism. After the International AIDS Conference in Vancouver, with the theme ‘One World, One Hope’, the stark differences in living with HIV became starker. Without access to treatment, there was not ‘one hope’. The anger because of continued denial of access to treatment to the world’s poorest, who are the majority of those with HIV, peaked in 2000 at the International AIDS Conference in Durban, South Africa. Treatment activists demanded greater access. A new scale of treatment activism was born. In time programs such as the WHO and UNAIDS strategy ‘3 by 5’, followed by the UNAIDS Universal Access initiatives, were launched. While the WHO and UNAIDS ‘3 by 5’ program itself did not reach its goal, from 2003 to 2005 there was a threefold increase in the number of people on ART in resource-poor settings (WHO 2006). The commitment to universal access had become enshrined as a key component of all HIV care and access to ART was no longer a privilege but a human right that had to be met as part of the Millennium Development Goals. Because of this there has been financial and political commitment to provide low- and middle-income countries with support to expand access to these life saving treatments for people with HIV.²

It has been suggested that it is no longer useful to debate treatment and prevention priorities; instead, analysis and discussions should prioritise how we can simultaneously integrate and strengthen prevention and care (treatment) and use every opportunity provided by one to reinforce the other (Lamptey and Wilson, 2005:104). Papua New Guinea is one country that is doing this. It is trying to expand access to ART treatments for its citizens with HIV and simultaneously enforce and strengthen treatment and care in order to prevent new and secondary infections. In 2009, Papua New Guinea had an estimated 98,757 people infected with HIV (Government of PNG, 2007). Through its National Strategic Plan on HIV/AIDS (2006–2010), PNG has prioritised seven areas, of which treatment, counselling, care and support is one.³ Under this prioritised area the goal is to reduce morbidity and mortality from AIDS-related conditions, to improve the quality of life for those infected with HIV and to encourage access to voluntary counselling and testing (VCT). One of the objectives to achieve this goal is to scale up access to ART throughout the country, including rural areas. This commitment by the Government of PNG and its partner organisations such as the faith-based organisations has successfully led to an increasing number of PLHIV on ART. However, the number of those on treatment still falls short of those in need. As of January 2008, (when this study commenced) 2,250 PLHIV were enrolled on treatment, which equated to 35% of those with advanced disease. While 38 facilities offer ART, as of January 2008 this represents only 14% of all health facilities in the country, with the result that PLHIV often have to travel long distances, in some cases for days, for treatment.

² For a discussion of the scale of ART as the first global public health intervention as the result of activism, a social movement and that was shaped by people with HIV, see Smith and Siplon (2006), Berkmand et al. (2005) and Friedmand and Mottiar (2004).

³ Gender has subsequently been added as the eighth priority area and has its own strategy paper.
The clinical benefits of ART are well documented. Less so are the social impacts, especially in resource-poor settings generally and in PNG specifically. In fact, there has been no published social research on people with HIV in Papua New Guinea to date.4 Increasingly, however, the social impacts in these settings are attracting the attention of health care providers, national HIV program coordinators and social researchers. Much of the work in this area has come from Haiti (see for example, Mukherjee, et al. 2005, 2006; Castro and Farmer 2005), and African nations such as Botswana, Uganda and South Africa (see for example, Hardon et al. 2006, 2007; Kaida et al. 2008; Bateganya et al. 2005). This current research on the lives of people with HIV in PNG is essential for thinking about ‘positive prevention’.

Aim of the study and the report

The aim of this study was to examine the social impacts of ART on PLHIV in Papua New Guinea. Seven objectives were outlined:

1. Conceptualise and understand the way PLHIV think about ART in their lives;
2. Explore the relationship between stigma and the uptake of ART;
3. Determine the barriers and facilitators for PLHIV to adhere to ART;
4. Understand PLHIV’s beliefs and knowledge about ART;
5. Explore the impacts of ART on PLHIV;
6. Explore the gender differences in the impacts of ART on PLHIV;
7. Understand the role of health care workers and families in the experience of ART.

The purpose of this report is to provide the community, PLHIV, the National Department of Health, faith-based and non-government organisations and research institutions, with the findings from this study in particular the quantitative data, which is complemented by exerts from the in-depth interviews with people on treatment to highlight key issues. The use of narratives in this report does not represent a thematic analysis of all the qualitative data from the study. Where informants spoke in Tok Pisin both the original and translated exert is provided. Any mistake in translation is unintended. While not all people in the in-depth interviews agreed to pictorially describe their experience on ART, where people did, we have included some of the images to provide an additional vehicle for method of understanding the social impacts of ART on people’s lives.

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4 In a recent publication by Butt and Eves (2008) on AIDS in Melanesia, which contributes a rich ethnographic understanding of how responses to HIV are shaped by culture in local milieu, there is not one chapter that specifically addresses research about people living with HIV.
This study engaged a mixed-method research approach. Good quantitative methods are useful in the gathering of reliable, statistically robust information about the behaviours, practices and beliefs of a given population. However, quantitative methods alone do not tell us about the cultural context of such findings. Therefore a mixed-methods approach was used. This provides reliable quantitative data about the population of interest while at the same time allowing a better understanding of the individual and collective experiences of those interviewed.

The survey

A cross-sectional survey of people with HIV who had been taking ART for more than two weeks was undertaken between February and July 2008. A total of 374 people with HIV on ART were interviewed using a non-probability, convenience sampling approach. A convenience sample was chosen because the number of PLHIV on treatment across the country was small, making it difficult to obtain a representative sample. People attend clinic for treatment infrequently, making it unlikely that an adequate sample size could be reached across all six sites in the time available.

The questionnaire gathered information about the following: demographics; knowledge and beliefs of HIV and ART; stigma and discrimination; health and well-being; disclosure; food security and alcohol use; adherence to treatment; sexual practices and; access to services. At the end of the questionnaire one qualitative question on the meaning of ART in people’s lives was asked.

The questionnaire was written and interviewer-administered in Tok Pisin and English. No names were recorded on the questionnaire. All questionnaires were coded by province and recruitment site. All questionnaires were entered and analysed using SPSS (v.15).

In-depth Interview

In order to explore the lived experiences of ART for PLHIV, in-depth (semi-structured) interviews were conducted with 36 PLHIV and 15 key informants.

Two separate interview schedules were developed. PLHIV were drawn from the convenience sample of PLHIV in the survey.

Key informants were chosen on the basis of their involvement in the care and support of PLHIV on ART. Informants included nurses, doctors, counsellors and pastoral care workers. The data from key informants is not included in this report.

Interviews were conducted in Tok Pisin and English and lasted approximately one hour, with the longest taking two. All interviews were transcribed verbatim, translated and subjected to a thematic analysis of codes derived from the qualitative data set. The qualitative analysis of this research is positioned within the interpretive tradition of the social sciences. As Geertz says, interpretation ‘is fundamentally about getting some idea of how people conceptualise, understand their world, what they are doing, how they are going about doing it, to get an idea of their world’ (in Panourgiá 2002:422). In-depth interviews were selected because they allow for a mutual narrative exploration of the issues. Participation for PLHIV and key informants was voluntary and informed consent was obtained. All identifying information has been altered and pseudonyms have been used for all informants in this report.

Visual method—drawings

Until recently, the use of visual methodology and methods has been scarce, a neglected dimension in our understanding of social life. In the past decade things have begun to change and more researchers are using methodologies that engage with the visual. Amongst others things, the visual offers people different modes of expressing and experiencing their lives. Bruner (1986) says some of the experiences we live ‘are inchoate, in that we simply do not understand what we are experiencing, either because the experiences are not storyable, or because we lack the performative and narrative resources, or because the vocabulary is lacking’ (p. 6–7). To dismiss the visual in the gathering of data is to unnecessarily limit and dismiss data sources. For this reason, PLHIV in the qualitative component of this study were asked to visually depict their experience/s of ART using coloured marker pens and paper.
Not all those who were involved in the in-depth interviews agreed to draw their experiences. Informants who drew images also provided the analysis of their drawings.

**Recruitment of PLHIV on ART**

To be eligible to participate in the study all PLHIV had to have been on ART for a minimum of two weeks, be over the age of 16 and able to provide informed consent.

Participants were invited to participate in the study by healthcare workers or other PLHIV. It was made known to potential participants, both by the healthcare workers and the researchers, that they were under no obligation to participate, that their access to ART would NOT be affected by their decision to decline involvement in the study, and that they could withdraw from the study at any time. Except at Kainantu, where researchers stayed for less than a week, researchers stayed at the sites between two and three weeks.

**Recruitment of key informants**

The key informants were health care workers in the field sites who were directly employed in the area of ART administration, the roll-out of ART more generally or the care of PLHIV on ART. The research team decided on who was a key informant at each of the sites.

**Site locations**

Participants were recruited through ART-prescribing sexually transmitted infection (STI) clinics, hospital wards, day care centres, PLHIV organisations, non-government organisations (NGOs), faith-based organisations and hospitals. Recruitment occurred in six provinces: the National Capital District (Port Moresby); Chimbu Province (Mingende); Southern Highlands Province (Mendi and Tari); Eastern Highlands Province (Kainantu); Western Highlands Province (Mt Hagen); and Morobe Province (Lae).

**Ethical approvals**

Ethics approval for this study was granted by the Papua New Guinea Medical Research Advisory Committee, the Research Advisory Committee of the National AIDS Council Secretariat of Papua New Guinea, the Papua New Guinea Institute of Medical Research Internal Review Board and the University of New South Wales.

**Informed consent**

Signed informed consent was obtained from all informants (PLHIV and key informants) involved in the in-depth interviews. Consent forms were written in Tok Pisin and English and explained to the participants if they were illiterate. In the situation where an informant could not read or write, a nominated witness, such as a health care worker, was asked to sign on their behalf after verbal consent was given. Two stages of verbal consent were obtained for the survey. Potential informants consented to the health care worker or PLHIV to being involved in the study and were directed to a nominated researcher. Once with the researcher, verbal consent was again given before the survey was undertaken.

**Greater involvement of People with HIV and AIDS (GIPA)**

A person living with HIV was employed as a member of the research team and trained in the methodologies of the study. They interviewed and surveyed PLHIV on ART, transcribed interviews, were involved in disseminating the preliminary results back to PLHIV at Igat Hope’s National Conference and participated in the stakeholder workshop to develop the recommendations and implications of the study for treatment and care of PLHIV on ART in PNG.

**Stakeholder group**

The stakeholder group was engaged in three ways. Prior to commencing the study, the survey was shared with two members of Igat Hope familiar with social research and their feedback was sought. At the National Conference for PLHIV organised by Igat Hope a closed session was held for positive people to hear preliminary results from the study and contribute ideas for how the results should be disseminated beyond the final study report. At the completion of the draft report a stakeholder working group (expanded from Igat Hope, the National Department of Health and the Catholic AIDS Service to include the World Health Organization and the GIPA Advocate from AusAID) was held for two days to review the draft report of this study and together agree on the key recommendations to be concluded from this study for the treatment and care of PLHIV on ART in PNG.
Sample demographics

**Gender**

Of the 374 study participants, 60.4% (n=226) were women and 39.6% (n=148) were men. At the time of the study (January 2008), 2,250 PLHIV were recorded on the national ART registry as being on treatment and of these 1,213 were women and 1,037 were men. The study sample accounts for approximately 16.62% of the population on treatment at that time. The women in the sample accounted for 18.7% of the national total of women on treatment and the men accounted for 14.17% of the national total of men on treatment at that time.

**Age**

The majority of participants in this sample were aged 25–34 years, with the median age 30 years (Figure 1). The youngest participant was 16 and the eldest was 69.5

The national surveillance data of age at HIV diagnosis between 1987 and 2006 did not record the age for slightly more than a third of all diagnoses. Of the remainder where age was recorded, most infections were diagnosed in the 20–29 age group.

When disaggregated by gender, the age distribution of the sample was somewhat different, with men considerably older than the women. The mean age for men was 36 years while for women it was 28 years (Figure 2).

This finding where women are younger than men at diagnosis is consistent with what is known from the national surveillance data of HIV diagnoses from 1987 to 2006 (see above comment). Where the data differs slightly from the national surveillance data is in the age categories. In this sample the peak age category for the women was 25–29 years while in the national surveillance data it is 20–24 years; for men in the study the peak age category was 30–34 years while in the national surveillance data it is 30–34 years. This slight difference could be explained by the difference between being diagnosed with HIV and being on treatment, which for many happens later.

**Time diagnosed with HIV**

While we did not collect data on how long people had been infected with HIV the majority of those in the study had only come to know their HIV status recently. Close to half of the sample (43%) had been diagnosed with HIV in the previous 12 months (Figure 3).

The mean time a person had been diagnosed with HIV was 8.5 months with the median being 4.5 months. Three people had been diagnosed for over 10 years with the longest having been diagnosed for 14 years and 9 months.

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Study participants had to be at least 16 years old. A number of PLWH on ART who asked to participate were under this age.
Time on treatment

The longest time that a person had been on treatment was 9 years and the shortest, two weeks. This data is not surprising given nearly half of participants had been diagnosed in the previous 12 months and that PNG introduced ART in 2004 as a pilot and has only begun to scale up access in the last few years.

Education

Most men (35.1%) and women (48.7%) reported primary school education as their highest level of education attained, with a greater proportion of women completing primary than men. There was a significant relationship between gender and level of education ($\chi^2 (4) = 19.924, p = 0.001$) (Figure 4). More men had completed secondary education compared to women. A higher proportion of women (23.5%) than men (17.6%) reported never attending school.

Marital status

Almost half the participants were married or engaged (46.8%), with almost a quarter widowed (24.3%) (Figure 5). However, of those who identified as married only 32.1% said that their partner lived with them in the same house.

Forty two participants identified that they were part of a polygamous relationship where there were two wives, 16 were in a marriage with three wives; two were in a marriage with four wives; three were in a marriage with five wives; one was in a marriage with six wives; and one was in a marriage with 12 wives. In total, 65 participants (17.4% of the total sample) reported being part of a polygamous marriage. However, nine of these reported that they were now separated from their spouse; therefore 15% of the total sample were currently in polygamous marriages. Of all those who were married (excluding those who were separated), 32% were in polygamous relationships with two or more wives.

The true extent of polygamous relations is likely to be under reported in this sample because the polygamous question was not asked of widows. During the qualitative interviews a number of informants who were widowed (namely women) spoke of their polygamous marriages. Even with the death of their husbands, these widows still saw themselves as connected to their co-wives and their co-wives children. For example, Sendy (Southern Highlands Province) shared in her in-depth interview that her husband and two co-wives had all died of AIDS-related illnesses and Dorethy, also from the Southern Highlands, shared...
Although the Western Highlands Province was the province with the highest proportion of HIV diagnosis in the period of January to June 2008, this does not mean that it has the highest overall prevalence. Rather, this may be an artifact for example of public awareness for testing, a long history of testing that preceded other provinces and the availability of treatment at two clinics within close proximity to each other providing access and choice. This, however, also does not mean that it is not the province with the highest prevalence; the reality is that based on the available surveillance data, we do not know either way.

Of the 65 participants in polygamous marriages, the majority reported living in the Western Highlands Province (n=38) – the province where from January to June 2008 35.2% of all HIV notifications originated (NDHo 2009). This was followed by those living in the National Capital District (n=12). The region of residence with proportionally the largest number of people in polygamous relationships was the Eastern Highlands Province, where four of the eight participants in the study reported being in such a marriage. Polygamous relationships were reported by people living in the Southern Highlands Province, Western Highlands Province, Enga Province, Morobe Province, Chimbu Province, Eastern Highlands Province and the National Capital District (in all but the Central and Madang Provinces).

Employment

With 85% of PNG’s society residing in rural areas and the recruitment sites used in the study being located in rural areas it was not surprising that the majority (43.9%) of those in this study reported their primary form of work to be working in their garden; the next group (25% of the sample) reported their primary form of work as doing housework (Figure 6).

Within all of these employment categories only two women specifically identified themselves as sex workers and only 10 men identified themselves as mobile workers such as truck drivers or seafarers. In risk discourses of HIV, these work professions are amongst those which are traditionally considered to place people ‘most at risk’ of HIV in PNG, yet in this study few people were ‘at risk’ according to this model.

The highest proportion of both men and women earned their living by working in the garden. More women than men identified housework as their main form of work while more men than women reported informal employment as their main form of work (Figure 7).

Number of people in household

The majority of participants (50.7%) reported that they were living in average sized households where between five and nine people lived with them. Nearly 30% (29.2%) said that one to four people lived in the same house as they did while 13.4% of the sample was living with between 10 and 14 people.

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7 Although the Western Highlands Province was the province with the highest proportion of HIV diagnosis in the period of January to June 2008, this does not mean that it has the highest overall prevalence. Rather, this may be an artifact for example of public awareness for testing, a long history of testing that preceded other provinces and the availability of treatment at two clinics within close proximity to each other providing access and choice. This, however, also does not mean that it is not the province with the highest prevalence; the reality is that based on the available surveillance data, we do not know either way.
Province of birth and residence

The participants in the study reported living in the three main regions of mainland PNG: the Highlands Region (64.8%); the Southern Region (28.8%); and Momase Region (6.3%). The highest proportion of participants lived in the Western Highlands Province (42.6%) followed by the National Capital District (27.1%) (Figure 8).

The data were collected in three regional areas of PNG: the Highlands, Momase (Lae) and the Southern Regions (Port Moresby). More time was spent collecting data in the Highlands Region so it is not surprising that over three quarters of the sample (76.2%) were born there; 17.5% were born in the Southern Region and 6% in the Momase Region. Only one person in the sample was born in the Islands Region.

Religious denomination and church attendance

The two main religious denominations that respondents identified with were Pentecostal (general) (22.3%) and Revival (20.7%). Slightly smaller proportions identified as Catholic (18.5%) and Seventh Day Adventist (SDA) (16.9%) (Figure 9).

This proportion of people identifying as either Pentecostal or Revival is in stark contrast to the National Census data in PNG which reports that the majority of the nation identify as Catholic followed by Lutheran (PNG National Statistical Office 2003). This demographic data suggests and is supported by the qualitative interviews that there is a phenomenon of conversion happening by PLHIV after diagnosis in order to attain healing from baptism and the acceptance of the Holy Spirit into their lives.

More than half of the participants reported attending church every week (‘always attends church’) (52.7%) followed by attend sometimes (28%). Slightly more people reported not attending church (10.8%) than those who attended often (8.6%) (Figure 10).

Languages spoken, written and read.

8 A similarly high rate of membership of PLWH in the Revival Church has been identified by Sr Mary McCarthy in her current doctoral work on hope and HIV in PNG (personal communication 2008). Amongst PLWH in Brazil a similar conversion to Pentecostal denominations has also been noted (Biehl 2007).
Slightly more than forty percent (41.4%) of the participants reported speaking Tok Pisin, Tok Ples (local dialect) with or without another language that was not English or Hiri Motu while a similar proportion of the sample (40.6%) reported that they spoke Tok Pisin and English with or without another language that was not Hiri Motu (Figure 11).

Close to forty percent (39.7%) of the sample reported that they could write in both Tok Pisin and English with or without another language that was not Hiri Motu while close to thirty percent reported that they could not write in any language (29.7%) (Figure 13).

Recruitment sites and provinces

Nearly half (47.3%) of the participants were recruited from the Western Highlands Province. While only 8.3% of the sample were recruited from the Southern Highlands Province this represented 50% of all people on ART enrolled on ART from this recruitment site.

Reading Tok Pisin and English with or without another language that was not Hiri Motu was the most common category of languages read by the participants (39.6%). Close to a quarter (24.3%) of the participants reported that they could not read any language (Figure 12).

Table 1: Recruitment by province

<table>
<thead>
<tr>
<th>Province of recruitment</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chimbu Province</td>
<td>23</td>
<td>6.15</td>
</tr>
<tr>
<td>Morobe Province</td>
<td>23</td>
<td>6.15</td>
</tr>
<tr>
<td>National Capital District</td>
<td>108</td>
<td>28.88</td>
</tr>
<tr>
<td>Western Highlands Province</td>
<td>178</td>
<td>47.59</td>
</tr>
<tr>
<td>Southern Highlands Province</td>
<td>34</td>
<td>9.09</td>
</tr>
<tr>
<td>Eastern Highlands Province</td>
<td>8</td>
<td>2.14</td>
</tr>
<tr>
<td>TOTAL</td>
<td>374</td>
<td>100.00</td>
</tr>
</tbody>
</table>
Keys findings

Knowledge and beliefs regarding HIV and ART

Medical knowledge about HIV amongst the participants in the study was very high, with at least three quarters answering every question correctly (Figure 14).

The highest level of knowledge (95.2%) was in relation to knowing that HIV could be sexually transmitted between a man and a woman. In the words of one woman, HIV can be transmitted:

"From promiscuity, sleep with a man, like you don’t use a condom and you sleep without it, that’s how it’s passed. Having unprotected sex and you don’t use a condom and you have sex flesh to flesh, man and woman don’t use a condom." (Lyn, 23, Eastern Highlands Province)

"Lo passin pamuk, silip wantaim man oseim yu no usim condom na yu silip nating, em save kamap lo displa. Silip nating na yu no usim kondom, na silip skin to skin man na meri ino usim kondom." (Lyn, 23, Eastern Highlands Province)

The lowest level of knowledge was found in relation to knowing whether mosquitoes could transmit HIV, with only 77.3% knowing that they could not and 13.4% believing they could. Close to 10% of the participants did not know if HIV could be transmitted by mosquitoes. Wilde (2007) also found that people in PNG believed that mosquitoes transmit HIV.

Furthermore, 10% did not know if a person on ART could still infect their sexual partner with HIV.

Close to 15% of the participants believed that condoms did not prevent a person from being infected with HIV. As Jack said:

"I don’t trust condoms. Sometimes when it comes out of the factory I don’t know if it might have holes in it and the virus might be transferred to the woman and if she dies then it’s my fault. That’s why I don’t want my wife getting the virus. That’s also why sometimes I don’t like to have sex with my wife." (Jack, 35+, Chimbu Province)

"Mi ino trustim kondom. Sampla taim ol wokim long factory ya em kam long em mi ino save gut na igat hole stap em nogut em bai transfere igo long meri kisin na dai em wrong stap long hand biling mi. Oseim na mi ino laikim meri bilong mi bai kisin. Oseim na sampla taim mi les long silip wantaim meri bilong mi." (Jack, 35+, Chimbu Province)

No relationship was found between gender and medical knowledge and beliefs regarding HIV. There was no relationship between time since diagnosed with HIV, or time on ART, and knowledge and beliefs regarding HIV. Furthermore, there was no relationship between religious denomination and knowledge and beliefs of HIV.

Distinguishing medical knowledge (i.e. information) from lifeworld knowledge (local ways of understanding and experiencing the world) of HIV is critical because it allows for the inclusion of views and beliefs that are often marginalised and left out. In the qualitative interviews it became evident that a tension existed between medical knowledge and lifeworld knowledge. Many of the participants attributed the cause of HIV to spiritual and moral discord and thus believed the cure was to be found in addressing the cause of this discord and returning to ‘harmony’ with God:

"I don’t trust condoms. Sometimes when it comes out of the factory I don’t know if it might have holes in it and the virus might be transferred to the woman and if she dies then it’s my fault. That’s why I don’t want my wife getting the virus. That’s also why sometimes I don’t like to have sex with my wife." (Jack, 35+, Chimbu Province)
This [Revival] church witnessed to me so I went to this church, I didn’t ignore the call. I just went got baptized and I got Holy Spirit and Holy Spirit worked inside… I heard many testimonies of how God had healed their sickness. Now I believe that God has healed my sickness too. (Mek, Western Highlands Province)

Displa [Revival] church em bin witnessim mi so mi bin go long displa hap, mi no passim bel. Mi go tasol mi baptize na mi kisim Holy Spirit na Holy Spirit em wok insait …Mi harim planit testimony long God ihealim sik blong ol. Nau mi belief olsem God ihealim sik blong mi tu. (Mek, Western Highlands Province)

Scientific knowledge about ART was high with at least three-quarters of participants responding correctly to the two questions about it (Figure 15).

This belief in cure of illness by turning to God is common throughout PNG and not restricted to HIV (Eves 2003, 2008, nd). Prayer, as Eves (2009) notes, becomes a treatment strategy. However, acceptance of Christian causes of illness is not always straightforward and does not exclude other healing strategies. Despite the fact that involvement in this study required that people be on ART, many still held a strong belief in the ‘medicalisation of morality’ (Eves nd) and believed that God would heal or even had healed them of HIV. Having already lost his first wife to HIV and then remarried, Mek was taking ART. His new wife, who also had HIV, did not take ART ‘because she fears God and has put trust in him’. Highlighting the extent of the tension in knowledges, Mek who has been ‘witnessed to’ by the Revival Church since being diagnosed with HIV he has put his ultimate faith in spiritual healing, but not at the cost of taking ART:

Maybe because of ART my viral load has gone down inside my body; that I wouldn’t know, but ART made my CD4 go up and I’m still alive. (Nathaniel, National Capital District)
The metaphor of the fence is drawn from the ART preparedness training in PNG that PLHIV undergo with an ART prescriber. Before a PLHIV begins treatment, the prescriber uses a visual flip chart to describe aspects of ART. To describe the impact of ART on viral replication there is a culturally appropriate image of a garden with a fence around it. The pig (HIV) destroys the fences and is able to destroy the garden (the immune system). Therefore a fence must be built to prevent the pig from breaking down other fences and destroying the garden.

The majority of people believed that ART could not cure a person of HIV (74.3%). However, like Joan, a 16-year-old girl from the Southern Highlands Province who simply said ‘it will cure’ ('Em bai pinis'), close to one fifth of the sample believed that ART could cure the virus. A slightly higher proportion reported this belief in a cure in an Indian study of people with HIV (26.6%) (Ramchandani et al. 2007). In this study less than a tenth (7.8%) were not sure if ART could cure someone of HIV whereas in the same Indian study nearly a quarter of the sample were unsure (23.1%). This is in contrast to the VSO Tokout AIDS in PNG report (Levy 2008) which showed that no one believed there was a cure for HIV once a person was infected (Figure 15).

There was no significant relationship between gender and belief regarding whether or not ART could cure someone of HIV. There was no significant relationship between gender or religious denomination and knowledge and beliefs regarding ART.

The majority of men and women believed that ART worked or worked well (90.6%) (Figure 16).
People described experiences and opinions that went beyond talking about ART as simply a medicine. When reflecting on the effect that ART had on HIV some people spoke of a changed relationship with their illness because they were able to forget they had HIV and in this way a sense of hope was restored:

I had no hope for my body...It has helped my body to work and forget about what is in my body. (Sasha, Southern Highlands Province)

ART really gave me life again. Treatment really helped me a lot. With that treatment I thought that there was hope in life in me. (Inok, Southern Highlands Province)

I thought that HIV was a friend of mine; it was here to stay with me. [With ART] I’ve forgotten already, my friend is lost already. (Tina, Chimbu Province)

Em I olsem mi ting olsem em I wanpela fren blong mi; Em I kam stap wantaim mi. Mi lus tingting pinis, fren bilong mi em I lus pinis. (Tina, Chimbu Province)

Along with her comment above, Tina drew the following pictures:

One man drew his satisfaction with ART in the following image:

Commonly referred to in the international HIV literature as the Lazarus Syndrome9 (cf. Trainor and Ezer, 2000), the return to life after diagnosis and illness was also expressed in the stories and drawings of participants:

But the people who are taking the medicine I see that they’re coming back to normal, I mean not normal but extra normal, they are recovering. (Joe, Morobe Province)

But ol lain we ol kisim marasin mi lukim ol wok long kam bek ken long nomol na ino nomol tasol extra nomol kain olsem, ol wok long go bek ken. (Joe, Morobe Province)

[Before ART] I was a dead man living in this community (Mek, Western Highlands Province)

[Bipo ART] mi dai man em mi stap insait long community (Mek, Western Highlands Province)

Images of HIV as a death sentence were strong amongst the drawings by people with HIV when describing life before ART in the in-depth interviews. Three images include the following:

9 The Lazarus Syndrome refers to the biblical story where Lazarus was raised from the dead.
The return to life after treatment is evident in images 7 - 10:

This idea of having been given life because of treatment was also seen in the narrative of Valerie, but her story points to an important difference. Having two infants die from complications associated with HIV, Valerie, who was diagnosed HIV-positive during her third pregnancy, described the effectiveness of ART in relation to giving life to her child—not herself:

*My faith in the medicine was that the medicine had done a great work through the birth of my child and I myself am in good health again. I say thank you to God for giving man this knowledge to come up with this medicine so that my child is alive. So the medicine has done a great work. (Valerie, Morobe Province)*

*Bilip bilong me long marasin em olsem marasin em wokim bikpela wok through long pikinini bilong mi em kamap na mi yet mi kamap gut gen. Mi tok thankyou long God long givim save long man na ol wokim marasin na pikinini bilong mi em kamap. So marasin em wokim bikpela wok tru. (Valerie, Morobe Province)*

But the effectiveness of treatments, people realised, was fragile and dependent on not developing drug resistance which therefore meant treatment adherence was critical. Inok, also a Voluntary Counselling and Testing counsellor, spoke of this fragility of hope:

*I have to take my medicines morning and afternoon. I cannot, they told me, miss the medicine. If I miss a medicine a day, the medicine will be resistant in my body. So it was that advice that they gave me so I have to take my medicine everyday morning afternoon, morning afternoon. So if I don’t take the medicine one day, then the medicine will be like resistant to my body so it won’t work again in my body. So to help myself with the medicine in my body I have to take it everyday. (Inok, Southern Highlands Province)*

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10 For international research on the fragility of hope and treatments see Kelly 2007 and Rhodes et al. 2009
**Access to services**

The majority of participants did not experience difficulties accessing treatment services and reported that they were satisfied with key areas of attending clinics providing ART.

**Source of treatment**

A majority of the sample (69%) reported accessing their medication at government hospitals while the remaining 31% reported accessing their medication at Catholic Health facilities. There was a difference in the source of treatment based on where people resided. In the Highlands Region 51.7% of the sample received their ART from a government facility while the remaining 48.3% attended a Catholic Health facility for their treatment. Since there are no Catholic ART services in the Momase Region it is not surprising that no one in the study who lived in that region attended a Catholic Health facility for treatment. In the Southern Region almost all (98.1%) of the sample received their treatment from a government facility.

The majority of people first heard about ART from a health service (66.5%), with less than 10% of people reporting family and friends (9.9%) and PLHIV networks (7.3%) (Figure 17).

[Figure 17: Where people first heard about ART]

**Experiences in accessing treatment**

Overall, access to treatment services was good. The majority of the respondents (65.2%) did not report experiencing any difficulties when accessing treatment, while 34.8% reported that they did. There was no significant relationship identified between gender and difficulty accessing treatment. No significant relationship was identified between occupation (and financial or logistical issues associated with employment) and difficulty accessing treatment.

There was a significant relationship between where participants received their treatment and having experienced difficulty in accessing treatment ($\chi^2 (1) = 8.174, p = 0.004$) (Figure 18). Those who attended Catholic Health facilities reported greater difficulties accessing their treatment service than those who attended a government-run facility. This is an artefact of the geographical location of the Catholic services, which are in the Highlands Region, where people travel long distances for treatment. This is also borne out by the analysis, which shows that although there was no significant relationship between region of residence and finding it difficult to access treatment, a higher proportion of those in the Highlands Region (39%) reported having had difficulties accessing treatment compared to those who lived in the Southern (27.6%) or Momase (21.7%) Regions.

[Figure 18: Difficulty accessing treatment by source of ART]

**Barriers to accessing treatment**

ART is provided free of charge in PNG. However, this does not mean there are not challenges in accessing clinical sites where ART is prescribed and as this study showed, finances are the major obstacle to treatment access with 60.5% of those who reporting difficulties accessing treatment identifying this as the primary cause. A multi country study in Africa (Botswana, Tanzania and Uganda) similarly identified transport costs as a major concern; however, they identified it as a particular concern for adherence (Hardon et al. 2007).
Access to services was reported as a barrier by almost a third (30.6%); this included living too far away, tribal fights resulting in road blocks and the hospital running out of medication (Figure 19).

For one woman who had to travel two days each way to access her ART clinic, combined issues of distance, the wet season and the financial cost posed a great challenge:

That day the river had flooded and I prayed to God, ‘God, whatever need I have, you know, where I want to go, you know so please this river must go down and you make the way for me and I must go.’ To travel from my village is very far. I have to pay K40 to come here and get my medicine and another K40 to go back home. It’s K80 to come and return. (Dorethy, Southern Highlands Province)

Dispela taim wara i bin taight na mi pray long God, ‘God mi gat wanem kain need yu yet yu save, mi laik i go long en yu save so please dispela wara mas i go daun na yu mekim rot bilong mi na mi mas i go’...Na long ples long kam long here em longwe. Mi mas baim K40.00 long kam long hia na kim marasin na K40 long go bek. Em K80 long kam na go (Dorethy, Southern Highlands Province)

But it was not just those who had to travel several days each way like Dorethy who reported financial difficulties in accessing the clinic. Even those who had to catch a PMV (public motor vehicle) in the major towns and cities had trouble:

I’ve not had to struggle or had difficulty in this area, but the only problem is regarding money to pay for the PMV to come to get my medicine. It’s the finance side that I find hard to come to the clinic but the medicine is free. (Valerie, Morobe Province)

Struggle, na hevi long dispela em mi nogat tasol, problem long sait long money long baim kar kam na dispela kain

Experience of attending the clinic

Participants in the study were predominately satisfied with key aspects of attending the clinic for treatment such as staff friendliness, the availability of education and support on taking ART, respect of privacy and the appreciation shown by staff of the difficulties of living with HIV (Figure 20).

The aspect that the participants were least satisfied with was the amount of time that they had to wait to see a doctor or nurse at the clinic (38.5%). This is not unique to PNG. In Botswana 57% of respondents reported that they spent four or more hours waiting at the clinic each time they visited (Hardon et al. 2007). Having to wait to see a health care worker meant sometimes waiting in very long queues outside the clinic where others could see them. For a few (‘Displa meri igo insait longdispla klinik em mas gat AIDS’) (Lyn, 23, Eastern Highlands Province) being made.

Therefore, attending clinics to access ART can in itself produce stigma. Some informants spoke of employing techniques to avoid shame, stigma and unwanted disclosure when accessing the clinic.

I don’t want people to know that that woman [I] have this sickness and she is going to the clinic. This type of thought comes to me. I feel ashamed. Now that I am married, it’s no good if my husband’s family says, ‘That woman must have this sickness and has gone into the hospital for AIDS people’. This thought still comes.
When I want to go I go through the x-ray room and then go to the back road and go inside. I go and spy, and if there is no one I know I go quickly inside the door. When I want to come back I spy and if there is no one I know then I quickly go outside to the back road. I go by myself. My husband follows me sometimes. My husband is usually afraid so he waits for me outside (Sophia, National Capital District)


The doctors and nurses are always smiling and saying hello like we are just normal people like everybody else...

However, not all participants felt the same shame:

I feel good to come and take medicine. When people stare at me I don’t mind. I’m happy collecting medicine and go back… I don’t mind and feel ashamed of people seeing me coming to the hospital. (Rebecca, Chimbu Province)

Mi save pilim orait long kam kisim marrasin. Ol lain lukluk mi no save bisi long ol tu. Mi save hamamas long kisim marasin na go bek… Mi no save bisi na sem long ol man lukim mi kam long hausik. (Rebecca, Chimbu Province)

Not everyone who participated in the qualitative interviews were happy with the clinics they attended. For Nathaniel it was over-crowded and he believed there was poor scaling up of ART to all newly diagnosed people:

From my point of view, I think these health workers can improve their performance on giving out ART to infected people. It will be better if the hospital system is efficient because sometimes the referrals to the hospital, we wait a long time. It usually takes extra time again to put them on ART. For our case, like people who are already on ART, when we come again we wait a long time as well because when it first started there weren’t many of us but now there’s so many and the Clinic is always full. So it seems that I see that we need more doctors, nurses and Clinics or similar sites where this sort of services facilities are provided so that people can go inside and have access to all this treatments or make this existing ones a bit bigger and provide a better service (Nathaniel, National Capital District)

Long lukluk bilong mi, ol dispela helt wokas, ol ken impruvim wok long givim ART long ol lain. I better em olsem may be em efficiency system bilong ol long hausik ya na sampela taim ol lain we ol I referim ol kam long hausik, ol save weit longpela taim. Save takim narapel a taim gen long ol go putim ol long ART. Olsem kain olsem mipela stap pinis long ART ya, taim mipela save kam ya, em mipela save weit longpela taim tu bikos bipo fes taim em mipela ol lain manneri namba I liklik. Nau planti lain save kam na klinik save pulap. So luk olsem mipela nidim ol planti ol dokta na nurses na mipela nidim olsem dispela klinik o ol sampela ol sites we ol operated ol dispela kain services facilities em can be bikpela liklik so that ol manmeri ken go insait gut na go accessim ol tritment gutpela liklik. (Nathaniel, National Capital District)

The aspect of attending the clinic that the participants were most satisfied with was that the staff were friendly (95.7%) and, as one woman from the National Capital District said of her relationship with the clinic staff:

My doctor advises me not to worry. I mean she checks me and jokes with me and all that so when I come I tell her about what’s happening at home with my husband. All those little talks makes me feel happy…The doctors and nurses are always smiling and saying hello like we are just normal people like everybody else. (Rita, 27, National Capital District)

The type of education and support that the staff provided focused on taking treatments on time but it also covered other aspects of living while on treatment such as nutrition, sexual practices and hygiene. There did not appear to be consistency in the recommendations provided in regards to sexual practices. While many were supported to sustain safer sex there appeared to be a number of health care workers who provided a different sex message. Under the guise of desirable outcomes such as improve nutritional intake on treatment and prevent the future transmission of HIV, health care workers are subtly, yet directly, trying to control the conduct of PLHIV:

Don’t eat greasy food, don’t have sex with like some other people and your hands and legs must not have cuts when you prepare food. (Monica, 32, Morobe Province).
This has particular consequences for sexual practices. Some people even became fearful of sex as a result of the health care worker's advice and have abstained from sex since:

It's like when I go for trainings they say that the dirt is below and the clean water is on top and when you shake this water the dirt and the clean water will mix like when you have sex with a man the virus of the man and the woman will work really hard and it will make you feel weak and symptoms will quickly appear and you will lose weight, feel very sick and die. I went to training and that's what they told me. That's why my thoughts on not sleeping with a man is strong this are strong and I won't sleep with a man and I must stay by myself and this virus disease will just live in me without any strength. (Tina, Chimbu Province)

Other support which was not about PLHIV conduct but helping to reduce stigma included counselling for the family and the village:

It's been two years since I was here and they [my family] have been receiving counseling as well and so now I feel that they feel free to talk with me, sleep, eat together, use blanket, clothes or share bits of food and other thing so now I feel that things are back to normal. It's like I went back and joined the family and have become their child again. At first I was also afraid of them but now I feel all right. And now, I am living like how we used to live before. They [the Sisters] also came and did some awareness and also gave some education sessions to my village...Some they understood and got the education from them like the school children, the working people or like those hospital staff and like those others coming and hugging us. (Salome, Southern Highlands Province)

The most extreme form of control exhibited by a health care worker regarding the sexual conduct of a PLHIV on ART was seen with Rondalis. Having experienced a profound change in her sexual desire since commencing treatment, she fell in love with and experienced a profound change in her sexual desire a PLHIV on ART was seen with Rondalis. Having

Other support which was not about PLHIV conduct but helping to reduce stigma included counselling for the family and the village:

Other support which was not about PLHIV conduct but helping to reduce stigma included counselling for the family and the village:

Em olsem ol I taim mi go long training nambaut [na] ol I tok pipia em I stap tamblo na klinpla wara em I stap antap na taim yu sekim dispela wara em pipia na klinpla wara bai mix, olsem taim yu sex wantaim man, em bai dispela virus bilong man na meri em dispela binatang em bai wok strong na em bai wokim yu na yu bai filim wk na sik bai sow aut hariap na skin blo yu bai lus na yu bai filim sik nogut tru na yu bai dai. Dispela em mi skul na ol I tokim mi olsem. Olsem na dispela tingting blo mi em I strong olsem mi noken silip wantaim man mi mas stap lo mi yet na dispela binatang em bai stap tasol na nogat strong bilong em. (Tina, Chimbu Province)

They told me not to eat greasy food and stopped me from having sex with men. Don't get married. They stopped me from eating cold food. Eat a lot of good food. You can go and get married but you will destroy yourself again so don't get married. (Rebecca, Chimbu Province)

Ol tokim mi noken kaikai ol gris kaikai na ol tambuim mi long noken silip wantaim ol man na dispela kain. Noken marit. Sampela ol tainbuim mi long noken silip naol kaikai na noken kaikia olsem, ol gutpela kaikai yu ken kaikai planti. Marit yu go marit tasol yu bai bagarap ken so noken marit. (Rebecca, Chimbu Province)

...I won't sleep with a man and I must stay by myself and this virus disease will just live in me without any strength...

...I won't sleep with a man and I must stay by myself and this virus disease will just live in me without any strength...

Nau mi stap ya em olsem mi sindaun igo go na olsem 2 years i kam igo na ol kisim counseling tu so nau mi pilim olsem ol pilim free long toktok wantaim, silip kaikai wantaim mi usim blanket clothes o olsem pilim half kaikai displa kain so nau mi feelim olsem bek to normal. Mi go bek joinim family ken na displa kain na kamap pikinini bilong ol gen na displa kain. Pastaim olsem mi tu fre gen long ol na displa kain na mi bin stap nau em olsem mi feel orait. Na mi stap normal gen olsem before mipla stap long em olsem mi stap gen. Olgeta kam na em bin kam wokim awareness long hap na wokim liklik toktok long hap long skulim ol. Sampela ol understand na kisim skul long em kain olsem ol skul pikinini na wok man meri o kain olsem ol haus sik wok man meri o kain olsem nabaut o kain holim passim mipla. (Salome, Southern Highlands Province)
I said, ‘I went to the hospital and all that and they didn’t give me the medicines because of you’. ‘If you didn’t come to the house and didn’t insist on marrying me, I wouldn’t have got a bad name’. Me, they will treat me well like before. (Rondalis, Western Highlands Province)

Mi tok, ‘Mi go long haus ik nabaut ya ol no givim mi marasin just bikos long yu ya’. ‘Yu no kam lukim mi long haus blong mi na yu no strong long manitim mi, em bai mi no nap kisim bad nem’. Mi ol bai trim mi gut olsem pastaim. (Rondalis, Western Highlands Province)

Wanting the research team to hear her story so that other young girls who undergo a renewed desire for sexual intimacy on ART do not get similarly treated she concluded by saying:

Later on who else will talk and they would fix this? Perhaps you’re afraid they’ll take you off ART and you’re hiding and coming; now you must go and tell the truth. Now, I am thinking of talking about this so I came so as to save others coming after me. ART doesn’t affect the desire to have sex. The desire for sex is still there. (Rondalis, Western Highlands Province)

Bihain bai husait bai toktok na ol bai streitim displa? Ating, yu prêt olsem nogut ol bai rausim yu long ART na yu hatim hatim na kam ya; nau yu mas go tokautim stre. Nau mi tingting long tokautim displa na mi kam olsem long seivim ol narapla kam bihain long mi. Olsem displa ART em mekim tu na ino mins olsem em stopim disaia blong pasin blong bungim bodi. Pasin blong bungim bodi em I stap. (Rondalis, Western Highlands Province)
Adherence

Adherence—not skipping a treatment dose and taking treatment at the prescribed time—is the most important factor for suppression of HIV and for the prevention of drug resistance. So too is the accurate assessment of adherence critical for the care of people with HIV. However, there are many different assessments of adherence, or rather a missed dose. This makes any straightforward understanding of adherence problematical. For example, in this study we did not compare rates of adherence made by people on treatment with those set out by their health care worker.

Lifetime adherence

Slightly less than half of the participants (45.6%) reported having ever missed a dose of their medication.

There were some regional differences in the proportions of people who reported having ever missed a dose ($\chi^2 (2) = 11.631, p = 0.003$). Those who lived in the Southern Region (59%) were most likely while those living in the Highlands Region (39.1%) were least likely to have ever missed a dose (Figure 21).

Although the relationship was statistically non-significant it appears that there is not uniformity throughout the Highlands Region regarding lifetime adherence. Those people who resided in Chimbu Province had the greatest lifetime adherence (68.2%) compared to those in the Eastern Highlands Province, where they reported the poorest lifetime adherence—less than 40% (37.5%) (Figure 22). However, the number of survey participants from the Eastern Highlands Province was extremely low.

Those who had been diagnosed with HIV for a longer period of time were significantly more likely to report having ever missed a dose ($\chi^2 (4) = 25.533, p = 0.000$). Those most likely to have missed a dose had been diagnosed with HIV between one and two years previously (63.2%), with those diagnosed less than six months previously (26.6%) the least likely to have missed a dose (Figure 23).
Not surprisingly, there was a significant relationship between the length of time participants had been on ART and having ever missed a dose ($\chi^2 (4) = 17.273$, $p=0.002$). Those least likely to have ever missed a dose were those who reported having been on ART for less than 6 months (32.4%). Those most likely to have missed a dose reported having been on treatment for one to one and a half years (58%) (Figure 24). The proportion of people who reported missing any dose of treatment did not vary significantly based on gender, church attendance, alcohol use, the source of treatment, occupation, education or having experienced any difficulty accessing treatment.

However, and very importantly, there was a significant relationship between religion and adherence. Excluding those who identified as Evangelical Alliance (because the number is too small) there was a significant relationship between religious affiliation and having ever missed a dose ($\chi^2 (6) =16.161$, $p = 0.013$) (Figure 25). Of all religious affiliations, those who identified as members of the Revival Church were significantly more likely than any other to have ever missed a dose of treatment (63.6%).

Implying an almost religious devotion, many of the participants spoke of taking their treatments ‘faithfully’.

*I don’t miss my ART; I faithfully take it.* (Nathaniel, National Capital District)

*ART bilong mi em mi no save lusim. Em mi save faithful long kisim.* (Nathaniel, National Capital District)

And the reason for this is because of the life it has given them:

*If I don’t take my medication it’s like I’m trying to kill myself so I must take this medication all of the time.* (Salome, Southern Highlands Province)

*Sapos mi ino drin marasin liklik em bai mi yet laik kilim mi yet so mi mas kisim displa marasin olgeta taim.* (Salome, Southern Highlands Province)

*Medication – some people may forget but I find it hard to forget because it has given me life and that’s why I’m still alive.* (Sasha, Southern Highlands Province)
Developing the notion of religious devotion to treatment as implied by taking treatment faithfully, Inok of the Southern Highlands Province shared that each morning when he woke for daily devotions he prayed the Rosary over his ART and then, and only then, when they were blessed, did he take them. He repeated this same dosing practice at the end of the day. Participants also spoke of maintaining adherence to ART to ensure the long-term effects of treatment, cautioning against what Stanley calls missing their medicine but what might be called a treatment break:

"I take ART daily so it can fence the virus. I see some people, many times when they see that they gain weight back they miss their medicine for some months and later they face some problems." (Stanley, 23, Western Highlands Province)

"ART Mi save kisim daily so em ken banisim binatang. Mi lukim sampela, planti taim oli kisim skin bek oli nabaut oli lusim ART sampela months bihain oli painim sampela kain problem nabaut." (Stanley, 23, Western Highlands Province)

The data reinforced the importance of religion in the lives of people living with HIV, both generally and specifically in relation to treatment. While not all of the participants believed that they will be healed of HIV by God, some did. One woman from Western Highland Province, who had recently been on a Revival crusade and told that she was cured and that she should now re-test for HIV, stated:

"One day I will quit this medicine, that's what I think because God will heal me." (Marianne, 24, Western Highlands Province)

Similarly, Monica from Morobe Province, who had just returned from a faith healing prayer group, was convinced she was healed and returned to the clinic where she had been interviewed the day before and shared with one of the researchers that she was returning to be re-tested.

**Adherence in the last week**

The majority of the participants (79%) had been 100% adherent in the previous week. This high rate of adherence was similar to results in other studies in the region. A study in China found that 80% of people on ART had been adherent to their treatment in the previous week (Wang et al. 2008) and another study in Australia found that 75% of their sample had been 100% adherent in the previous month (Herrman et al. 2008), whereas in India a recent study found only 60% of participants had been fully adherent (Cauldbeck et al. 2008). In this study, of those who had missed a dose in the previous week, most reported missing only one (7.8%), with a slightly smaller percentage having missed more than seven doses (5.7%) or two to three doses (5.4%) (Figure 26).

![Figure 26: Frequency of missing a dose in the last week](image)

A study by Murphy et al. (2000) found that one quarter of their patients believed that they were still adhering to their treatment if they took their treatment within a 24-hour period. With studies like this in mind, Llabre et al (2006) suggested that studies on adherence fix the time by which a treatment dose is late (for example four hours) so that adherence assessments could have greater compatibility. For this reason, and because of the implications of taking a dose of ART later than the prescribed time and not just missing the dose altogether, in this study, participants were asked how frequently in the last week had they taken their treatment later than the time the health care provider had advised they take it.
This was an appropriate wording for PNG since the ART prescribers give the person a specific time to take their treatment such as ‘7 am and again at 7 pm’. The majority (65.4%) of the sample reported that they had taken their treatment at the correct time as told to them by their ART prescriber. The most frequent number of doses taken at the wrong time in the previous week was two to three times (12.4%); however, a similar proportion had taken their treatments at the wrong time more than four times in the week before the study (11.6%) (Figure 27). Compared to a similar study in China, people in PNG were far more adherent to taking their treatment on time. In China, Wang et al. (2008) reported that only 21.1% of their sample took their treatment on time. Yet compared to the results of studies in Africa it appears that PNG is less adherent to the timing of treatment. In Tanzania, approximately 93% took their treatment at the right time while in Botswana 98% did (Hardon et al., 2006).

Facilitators and barriers

Together, these high rates of adherence in the previous week suggest that any problems with adherence in PNG are not currently of major concern. However, as people live longer on treatment, long after the most dramatic improvements in health and well-being and before long-term side-effects emerge, adherence may become increasingly important in PNG. Therefore efforts to sustain adherence are important. A similar argument has been made about adherence studies in Africa (see Mills et al. 2006).

Of the sample who reported having ever missed a dose since being on ART, the most common reason for not adhering to ART was forgetting to (51.2%), which is a common reason for non-adherence cited by other studies (Brigido et al. 2001; Lauret et al. 2002; Michaels 2005; Wang et al. 2008). Other common reasons included not having enough food to take with medication (15.3%), being busy looking after children (14.7%), medication being a reminder that they have HIV (13.5%) and other people being around at the time treatment is due (12.3%) (Figure 28).

A study in Rwanda found that the fear of having too much of an appetite and not enough food was an obstacle to adherence identified by 76% of the sample—the largest obstacle identified (Au et al. 2006).

There did not appear to be a significant relationship between education and adherence (ever having missed a dose, having missed a dose in the last week or in the last week not having taken medication at the time the doctor prescribed) or between gender and adherence.

When those participants who reported having ever missed a dose of treatment were asked if there were additional reasons for why they had difficulties adhering to ART, almost a quarter cited issues to do with time (24.6%) and being busy (24.6%). Issues to do with time included having woken up late and not having a watch or clock to identify the time to take treatment, in other words not having reminders to take treatment. Reasons given for being busy included doing house work, looking after grandchildren, talking with friends or shopping at the market. The people who identified availability issues referred to the availability of treatment in the hospital or in one case the failure of a health care worker to attend to the ward with the treatment (Figure 29). And as one woman on treatment described her reason for not adhering everyday:
Those who cited family-related reasons spoke of wanting to stay alive with their family and wanting to look after them or to stay alive and have children. ART effectiveness was a concern, with people saying that they wanted ART to work, to stop disease progression and to avoid opportunistic infections. Others reported reasons for adhering to treatment included being involved in the church, wanting to stay alive to receive healing from God (spiritual), wanting to extend their lives, to put lives in order, and to earn more money (personal) (figure 31).

Sometimes I get tired like taking tablets every day. (Rita, 27, National Capital District)

Among the entire sample, some of the most common reasons identified for adhering to treatment included wanting to look healthy (94.7%), not wanting to die (92.9%), following doctors advice (92.9%) and wanting the medicine to work (91.2%) (Figure 30).

Although living to look after family and to live long enough to see children go to school were the sixth and seventh most common facilitators for adherence identified by the sample, from the qualitative interviews the importance of children as a driver to live (and thus by implication adhere to treatment) was evident, particularly for women, who made comments such as 'I will look after my children' (Salome, Southern Highlands Province). For example, Gina who was infected after being gang raped and who conceived a child during the ordeal, gave up her child to a guardian soon after he was born. Months later her child was returned to her and of this she said:

I had no choice, I had to take it [my son], that was the very moment that ...it was really like I couldn’t control so... I said it was okay, the child was an innocent kid and I had to take responsibility even though I had no strength; I didn’t have enough strength to take care of the child. I took the child and I did everything I could do... So I had to stand up as a mother of a child and I said it was okay, I have to do something good and that was the decision that I made at that moment and good things came out of me. (Gina, National Capital District)

Of the participants who reported other reasons for adhering to their ART treatment, roughly equal proportions cited reasons to do with family (34.3%) and ART effectiveness (31.4%).
Food security and alcohol

Food

Food is important when taking ART because it is required to facilitate the adequate absorption of treatment and to help restore health to people with HIV. Poor food security, as Mukhrjee et al. (2006) writes, can threaten HIV and AIDS programs.

Since taking ART, 72.8% of the sample reported that they had experienced an increase in their appetite with two women describing the effect of treatment on their appetite in the following way:

*The medicine has expanded my stomach and I want to eat plenty of food.* (Gina, National Capital District)

*My sister-in-law used to say, ‘Before you don’t eat like that, now what’s wrong and you are cooking during the day?’ She will come and ask me like that. I used to say that it’s because of this medicine that it’s doing that. The snake that is inside is dead and I’m always hungry.* (Betty, Chimbu Province)

Meri tambu blong mi save tok oseem, ‘Bifo yu no save kaikai oseem nau yu oseem wanem na kuk long sun istap?’ Em bai kam askim mi oseem… Mi save tok oseem em dispela marasin mi drink na mekim. Sinek istap insait ya idai na mi hangre klostu, klostu’ (Betty, Chimbu Province)

Some 21.8% said that their appetite had stayed the same while 5.4% reported that their appetite had decreased since commencing treatment (Figure 32).

Concerning food, both of us find it difficult. No food—we just drink cold water and we go to bed… No food, I take treatment without it. I train myself in case there is no food; I take it without food even when it’s there. It’s not good if I take it everyday with food and sometime if there is no food then it will be hard to take medicine again. And it’s no good if I do this and then who knows what will happen to me internally, that I wouldn’t know. So what I do, one day I take it with food and the other day I take it without. Sometimes I take it with food and other times I take it without food. (Rosa, 23, Western Highlands Province)

Long sait blong kaikai mitupela save painim hat. Nogat em mitupela save drink kol wara na mitupela save silip… Nogat kaikai em mi yet save dring nating. Mi yet save lainim mi nogut nogat kaikai mi save kisim nating kaikai stap tu mi save kisim. Nogut mi kisim everyday wantem kaikai na sampla taim nogat kaikai em bai hat long dring marasin gen. Na nogut mi mekimi oseem na mi kisim bai insait blong mi bai wanem gen, em mi no save. So what mi save mekim wapela deim mi kisim wantaim kaikai na sampla taim mi kisim nating. Sampla taim mi kisim wantaim kaikai na sampla taim mi kisim nating. (Rosa, 23, Western Highlands Province)

City life is hard, we don't work. We don't work. I live with his relatives and they don't know what kind of woman I am, they don't know. Normally they just sit and do nothing and get hungry at lunch, then they look for food. But when he goes to the village and he doesn't stay in the house or goes to another place, I do not have any support. The centres are there. So I go to the centres to get a little food to go with my medicine. When there is no food I say ‘Ah I will not die’ so I drink a lot of water and take my medicine. Moresby food isn’t good. (Sophia, 25, National Capital District)

When those whose appetite had increased were asked if they had enough food to satisfy their hunger, 32.7% reported that they did not have enough food (Figure 33). A study in Africa found that in the initial stages of ART treatment when people experienced an increase in appetite, they could not afford the food to satisfy their hunger (Hardon et al. 2007).

In the words of those who could not afford food in PNG the following was shared:

*This was not a reference to lipodystrophy.*
Ol centres em ol stap. So mi save go long ol centres long kisim liklik kaikai long go wantaim marasin bilong mi. Stap nogat kaikai taim mi save tok ‘Ah mi nonap dai’, mi save drink planti wara na drink marasin. Mosbi kaikai ino gutpela. (Sophia, 25, National Capital District)

There was a significant relationship between region of residence and whether people whose appetite had increased since taking ART had enough food to satisfy their hunger ($\chi^2 (2) = 17.586, p = 0.000$). Those who lived in the Southern Region were most likely (52%) to report not having enough food to satisfy their hunger (Figure 34).

There was no significant difference between the proportion of people who reported having enough food to satisfy their hunger and gender. However, a higher proportion of males (74.2%) reported having enough food compared to females (63.4%).

### Alcohol

Discussions of alcohol (and other drugs) are common in relation to HIV-prevention and in positive living. In relation to prevention, alcohol is often thought to contribute to the spread of HIV and alcohol consumption has been feared to reduce adherence and interfere with ART effectiveness. The majority of participants in this sample did not drink alcohol.

Close to eighty percent of participants reported that they did not drink alcohol while 15% only drank once in a while (Figure 35). One of the men who continued to drink and smoke cigarettes on ART explained his behaviour as an attempt at normality:

This won’t help me but we feel normal so we just take it (Eric, 35+, Southern Highlands Province)

Dispela em no nap [helpim] tasol mipela save filim nomol so mipela sa kisim tasol. (Eric, 35+, Southern Highlands Province)

Amongst those who reported not drinking alcohol, the main reasons for not drinking were never having drunk alcohol (37.8%) and not drinking because they had ceased as a result of having HIV (27.6%) and/or starting ART (13.1%) with reasons to do with HIV making up 40.7% together. The high proportion that stopped drinking as a result of HIV- and ART-related issues highlights the importance placed by participants on adopting positive living habits in the presence of illness (Figure 36).

Having being diagnosed with HIV and then having to take ART for the remainder of their lives, many of the participants (both men and women) spoke of undergoing a profound change in their lives, often but not always coinciding with a religious conversion:

Before I used to drink and misbehave and all this but when I got this result, I don’t drink anymore. (Rosa, Western Highlands Province)
I used to tell them that, ‘I am a dead man, I already went six feet under but I came back through God’s power. He saved me and I have quit all earthly enjoyments, all bad behaviours of this earth and give your life to God’. (Ken, Chimbu Province)

Mi save tokim ol olsem, ‘Mi dai man ya, mi go pinis long six feet ya mi kam bek tru pawa blong God, em savim mi na lusim kainkain pasin hamamas, kainkain pasin nogut blong dispela graun na givim life blong yu long Bikman’. (Ken, Chimbu Province)

It’s like I used to go to parties, drink beer and have multiple sexual partner but I have changed this type of behaviour a bit. Because I am now living with the sickness I now can cause some kind of damage to my body while I’m on treatment and doing it. Or drink plenty beer or go partying where there is no good rest, no good food or like wise I know that I will destroy myself and will not live a long time. Now that I am on drug this ART medicine has changed my thoughts like if I want to live longer on earth I have to quit somethings. Like things that are good I must take hold of and do like take medication and eat good food etcetera. I mentioned something earlier on, on drinking and roaming around, this was when we were normal. And drinking when we were normal but now we are on medicine we have changed those things. Like it reminds us that now we are sick people so we must look after ourselves. (Sophia, National Capital District)

And like beer, [they said] don’t take alcohol. Alcohol it won’t help the body with medicine. So we take the medicine, beer is completely out of our head so we don’t take beer while taking the medicine. (Inok, Southern Highlands Province)

Of those who continued to drink while taking ART a greater proportion of the sample reported a decrease in alcohol consumption compared to those who reported that their alcohol consumption had increased or remained the same (Figure 37).

Sometimes this advice of abstaining from alcohol came directly from the health care professionals:

The message I got that was helpful for me was to take the drug on time, you be faithful, don’t have sex with multiple sex partners, and don’t have sex even you can go without sex for 2-3 months. And this is the other good information that I practice and have seen that’s helpful in my life. Okay, another they told me is not to smoke, not to chew betelnut, don’t drink beer, wash hands, concerning hygiene side, eat three balance meals per day. These are the things that normally assist me and helps my life and am living like that. (Norman, Western Highlands Province)

And like beer, [they said] don’t take alcohol. Alcohol it won’t help the body with medicine. So we take the medicine, beer is completely out of our head so we don’t take beer while taking the medicine. (Inok, Southern Highlands Province)

Of those who continued to drink while taking ART a greater proportion of the sample reported a decrease in alcohol consumption compared to those who reported that their alcohol consumption had increased or remained the same (Figure 37).
Disclosure of HIV status

There was a high level of disclosure before treatment where almost all people (91.6%) had disclosed their HIV status to at least one person before they commenced ART. The majority of the participants had disclosed to a member of their family, whether it be a parent (57.7%) or sibling (63.9%). The proportion of those who reported not having disclosed their status to anyone before ART is similar to that found in people on ART in Botswana and India (Wolfe et al. 2006; Ramchandani et al. 2007) (Figure 38).

One woman who was infected by her husband explained that she did not feel ‘guilty’ disclosing to her children that she had HIV because:

*I never went out looking for this; it came because of my partner...When I told the children they cried, the boys were really angry, they said they’ll go down to the cemetery now and break that [their father’s] headstone, really show their anger to this dead person.* (Audrey, Morobe Province)

However, not everyone felt ready to disclose their HIV status (or that of deceased family members) to their children:

*My children don’t know. We used to tell them that our father [father and two mothers] got sick and they died of malaria and typhoid.* (Sendy, Southern Highlands Province)

Ol pikinini biong mi ol no save. Papa bilong mipela tu, mipela save tokim ol osem [papa na tupela mama], em ol isik na ol idai...ol kisim malaria, typosid na ol idai. (Sendy, Southern Highlands Province)

Reflecting on her disclosure long before going onto treatment Sasha said that she has been completely open about having HIV:

*Oh that was a long time and I have already told so many men and women. Even before I started taking the medication I had already told so many men and women that I am this kind of woman. I come out in public and singing places where I hold the loud hailer and talk and give counseling to young men and women or those men and women that go around too much. I feel happy to tell them because I don’t want them to follow this road that I am on.* (Sasha, Southern Highlands Province)

The reason she felt comfortable to disclose was not a matter of being innocent as seen with Audrey from Morobe Province but because of her belief that we all have to die some time and HIV is just one way:

*I think that we are all going to die in the end. We will all die, this sickness just came recently but death has been around for a long time. When God created Adam and Eve, death was around and HIV has just come so HIV won’t kill us. Death is in any direction and PLHIVA, we can still be alive and people without HIV can die before us. It’s this thought that strengthens me to tell others that I have HIV.* (Sasha, Southern Highlands Province)

While a greater proportion of men (47.6%) than women (34.1%) had disclosed their HIV status to their spouses before ART, there was no significant relationship between disclosure and gender.

There was a significant relationship between region of residence and disclosure to parents before ART ($\chi^2 (2) = 20.179, p = 0.000$) A greater proportion of those residing in the Highlands Region had disclosed to their parent/s than those in the Momase or Southern Regions (Figure 39) and this may be due to more people living in their villages and being in closer proximity to their families than those who reside in other regions.

Of the 15 people who identified that they had disclosed to another person, four people reported that it was to their in-laws and another four reported that it was to other family members such as their aunt or uncle. The remaining reported disclosing to others such as members of the community, such as neighbours, while another identified having disclosed to God.
Among those who had not disclosed to anyone, common reasons reported were being afraid of others talking about their status (78.6%), afraid of being verbally abused (71.4%) and not wanting to worry their families (67.9%) (Figure 40).

It was not until he returned home that he understood what had happened:

I was getting ready for bed and my wife told me ‘I would like to talk to you’ and I said “What is it?” ‘I heard that you are HIV-positive’. I was really shock and I asked her, ‘Who told you that I was HIV-positive?’ and she said ‘Your mum told me’. Then I asked her who told my mum and she said Peter my brother told my mum that I was HIV-positive. I got very very frustrated. I got very very angry and I said ‘Why didn’t he tell me in the first place that I was HIV-positive if he knew my HIV status?’ (Inok, mid 40s, Southern Highlands Province)

I disclosed my status so the family is aware and they help me and we live together....

Disclosure is an ongoing process rather than a one-off event. While 91.6% of the sample had disclosed to someone that they had HIV before taking ART, only 65.6% of people had disclosed their HIV status to someone since being on ART. Going onto ART saw a 26% reduction in disclosure. The reason for this is unknown; however, rather than being an experience of increased stigma on ART, it may have been due to an improvement in health which led people to feeling that they no longer had to tell people. With similarly high rates of disclosure, one study in South Africa found that there was no correlation between being on ART and disclosure (Skogmar et al. 2006). For 62.4% of all participants, being on ART made it easier to tell others their HIV status while for more than a third, treatment did not facilitate disclosure (Figure 41).

Of the 15 people that gave other reasons for not disclosing, nine said they did not disclose because of stigma while another two said it was for reasons of self care. The remaining reasons such as concern for impact on others were reported only by one participant.

One of the participants who reported that he had not disclosed his HIV status to anyone before he went onto ART said it was because his family knew his HIV status before he himself did. After he had requested an HIV antibody test while in hospital in another province, his brother kept telling him that the results were not available.
For a person for whom ART had facilitated disclosure, treatment provided the opportunity to sit and think about disclosure:

At first, I did not disclose my status and I started ART. Even when I was taking ART, the first time I was on ART, I did not disclosed my status until I came to a time when I was sitting and thinking and weighing out and I was thinking to myself and I said, ‘Perhaps it’s better to sit down and tell the family I am with…’. I’ve got this problem and it’s not good that I hide it so I should talk to them and suppose they get ride of me from the house or whatever they want to do to me it’s alright but to be on the safe side I think it’s good to disclose to them… I disclosed to them and they didn’t get rid of me or get angry or didn’t do any other things, they said, ‘Oh it’s okay, you’re part of our family’. They all accepted me but they felt sorry for me. And we discussed about it and now we live together. Now that I’ve disclosed to the family from there on after I disclosed my status to the family I’ve not found any stigma or discrimination within the family because I disclosed my status so the family is aware and they help me and we live together. I felt abit safe as I was on treatment so I told them. (Nathaniel, National Capital District)

But people who are not like that, who are not positive, I don’t even disclose to them that I am taking this ART. Because sometimes they have this mentality that I am taking this medicine and I’m living long then they will say that there’s medicine that I can take and live long and then they might go and have unsafe sex. So that’s what I had in mind so I don’t disclose to other negative people that I’m taking ART but they know that I am a HIV - positive person but I am living positive. (Inok, Southern Highlands Province)

While some found it easier to disclose that they had HIV after going onto ART, there was a caveat to Inok’s disclosure where, although he was happy to disclose that he was HIV-positive, he would not disclose that he was on ART to people who were not HIV-positive:

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There was a significant relationship between gender and whether being on ART made it easier to disclose one’s HIV status ($\chi^2 (1) = 4.051, p = 0.044$). More men (68.9%) than women (58.3%) reported that being on treatment made it easier to disclose their HIV status (Figure 42) and this is most likely related to issues of stigma and blame.

Close to 90% of the participants reported being happy to very happy with the support they had received following disclosure (Figure 43).
Amongst those who disclosed their HIV status, the main types of support received were practical and physical support (38.4%) and emotional support (33.3%). Spiritual support was the least common form of support provided (Figure 44).

Examples of support provided by people who had been informed included, but were not limited to, the following:

*My mother, my sister they usually help me with firewood, gardening or some even find food. My [dead] husband’s relatives don’t help me that much.* (Dorethy, Southern Highlands Province)

*Mama bilong mi, sista bilong mi ol save helpim mi long sait bilong paiawod, gaden o sampela ol save panim kaikai. Ol lain bilong man, ol no save helpim mi tumas.* (Dorethy, Southern Highlands Province)

*Once they [my family] sent me K300.00 through the post office when my husband died. They said ‘You cook food for your husband and use it for his funeral’.* (Sendy, Southern Highlands Province)

*Wanpela taim ol [femili bilong mi] bin putim K300.00 long post office long taim masta bilong mi idai. Ol tok ‘Yu cookim kaikai bilong em na matmat bilong em’.* (Sendy, Southern Highlands Province)
Health and well-being

Besides reducing viral load, one of the primary goals of ART is to improve the health and well-being of people with HIV and this improvement in health-related quality of life has been well documented (Eriksson et al. 2000; Carrieri et al. 2003; Burgoyne and Renwick 2004; Hughes et al. 2004; Teixeira et al. 2004; Tramarin et al. 2004). For people living with HIV in Papua New Guinea, going onto ART meant an improvement in key areas of health and well-being, including physical and mental health, quality of life, satisfaction with health and importantly a reduction in the number of days in bed per month.

Physical health

Nearly 90% of all respondents reported that before going onto treatment their physical health had been bad to extremely bad (Figure 45).

Figure 45: Rating of physical health before ART

In comparison, on treatment only 10.4% of the participants reported that their physical health was bad or extremely bad (Figure 46).

Figure 46: Rating of physical health on ART

The greatest improvements on ART were seen amongst those who reported their physical health as either ‘excellent’ (28.4% increase in this category) or ‘good’ (28.3% increase).

Identifying the physical impacts of HIV on the body, two informants drew the following images:

Image 11: Impact of HIV on the body

Image 12: Impact of HIV on the body

The extent to which people felt that HIV had affected their physical health was related not only to what they could no longer do, such as work in the garden, but also to how they looked:

When I came down nobody recognised me; I went so dark like a saucepan. (Monica, 32, Morobe Province)\(^\text{13}\)

Mi kam daun em ol man ino luksave long mi; mi go dark nogut stre, olsem sauspen. (Monica, 32, Morobe Province)

Sometimes when strong winds blow from the mountains I used to feel that it would blow me away because I didn’t have any strength. (Jason, Southern Highlands Province)

Sampla taim strongpla wind i kam olsem long mountain mi pilim olsem em bai kam blowim na karim bikos mi ino gat strong stre. (Jason, Southern Highlands Province)

The effects of treatment saw people not just regain strength so they could ‘climb mountains and make gardens’ (Eric, 35+, Southern Highlands), but also, as Chris shared, look ‘normal’:

This best friend of mine said… ‘The medication has changed you, you’re a healthy man and you look just like us, a normal man’. (Chris, 33, National Capital District)

\(^\text{13}\) This reference to as dark as a saucepan refers to the saucepan darkened on an open fire.
And visually this impact looked like the following:

Image 13: The body after ART

Despite the clearly positive impact of treatment, this does not negate the side-effects that people also spoke of:

They had itchiness because I saw it on some of my friends that had started ART. Itchiness and nausea, felt like vomiting and we had to encourage that it will go away slowly. Eventually your body will get used to it and it will become normal. (Audrey, Morobe Province)

Mental health

Prior to treatment the majority of respondents (80.3%) reported that their mental health was bad to very bad. Only 9.2% felt that their mental health was good to extremely good before commencing ART (Figure 47).

There seemed to be at least two categories of causes for poor mental health prior to treatment. One was a response to being diagnosed with HIV (i.e. depression and suicidal thoughts) and the second was a consequence of viral activity (i.e. cognitive impairment or dementia):

...thinking made me deteriorate quickly. I ran away to Moresby, I wanted to commit suicide. I thought that was the end of me. (Jason, Southern Highlands Province)

...em tingting tasol mekim nau mi bagarap hariap. Mi ronawe go Mosbi, mi bin laik comitim suicide.. That’s the end of me, mi kisim displa kain tingting. (Jason, Southern Highlands Province)

I thought I should get a rope and hang myself and I will die. That was the main thought that came to me that time. I was depressed, I will hang myself and die or I will go to the road and get hit by car and die. This was the first thought I thought about then I thought forget it, I must try to go to the hospital and get medication. (Betty, Chimbu Province)

... thinking made me deteriorate quickly. I ran away to Moresby, I wanted to commit suicide.... (Betty, Chimbu Province)

No significant relationship was identified between physical health either before or after ART and gender, region of residence, time diagnosed with HIV, time on ART or occupation.

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Treatment had a positive impact on the mental health of the participants. There was a significant relationship between mental health prior to treatment and mental health after ART ($\chi^2 (4) = 15.858, p = 0.003$). Nearly 70% of those who reported that their mental health was bad to extremely bad before treatment rated their mental health on ART as good to extremely good. (Table 2)

<table>
<thead>
<tr>
<th>Mental Health rating before and on ART</th>
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<tr>
<td>Good to extremely good n (%)</td>
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<td>Good to extremely good</td>
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<td>Somewhat good</td>
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<td>Bad to extremely bad</td>
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<td>Total</td>
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Over 90% reported that their mental health had been good to extremely good since being on ART (Figure 48). Mental health on ART saw a reduction of 72% of participants reporting their mental health as bad to very bad. However, there were still people like Apa who felt that their mental health was poor as a result of both the virus and ART:

Sometimes you’ll get nightmares and bad dreams. Sometimes you’ll loose concentration. Like if a man is talking, and you think you’re paying attention and the man who is talking to you will think you’re paying attention but your mind is wandering and you’ll loose concentration. (Apa, National Capital District)

There was a significant relationship between ratings of physical health and mental health since being on ART ($\chi^2 (4) = 79.580, p=0.000$). Of those who reported that since commencing ART their physical health had been good to extremely good, 81.3% reported the same of their mental health. A third of those who reported that their physical health had been bad to extremely bad on treatment reported the same of their mental health on ART (Table 3).

<table>
<thead>
<tr>
<th>Relationship between ratings of physical and mental health on ART</th>
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<tr>
<td>Mental Health rating on ART</td>
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<tr>
<td>Good to extremely good n (%)</td>
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<td>Bad to extremely bad</td>
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<td>Total</td>
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There was no significant relationship between rating of mental health before or after ART and gender, time on ART, time since diagnosed with HIV or occupation.
Quality of life

The majority of participants (72.2%) reported that in the year before taking ART their quality of life had been very bad, bad or neutral. Only 5.4% reported that their quality of life prior to ART had been very good (Figure 49).

The majority (65.8%) of participants reported that with ART their quality of life had improved while fewer than 10% reported that compared to the year before treatment, their quality of life had deteriorated in the previous month on ART (Figure 50).

A third of participants who reported their quality of life in the year before treatment had been very good said that in the month before the survey their quality of life had deteriorated. Approximately 90% of all participants who reported that in the year before ART their quality of life had been bad to very bad reported that in the previous month on treatment their quality of life had improved (Table 4).

This improvement in quality of life has seen people return to working in their gardens, being more self-reliant and, as Sophia shows, enjoying life:

I was sick and about to die; ART brought me back and now I am living. It has changed me to be like the person I was before. Now I’m starting to look after myself in terms of food, in terms of staying with man and in terms of all these things I am fixing myself. Thinking clearly first not like before, not caring and roaming around aimlessly. Before I was weak which I mentioned; now I can roam everywhere. You talk about dancing put the music and I will dance. You talk about break dance, I will dance and the beer will go warm while I’m dancing on the dance floor. (Sophia, National Capital District)

Satisfaction with health

Before treatment the majority of participants reported that they had been unhappy or very unhappy (67.6%) with their health. By comparison, only 11% of the participants reported that they had been unhappy to very unhappy with their health in the previous month on treatment. On treatment the majority of the sample rated their satisfaction with health as happy to very happy (74.9%) (Figure 51).
There was no significant relationship between gender and satisfaction with health before or on treatment.

Not surprisingly, there was a significant relationship between satisfaction with health in the previous month on treatment and satisfaction with health in the year before treatment ($\chi^2 (4) = 15.858, p=0.003$). Of the people who reported that they had been happy or very happy with their health in the previous month on ART, 71.8% reported that they had been unhappy or very unhappy with it in the year before going onto treatment. This shows a very clear impact of treatment (Table 5).

There was a significant relationship between satisfaction with health in the previous month on treatment and rating of physical health on ART ($\chi^2 (4) = 24.330, p=0.000$). The majority (80.4%) of those who reported that their physical health on ART was good to extremely good rated their satisfaction with their health in the previous month on treatment as happy or very happy. Surprisingly 43.6% of the sample who reported that their physical health on ART was bad to very bad reported their satisfaction with their health in the previous month on treatment as happy or very happy (Table 6).

In the year before going on ART, more than a third (39.6%) of the respondents reported that they never spent time in bed. However, a similar proportion (37.5%) reported that they had spent almost every day of the month in bed before they had started ART (Figure 52).

Putting into narrative what ‘number of days in bed per month’ actually feels like, two women shared the following:

*I was dying and I only wanted to sleep in bed. I kept on doing that and I slept and slept.* (Marianne, 24, Western Highlands Province)

*Before my body was dead; I slept on my bed and didn’t get up and move.* (Rebecca, Chimbu Province)
Showing this experience of being bed ridden, one person drew the following (Image 14) to describe life before treatment:

![Image 14: Living with HIV before treatment](image)

In the previous month on treatment, 80.7% of the participants reported that they had ‘never spent a day in bed each month. This in turn meant that they could participate in family and community life. The previous month on treatment compared to the month before treatment saw a 33.7% reduction in the proportion of people spending everyday in bed. There was also a 41.1% increase in the proportion of those who reported that they had ‘never spent a day in bed’ in the previous month on treatment compared to the month before treatment. Again, this shows the positive impact of ART on the health and well-being of people with HIV (Figure 52).
Stigma and discrimination

Experiences of stigma create additional challenges for people with HIV (Busza 2001; Lau et al. 2003; Kalichman and Simbayi, 2004; Paxton et al. 2005). Research has shown that HIV-related stigma can affect quality of life negatively and can result in verbal and physical abuse (Klein et al., 2002; Ogden and Nyblade 2005). In this study, verbal abuse as a result of HIV was more common than physical abuse and women were more likely than men to experience both forms of HIV-related discrimination.

Close to half (47.3%) of the sample reported having experienced some form of verbal abuse as a result of their HIV status. A higher proportion of females (53.4%) reported being verbally abused than males (37.9%) (Figure 53).

Experiences of verbal abuse were higher amongst those who had disclosed their HIV status. Of those who experienced verbal abuse as a result of HIV, 77.6% had disclosed to someone. While the act of disclosure is important in facilitating the provision of care and support, it can also make a person more vulnerable to verbal abuse. This is not the first study to show that disclosure and HIV-related discrimination are enmeshed (cf. Busza 2001; Paxton 2002; Klitzman et al. 2004; Ogden and Nyblade 2005).

Not everyone had experienced verbal abuse and indeed some had experienced accepting and caring family and community environments. Eric’s wife usually treats us the best. They don’t swear at us, everything they do they treat us the same, they don’t divide us and say we’re sick people and go and sleep somewhere else, these things they don’t do. We will use the same things like plate, cup, betelnut, smoke, sleep in one bedroom, wash and use the same towel, this is all normal. (Eric, 35+, Southern Highlands Province)

Reflecting on how the village had first responded with gossip and discrimination Eric’s wife Salome shared the following:

I first told my mother about it and the both of us went and then she told my father, my sister and my other immediate family members later. People saw that my baby was breast feeding but when I stopped breast feeding the baby, the people in the village became suspicious, like how can the woman leave the child. The baby wanted breast milk and was really crying. And I carried him around and the villagers were asking a lot of questions as to why I was not attending to the child and the rumors started going around that I am infected with the virus so I can’t breast feed the baby. They were saying that my husband infected me with the virus and now I am one of those infected people … A little girl was in my house when I cooked sweet potato and gave it to my eldest daughter. That little girl was hungry so I gave her a piece and she ate it. She went to her house and told her mother that I gave her sweet potato. Then the mother asked her if I had had a bite from it before giving her or where exactly I had taken the sweet potato from and given it to her. The little girl told her mother that I had cooked the sweet potato over the fire and it was on the fire ashes when I gave it to her. And then the mother came shouting at me and asked why I had given the food to her daughter. She practically broke her daughter’s mouth putting in her fingers removing whatever remained of the food and washed her mouth with the bucket of water that was behind the house. She was like, ‘I am going to take her to the hospital and they will test her blood’. She said ‘Why did you give food to my child?’ When she said that we had an argument and I grabbed a pipe and wanted to crack her head but my sister came and stopped me. (Salome, Southern Highlands Province)
They don’t swear at us, everything they do they treat us the same, they don’t divide us and say we’re sick people and go and sleep somewhere else.....

Olsem mi tok ya, pastaim tru mi tokim mama bilong mi na mama bilong mi taim mitupla wantaim go na mama bilong mi gen tokim papa bilong mi, sista bilong mi na ol family bilong mi tasol bihain. Nau ol lukim olsem bebi drin susu na displa kain taim mi lusim em nau em olsem ol man meri long village ol suspect olsem how na meri lusim pikinini na displa kain. Pikinini laik drink susu na krai. Na karim em raun taim, ol man meri stat long askim askim narapla go go na displa kain na toktok spred out na ol harim olsem em kisim displa kain sik, man bilong em givim em displa kain sik na go ol bin tok olsem....Wanpla liklik gal ya em kam na mipla stap wantaim long haus bilong mi na mi kukim kaukau na mi givim long displa liklik gal bilong mi ya, first born ya na em tu na mipla kaukau nau na liklik gal ya kam stap na em hangre na so mi givim kaukau long em nau em kaikai go nau em go tokim mama bilong em. Em tok meri ya givim mi displa kaukau ya. Nau mama ya askim em na toktok em putim long maus na givim yu o em putim long wanen hap na givim yu? Na em tok negat em kukim na em stap long ashes long en na em givim mi. Nau meri ya kirap na toktok why na yu givim kaukau long pikinini bilong mi? Em singaut singaut ikam. Em brukim maus bilong pikinini bilong em, fingerim em nabaut na karim em go arare long haus na wasim em wantaim bucket vara. Ayo, nau tasol mi karim em go long haus sik na em bai testim biot bilong em, em tok. ‘Why na em givim kaikai long pikinini bilong mi’ em tok Nau em mekim displa kain toktok na mitupla kros fight gen na mi karim pipe go na mi laik brukim het bilong meri ya na mekim nau sista bilong mi kam na holim mi gen. (Salome, Southern Highlands Province)

Of those who reported experiencing some form of verbal abuse as a result of their HIV status, 40.4% reported that since going on ART this experience of verbal abuse as a result of HIV had either stayed the same or had intensified (Figure 54).

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Figure 54: Experience of verbal abuse due to HIV status for those who reported verbal abuse since taking ART

After going onto treatment and marrying an HIV-negative man Rondalis found herself the victim of gossip:

Because of you people are gossiping about me. I’m an HIV- positive woman and has married a good man [HIV-negative] and because of this I wanted to quit taking treatment and wanted to die. I wanted to suicide but didn’t want to. I said that and he replied, ‘No. You’re alive, a human being. Don’t do that’ (Rondalis, Western Highlands Province)

Yu mekim ya ol man toktok baksait long mi. Mi HIV meri na maritim gutpla man na displa kain so mi laik lusim marasin na mi laik dai ya. Mi laik susaid na mi les ya. Mi tok olsem na em tok, ‘Nogat. Yu laip ya, human being ya. Noken mekim olsem.’ (Rondalis, Western Highlands Province)

The majority (85.4%) of people in the study had not experienced physical abuse as a result of their HIV status. However, 14.6% did report some form of physical abuse that was linked to being HIV-positive.

For one young girl who was infected after having a sexual liaison with a school teacher the physical abuse and discrimination came from her family:

They said, ‘Don’t sleep in our house’; they hit me and say ‘Go and stay there’. They said, ‘You go and stay over there’. So I stayed at home. I sleep in a traditional grass house while they sleep in the permanent house. I sleep on the ground...My brother and sister they rejected me, only mama helps me. (Joan, 16, Southern Highlands Province)
Key findings - Stigma and discrimination

No significant relationship was identified between rating of physical health before or after ART and experiences of either physical or verbal abuse as a result of ART.

Other forms of discrimination which were not physical or verbal abuse also existed. This included the experience of Apa when he went to visit a sister:

When I went to my cousin sister’s house and when she saw me she didn’t talk to me and stayed at a distance from me. While I was there I was really hungry and I sat down and looked. When I went there, they were still cooking by the time I arrived but while I was sitting down they finished cooking. While I was looking she got a plate which they use to give food to the dog. She got the dog’s plate and washed it. After it was washed I sat down and saw her serve food and I thought it was the plate of food for the dog that she would give, but she got up and gave me the plate. At that moment I cried terribly and I didn’t eat this food (Apa, National Capital District)

Of those people who reported having experienced physical abuse, 65.4% said that it had improved since being on treatment while 34.6% said that their experience of abuse while on ART had either stayed the same or gotten worse (Figure 56).

Others feared discrimination and so accommodated their practices to avoid the possibility of it:

I came here and used a different name...because I didn’t want my family and especially my husband, cause I myself was shocked to find out that I had HIV, so I came in and used a different name so when I got really sick they would never know. (Rita, 27, National Capital District)

When I see them coming, I get frightened and take another route. I hide myself with an umbrella because of the way they react towards me; why should I talk to them? It’s not good if I go to talk with them and they don’t want to and run away from me. (Salome, Southern Highlands Province)
Mi lukim ol kam taim mi save fret long ol na saitim gen long displa sait rot na go o displa kain. Mi save haitim mi yet long umberalla o displa kain becos ol save wokim olsem na why na bai mi toktok long ol na displa kain? Nogut mi go na toktok wantaim ol na ol bai les na runaway o kain olsem. (Salome, Southern Highlands Province)

These rates and experiences of stigma and discrimination have been found elsewhere in the region. A multi country study in Asia that solely addressed these issues highlighted that that the majority of people with HIV experienced some form of discrimination as a result of HIV and that the majority of such practices were experienced in the health care setting. Furthermore, unlike the positive relationship between ART and a reduction in stigma expressed by some, an Indian study revealed that because of stigma only 3% of PLHIV on ART had managed to tell their family that they were HIV-positive (Panda et al. 2005). Research has also linked side-effects of treatments with stigma (Persson 2005).
Sexual practices

Improvements in health and well-being on ART and beliefs of reduced infectivity have been expected to increase sexual activity in the developing world (cf. Kaida et al., 2006). Although as Gina, a woman in this study, said, ‘everybody has the right to have sex’ (Gina, 33, National Capital District), there was a low rate of sexual activity amongst the sample in this study. Contrary to what may be expected with improved health on ART, these findings are not all that dissimilar to those found in other developing countries (cf. Kaida et al. 2008). A meta-analysis of studies on sexual behaviour and ART in developing countries shows that more than half of people on ART are practicing abstinence (Kennedy et al. 2007).

In the sample, 39.4% reported that they had had sex since being diagnosed with HIV while 60.6% had not. Since commencing ART even fewer had had sex: 36% reported having had sex since being on ART while 37.9% had had sex in the previous six months.

There is a significant difference between the proportions of men and women who reported having had sex in the previous six months with men more likely than women to have had sex in that time ($\chi^2 (1) = 4.03013, p = 0.045$) This level of women reporting sexual intercourse in the previous six months (33.8%) is slightly less than the average found in women across a three-country study of Brazil, South Africa and Uganda, where 46% had had sex in the previous month, but the same as that for women in Uganda (33%) alone (Kaida et al. 2008) (Figure 57).

There was a significant relationship between marital status and whether a person in the study reported having had sex in the previous six months ($\chi^2 (4) = 94.96396, p = 0.000$). Those participants who identified as being married or engaged (63.8%) were proportionally most likely to have had sex in the previous six months compared with people of any other marital status. Those who had never been married (4.2%) or were widowed (10.2%) were least likely to have had sex in the previous six months. Sexual activity for women in Brazil, South Africa and Uganda was strongly associated with marital status (Kaida et al. 2008) (Figure 58).

There is no significant relationship between time since being diagnosed with HIV and whether or not a person had had vaginal sex with a regular partner in the previous six months, but again we see a pattern which indicates that over time more people began to have vaginal sex with their regular partner (Figure 59).

What we should be preaching and telling people is, don’t do it…I still think that condoms aren’t the answer.

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14 Caution needs to be taken with the meta-analysis study by Kennedy et al. (2007), which they themselves acknowledge, because it is based on only three studies – the only published studies on sexual behaviour and ART in the developing world at the time that met the inclusion criteria. The paucity of research highlights not only the importance of this data to the growing area of research but also the need for more research that examines sexual behaviour and ART.
There was no significant relationship between the length of time on ART and having had vaginal sex in the previous six months with a regular partner. However, a pattern did emerge in relation to time on treatment and having vaginal sex. It appears that the longer a person is on treatment, the more likely they are to have vaginal sex with their regular partner. This may be a result of improved health and well-being or it may be a result of increasing confidence in living with HIV and less fear in being infectious as people feel their viral load decrease (Figure 60).

Surprisingly, there was no relationship between having sex in the previous six months and health and well-being either before or after commencing ART.

There was a strongly held belief amongst a number of the participants in the qualitative arm of the study that they must abstain from sex for a number of different reasons including, but not limited to, notions of social and individual responsibility to avoid transmitting the virus and having been counselled that to continue having certain sexual relations was a sin:

*What we should be preaching and telling people is, don’t do it…I still think that condoms aren’t the answer. The answer is no sex and that’s it.* (Isaach, National Capital District)

*I encourage other people not to dream about sex. You should abstain completely…it’s people living with the virus who decide whether this virus goes on or not. So if everyone is really honest and take responsibility and abstain from sexual behaviours the virus will die with them.* (Audrey, Morobe Province)

*I haven’t slept with another man. I was counselled that if and when you sleep with a man you will commit a sin and because of this I’ll stand before judgment in heaven. This disease is just like murder or killing of someone so you don’t sleep with another man. If you want to have sex, have sex only with your husband and always use condom. So since I got tested till now I have not slept with another man. I only stay with my husband or otherwise I am by myself.* (Salome, Southern Highlands Province)

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**Key findings - Sexual practices**

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**Sexual practices**

During that time I’ve not had sex with a woman, since the doctor told me I had the bad virus, I haven’t had sex with a woman because I thought that I would kill this woman. And this will multiply so this country will be destroyed, so I’ve said no to sex with women because that isn’t good. (Mek, Western Highlands Province)

Displa taim, mi no bin silip wantaim wanpla meri, taim dokta bin tokim mi olsem mi gat binatang nogut, mi no silip wantaim wanpla meri becos mi ting olsem mi bai kilim displa meri. Na displa em bai multiplim so bagarapim displa country, so mi tok maski long silip wantaim meri becos displa ino gutpela (Mek, Western Highlands Province)

I think I made up my mind and in my prayers I always tell the good Lord to uphold me and help me not to have the desire to have sex. So from 2004 till now I’m saying no to sex. (Joanne, Chimbu Province)

Yet for others, abstinence was a more personal issue:

Why? I don’t want it. This came about because of this so I don’t want it. (Monica, 32, Morobe Province)

Why? Mi ino laikim. Em kamap long displa kain samting so mi ino laik. (Monica, 32, Morobe Province)

There was also a fear that sex would lead to re-infection:

Before when I was not sick, I use to think that I want to sleep with men. Okay, now that I’m on medication I just don’t want to sleep with men. I said, ‘What if I give them my disease and they give me their disease [HIV] too like I will get double sickness or something’ (Betty, Chimbu Province)

However, for a few it was a matter of lacking the desire for sexual intimacy since commencing treatment:

Before I felt like having sex with anyone at anytime but now that I am on ART it had decreased my sexual drive. (Jack, 35+, Chimbu Province)

Bifo long displa, mi feelim laik long wokim raun taso taim kisim taim nau na mi start long ART, em daunim displa ol sexual pasin long laif bilong mi. (Jack, 35+, Chimbu Province)

**Sex with a regular heterosexual partner**

Of those who had had sex in the previous six months, 90.6% of participants reported having had a regular partner of the opposite sex. Of those with a regular partner 94.4% identified that they had had vaginal sex in the previous six months.

Only a few participants in the qualitative study spoke of an improved desire for sexual intercourse since commencing ART. One such woman was Sophia:

When I take drug it makes me want to have sex all the time. When I was normal [didn’t take ART] I didn’t like having sex. I saw sex as something, when my husband and I sleep on the bed I tell him not to touch me. I put the pillow and say, ‘That is your border on this side and my border is this side. (Sophia, National Capital District)

But I felt less when I took the medicine. Now I can’t help wanting sex all the time, my husband always tells me to stop touching him and I have to push him away. (Sophia, National Capital District)
Fewer than half (46.2%) of the participants who had had vaginal sex with their regular partner in the previous six months reported that they had always used condoms. Lower proportions indicated that they had never (22.7%) or sometimes (23.5%) used condoms. There was high condom use (62.2%) the last time participants had vaginal sex with their regular partner. This was slightly less that that found by Bateganya et al. (2005), where condom use by a person with HIV on ART was 71% at last sexual intercourse with spouse.

There were no significant relationship between gender and frequency of condom use or condom use at the occasion of vaginal sex with a regular partner. Interestingly, however, was that a greater proportion of women than men reported never using a condom while a greater proportion of men than women reported always using a condom (Figure 61).

In fact, from this study, the longer the participants knew that they had HIV the higher the proportion of those reporting always using condoms (Figure 62).

Knowledge of whether or not the use of condoms during sex could prevent the transmission of HIV from one partner to another did not influence participants' levels of condom use. Rather than time or knowledge being a factor for significance of frequency of condom use during vaginal sex it may be that use of condoms was an artifact of the counselling that was received.

There was no significant relationship between the length of time participants had been diagnosed with HIV and condom use with a regular partner at the last vaginal sex act (see Figure 63). However, after those who had been diagnosed between 7 and 12 months, those who reported using condoms the most were those who had been diagnosed for over 4 years. In terms of using a condom the last time they had vaginal sex with a regular partner, there was a 30 percent decrease in condom use among those diagnosed with HIV for between one and two years compared with those diagnosed for between seven and 12 months. From two years onwards there was an incremental increase. This suggests that there may be something happening in the lives of those diagnosed between one and two years which is influencing their sexual practices.
Excluding the two participants who identified as belonging to the Evangelical Alliance Church and had both used condoms the last time they had vaginal sex with a regular partner, the church denomination that showed the highest proportion of condom use at the last act of vaginal sex with a regular partner was the Lutheran Church (72.2%) followed by those who identified as Pentecostal (63.6%) and Catholic (61.9%). Those with the lowest condom use on last vaginal sex act were those who identified as United (50%) followed closely by Revival (57.1%) and Seventh Day Adventist (57.1%) congregational members (Figure 64).

Displaying a sophisticated knowledge of reduced viral load and the risk of HIV transmission, Sasha from the Southern Highlands Province and her husband, who is HIV-positive, speaks of having stopped using condoms since being on ART:

_The sister told me that the virus in the man might be passed on to me so I should use a condom, so she said for us to use a condom but the man used to say no. So when we are taking ART we sleep without using condom… Before when both of us were on Bacterium we used safety and sleep together but now that we are on ART he himself tells me that ART makes it difficult for the virus to pass through. He tells me this and I think that he is telling the truth._ (Sasha, Southern Highlands Province)

The majority (91.2%) of participants with a regular partner had not had anal sex in the previous six months. However, 11 people (8.8%) had had anal sex with a regular partner. Condom use for anal sex was very low with only two people (18.2%) reporting that they used a condom the last time they had anal sex with their regular partner. That is, nine people (81.8%) had unprotected anal intercourse. In comparison, a much smaller proportion of people reported any unprotected vaginal sex with a regular partner (37.8%).

One woman who spoke of having anal sex with her husband said that her husband would put her in all manner of ‘positions’ and perform all kind of ‘acts to my skin’ which caused her pain which she treated with pain killers and bed rest:

_I feel very bad and I normally cry. I used to tell him, ‘You are wrong’. Because he comes through the front [vagina] it’s not enough for him, he comes through my back [anus]. And I usually tell him, ‘Through the front I feel alright…’_ (Marianne, 24, Western Highlands Province)

Nearly all of the participants had disclosed their HIV status to their regular partner (91.8%). This rate of disclosure is much higher than that found in other studies, which report disclosure rates to partners at between 62% and 79% (Olley et al. 2004; Nachega et al. 2005; Skogmar et al. 2006). The majority (85.7%) of participants in regular heterosexual relations who had had sex in the previous six months knew the HIV status of their sexual partner. Of those who reported knowing their partner’s HIV status,

15 It is often assumed in PNG that serodiscordant relationships are rare but this figure shows that this is not the case or that if there are such relationships it will be men who are infected and not women. In a recent article in The Weekend Australian on HIV in PNG a story of a serodiscordant couple was highlighted and it was the woman who was positive (Toohey 2009).

16 Seroconcordant relationships are those where both partners are HIV-positive, serodiscordant relationships are those where one partners is HIV-positive and the other is HIV-negative while serononconcordant relationships are where the HIV-positive person is unaware of the status of their partner.
74% said their partners were HIV-positive while 26% were HIV-negative.\textsuperscript{15} Taking into account those who did not know the HIV status of their regular partner, a greater proportion of participants in regular heterosexual relationships reported these as being seroconcordant (64.7%) rather than serodiscordant (21%). A further 14.3% were in serononconcordant relationships (Figure 65).\textsuperscript{16}

Equal proportions of men and women were in seroconcordant, serodiscordant and serononconcordant relationships, with slightly more women in serodiscordant relationships (Table 7).

<table>
<thead>
<tr>
<th>Serostatus of regular relationship</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seroconcordant (n=77)</td>
<td>36 (66.7)</td>
<td>41 (62.1)</td>
</tr>
<tr>
<td>Serodiscordant (n=25)</td>
<td>10 (18.5)</td>
<td>15 (22.7)</td>
</tr>
<tr>
<td>Serononconcordant (n=18)</td>
<td>9 (14.8)</td>
<td>10 (15.2)</td>
</tr>
</tbody>
</table>

There were no gender differences recorded in the proportion of women and men who had disclosed their HIV status to their regular partner or who knew the HIV status of their regular partner. Although not significantly different, people in serodiscordant relationships are more likely to report always using a condom than those in concordant on nonconcordant relationships (60% vs 43.1% and 41.2%). Of concern is that those who do not know the status of their regular partner are more likely than those in any other relationship to report never using a condom (41.2%) (Table 8).

<table>
<thead>
<tr>
<th>Frequency of condoms use</th>
<th>Never n (%)</th>
<th>Sometimes n (%)</th>
<th>Often n (%)</th>
<th>Always n (%)</th>
<th>Total n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seroconcordant</td>
<td>15 (20.6)</td>
<td>20 (27.8)</td>
<td>9 (8.3)</td>
<td>31 (43.1)</td>
<td>72 (100)</td>
</tr>
<tr>
<td>Serodiscordant</td>
<td>2 (6.3)</td>
<td>6 (24.0)</td>
<td>2 (8.0)</td>
<td>15 (60.0)</td>
<td>25 (100)</td>
</tr>
<tr>
<td>Serononconcordant</td>
<td>7 (41.2)</td>
<td>2 (11.8)</td>
<td>1 (5.9)</td>
<td>7 (41.2)</td>
<td>17 (100)</td>
</tr>
</tbody>
</table>

While condoms are necessary for the prevention of HIV transmission, it is not always the choice of the person with HIV not to use them, as the experience of Rita, whose husband is HIV-negative, highlights:

\textit{We don’t use condoms when we have sex. My husband doesn’t want to use them. I tell him but he insists on not using them. Maybe he has accepted what I have…} (Rita, 27, National Capital District)

However, condoms were not absent in all serodiscordant relationships. As one man from the Southern Highlands Province shared of trying to guarantee the ongoing care of his children:

\textit{In my marriage, well I know that I’m HIV-positive and that if I have unsafe sex, then in love my wife and she loves me and we have children. Who will look after them? That’s the problem, the big problem that I have in my mind. So I have to stay positive and she has to stay negative.} (Inok, mid 40s, Southern Highlands Province)

There was a significant relationship between whether the regular partner of a participant in this study had HIV and the region of the participants residence (excluding the Momase Region) ($\chi^2$ (1) = 4.046148, $p = 0.044$). Of those who knew their partner’s HIV status, those from the Highlands Region were significantly more likely to have a regular sexual partner who was HIV-positive (78.8%) than those who were living in the Southern Region (55.6%) (Figure 66).
Casual heterosexual sex

The numbers who reported having casual sex are low so some caution needs to be taken not to overinterpret these figures. Only 22 people reported having vaginal sex with a casual partner in the previous six months. Of these people, 63.6% (n=14) reported that they had used a condom the last time they had vaginal sex with their casual partner. Slightly more than half of the participants who had had casual vaginal sex in the previous six months reported that they used condoms all of the time with their casual partner/s, while close to a third reported that they never used condoms with their casual partner/s. Of the 20 from the 22 who answered whether or not they had disclosed their HIV status to their casual sexual partner, 15 identified that they had not while five had. Three participants (two men and one woman) reported having had anal sex with a casual partner in the previous six months. Neither of the men had used a condom the last time that they had had anal sex with a woman.

He told me, ‘I love you and we live together. So according to my own faith, your sickness will not infect me’ he said....

The majority (70.4%) of participants reporting casual sexual partners had not disclosed their HIV status to their casual partner with a similar proportion (66.7%) not knowing the HIV status of their casual sexual partner. Some 33.3% knew the HIV status of their casual partner, the majority of whom (66.7%) were HIV-negative.
Sex work

The majority of men had not paid for sex with a woman in the previous six months with only ten men (7.7%) in the sample reporting that they had done so. Of these ten men, six had bought sex five or less times within the previous six months with three men buying sex once or twice a month. Only one man reported that he had purchased sex six to ten times a month for the previous six months. Of the nine men who had paid for sex in the previous six months and answered the question on condom use with female sex workers, six said that they had used a condom the last time that they had vaginal sex with a female sex worker with two saying they sometimes did and one reporting that he never used them. Only one man who reported buying sex from a woman reported that he had engaged in anal sex with the female sex worker. He also reported that he sometimes used a condom.

Male-to-male sex

Very few men reported having had male-to-male sex. Only five (3.8%) of the total number of men reported having had male-to-male sex. All men who had had male-to-male sex had casual and no regular partners. In relation to sexual positioning, two of the men were receptive while two were insertive. One man was both insertive and receptive. Of these men, four used condoms all of the time with their casual partners while one man never used them. The one man who never used condoms was the only man not to use a condom the last time he had engaged in anal sex with another man and his preferred sexual position was penetrative. Of these five men, two said that their casual partner/s knew that they had HIV while three said that they had not disclosed. One of the five men was aware that his casual partner had HIV while the remaining men were unaware of the HIV status of their casual partners.

While none of the men in the quantitative study reported having had sex with both men and women in the previous six months, in the in-depth interviews Nathaniel spoke candidly of having sexual intercourse with both ‘gays’ and women:

In-regards to my sex life, after I found out my HIV status, I have had sex. I had cut down on my sex life but on the way I think I had sex three times only. It’s like when I haven’t had sex for a long time I feel like I must have it. It’s been a part of me already so I have to do it; at least I had sex three times. This three times I had sex, once was with a woman and the other two. But this other woman that I fucked, I was a bit scared because woman do go around and I don’t know so I was a little scared and I used a condom and fucked her (Nathaniel, National Capital District)

Nathaniel’s sexual practices point clearly in the direction of needing to address sexual practices rather than sexual identity in the prevention of Papua New Guinea’s HIV epidemic.
Recommendations

Ongoing research into the lives of people with HIV generally and people on treatment specifically is needed.

Knowledge acquisition for people who test HIV-positive should be seen as an ongoing process rather than a one-off event to address knowledge and beliefs about HIV transmission such as mosquitoes. It may also be important to look at how HIV knowledge is imparted in the clinical encounter. People with advanced disease, in particular those suspected of having central nervous system involvement as evidenced by memory loss, motor and behavioural changes, should be provided with the antiretroviral therapy preparedness education again once they start ART treatment and their mental health improves.

While the ART is itself free, accessing treatment is expensive with the most common barrier to access is financial cost. Financial costs of travelling to treatment sites need to be taken into account. It may be that governments and faith-based organisations need to address structural issues such as location of ART sites so that people do not need to travel vast distances. For example, it may be worth considering training health care workers at the district level to prescribe ART, especially in the Highlands Region where access is most difficult.

Continue to use culturally appropriate language to describe the effects of ART on the immune system and HIV replication. The success of this strategy was evident from the way people in the study were talking about ART being a fence, which is the image used in the ART preparedness chart employed by ART clinics in PNG to describe the impacts of ART.

Strengthen the Expert Patient Trainers (EPT)17 program staff to understand the complexity of, and ability to address issues of sex, sexuality and sexual intimacy with health care workers. Incorporate sex, sexuality and sexual intimacy training into all HIV training courses, including but not limited to ART prescriber and testing trainings.

Safe sex messages need to be reinforced not only for vaginal sex but also for anal sex, irrespective of whether this is between two men or a man and a woman. Anal sex needs to be more widely discussed as a mode of HIV transmission amongst the heterosexual community.

Within safe sex messages, the discussion by many health care workers needs to be broadened to address other practices including masturbation, oral sex and other creative safe sex practices. Abstinence should not be the primary safe sex message given to people living with HIV.

Care and support needs to be developed to address an emerging group of people living in serodiscordant couples.

We need to work closely with the Revival Church in order to bring about better adherence to ART treatment regimes of its members.

A sustainable and long-term food program must be developed, particularly the Southern Region, to address issues of hunger for people on treatment. It is important that issues of food security are not trivialised and that they are addressed immediately since food shortage is the second most common reason for non-adherence to ART.

Although almost all people were satisfied with their support following disclosure, being on ART was less likely to support women to disclose their HIV status. Therefore, programs need to be developed that address issues that are specific to women around disclosure. These programs may also need to include reminding women (and men) that they have a right to disclose when ready.

Counsellors need to be well trained in handling issues surrounding disclosure and experiences of HIV-related discrimination including how to support people using the HIV/AIDS Management and Prevention Act 2003 (the HAMP Act). The Law and Justice Sector needs to be aware of and trained in the HAMP Act so that PLHIV who experience HIV-related stigma and discrimination which are discordant to the law are supported in pursuing their legal rights.

Programs to support women with HIV need to address the women’s vulnerability to experiences of HIV-related verbal and physical abuse. In addition, programs that facilitate PLHIV to have a greater awareness of and access to using the HAMP Act need to be supported.

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17 EPT is training provided by HIV-positive people to health care workers in the care of PLHIV as part of their ART prescribing training, which is part of the Integrated Management of Adult Illnesses (IMAI) training.
References


