Hope in a Time of HIV and AIDS:

Port Moresby, Papua New Guinea: a pastoral approach

by

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Abstract

*Hope in a Time of HIV and AIDS: a pastoral approach* seeks to develop strategies for pastoral ministry that might nurture hope. The study is informed by evidence gathered from social research and reflective engagement with the Christian tradition. It addresses the question, what is it like living with HIV in Port Moresby today? It investigates the effect of an HIV diagnosis on people in relationships and the influence of cultural and contextual factors. Employing ethnography as its method, data were collected using participant observation, in-depth interviews and document analysis. Data analysis used a grounded theory approach.

The study concludes that people find hope for living by drawing on the resources of the community, especially support from caregivers within the family, from faith communities and by accessing health services. They can manage their infection and find enjoyment in their lives. On the other hand, people living with HIV who have no home or resources in the city and depend on government, community and church services for care, struggle to survive. Faith sustains many in times of crisis.

Strategies for pastoral ministry include support and care of individuals and families affected by HIV and also encompass social, cultural and political action to strengthen communities and challenge the structural injustice underlying the HIV epidemic.
Statement of Authorship

I affirm that this thesis contains no material that has been accepted for the award of any other degree or diploma in any university or other institution. To the best of my knowledge, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Signed: ..........................................................

Date: ...........................................................
... you have rescued me.

Psalm 22.21c

I came that they may have life, and have it abundantly.

John 10.10b
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## Abbreviations and acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABC</td>
<td>Abstain; Be Faithful; Use a Condom Prevention Strategy</td>
</tr>
<tr>
<td>ABC</td>
<td>Australian Broadcasting Commission</td>
</tr>
<tr>
<td>ADB</td>
<td>Asian Development Bank</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>AusAID</td>
<td>Australian Agency for International Development</td>
</tr>
<tr>
<td>BAHA</td>
<td>Business Coalition Against HIV and AIDS</td>
</tr>
<tr>
<td>CBCPNG/SI</td>
<td>Catholic Bishops' Conference of PNG and Solomon Islands</td>
</tr>
<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
</tr>
<tr>
<td>CP</td>
<td>Central Province</td>
</tr>
<tr>
<td>EHP</td>
<td>Eastern Highlands Province</td>
</tr>
<tr>
<td>FBO</td>
<td>Faith Based Organisation</td>
</tr>
<tr>
<td>GP</td>
<td>Gulf Province</td>
</tr>
<tr>
<td>HAMP</td>
<td>HIV and AIDS Management Policy</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HREC</td>
<td>Human Research Ethics Committee</td>
</tr>
<tr>
<td>IMR</td>
<td>Institute of Medical Research</td>
</tr>
<tr>
<td>K</td>
<td>Kina (PNG currency)</td>
</tr>
<tr>
<td>MCD</td>
<td>Melbourne College of Divinity</td>
</tr>
<tr>
<td>MRAC</td>
<td>Medical Research Advisory Committee</td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother to Child Transmission</td>
</tr>
<tr>
<td>NAC</td>
<td>National AIDS Council</td>
</tr>
<tr>
<td>NACS</td>
<td>National AIDS Council Secretariat</td>
</tr>
<tr>
<td>NCD</td>
<td>National Capital District</td>
</tr>
<tr>
<td>NDOH</td>
<td>National Department of Health</td>
</tr>
<tr>
<td>NGO</td>
<td>Non Government Organization</td>
</tr>
<tr>
<td>NIV</td>
<td><em>New International Version of the Bible</em></td>
</tr>
<tr>
<td>NRI</td>
<td>National Research Institute</td>
</tr>
<tr>
<td>NRSV</td>
<td><em>New Revised Standard Version of the Bible</em></td>
</tr>
<tr>
<td>NSO</td>
<td>National Statistical Office</td>
</tr>
<tr>
<td>OIC</td>
<td>Officer-in-Charge</td>
</tr>
<tr>
<td>PLWH</td>
<td>People Living with HIV</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living with HIV and AIDS</td>
</tr>
<tr>
<td>PMGH</td>
<td>Port Moresby General Hospital</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>PMV</td>
<td>Public Motor Vehicle</td>
</tr>
<tr>
<td>PNG</td>
<td>Papua New Guinea</td>
</tr>
<tr>
<td>SHP</td>
<td>Southern Highlands Province</td>
</tr>
<tr>
<td>SI</td>
<td>Solomon Islands</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Program</td>
</tr>
<tr>
<td>UNFPA</td>
<td>United Nations Population Fund and Population Reference Bureau</td>
</tr>
<tr>
<td>UNGASS</td>
<td>United Nations General Assembly Special Session</td>
</tr>
<tr>
<td>UNICEF</td>
<td>United Nations Children’s Education Fund</td>
</tr>
<tr>
<td>UPNG</td>
<td>University of Papua New Guinea</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
</tbody>
</table>
Glossary

The following are Melanesian Pidgin words used in the text.\footnote{Francis Mihalic, *The Jacaranda Dictionary and Grammar of Melanesian Pidgin* (Milton, QLD: Jacaranda, 1971).}

*Words belonging to other local languages are translated in-text, only.*

- **Belhat** (English: belly hot) angry
- **Bikhet** (E: big head) disobedient, proud, disrespectful
- **Bikman, Bikpela** (E: big man, fellow) God
- **Bilum** traditional string bag
- **Buai** betel nut, popular areca nut for chewing
- **Bumbums** brand of disposable baby napkins
- **Danis ples** (E: dance place) night club
- **Gutpela sindaun** good relationships, living harmoniously
- **Haus krai** (E: house cry) gathering of family, friends to mourn a death
- **Kai ba** (E: food bar) food shop
- **Kastam** (E: custom) traditional way of thinking, acting
- **Kundu** traditional drum
- **Motu** language of the Papuans
- **Pamuk meri** prostitute
- **Ples** (E: place) village, home, ancestral land
- **Raskols** gangs involved in crime
- **Sik bilong ples** illness with no scientific explanation, associated with village, sorcery
- **Sretem ol samting long ples** to resolve some conflict within the clan or village
- **Tambu** in-law
- **Tok pisin** (E: talk Pidgin) Melanesian Pidgin language
- **Tok ples** (E: talk place) language of the village, local language, mother tongue
- **Wantok** (E: one talk) same language group, tribesman
- **Wasman** (E: watchman) guardian, shepherd
1. Introduction

If people cannot speak of their affliction they will be destroyed by it, or swallowed up by apathy. It is not important where they find the language or what form it takes. But people’s lives actually depend on being able to put their situation into words, or rather, learning to express themselves, which includes the nonverbal possibilities of expression. Without the capacity to communicate with others there can be no change. To become speechless, to be totally without any relationship, that is death.¹

A story

As I walked around the ward Ellen caught my eye. She was sitting up on her hospital bed, cross-legged, watching me approach. I smiled at her and she smiled back. She was neatly dressed in a colourful skirt and top. I could see no signs of illness. She was alone. I sensed in her an eagerness to talk. I paused and shook her hand. We introduced ourselves. She talked about herself: twenty-six years old, married with three children. At this point of her story she began to speak more quickly. Her youngest child, her three-month old daughter, had died late the previous year in the children’s ward of the hospital. She was clearly distressed as she told the story, though, rather than crying openly, she held back her tears and spoke with a smile that hid the deep emotions she was expressing.

Reaching for a small purse under her pillow, Ellen pulled out four photos. But they were not ordinary photos. Someone had cut around the figures in the photos making each of the four photos smaller and emphasising the members of her family, their moods and their relationships. The first was a photo of Ellen and her husband. The photo captured a happy moment. The next photos of Ellen’s two older, lively children made me smile. The photos, also small and cut around the figures, showed two vivacious children at play. In the last picture a baby lay in a decorated box. Closer inspection revealed that this tiny child was lying in a small coffin, surrounded by colourful flowers, her eyes closed. I was deeply moved as I gazed at this photo with all the grief and loss and hopes of a mother for a much-loved child. This photo, too, had been cut and was the shape of the little coffin. There was no clue as to the setting, just the coffin and the still child, surrounded by signs of deep affection.²

² Ellen is not alone. Compare Maura’s poem Bundle of Joy expressing her feelings on losing her two babies to AIDS. Maura Elaripe Mea, Hope for Living (Port Moresby: np, 2001). See Appendix 1. See also Manoka’s story, Appendix 4.2
1.1. **Background**

In 2001 I completed a study that reflected on my ministry among people living with HIV. I became aware of how little is known about the experience of people in Papua New Guinea (PNG) who suffer both as a result of their positive Human Immunodeficiency Virus (HIV) diagnosis, from Acquired Immune Deficiency Syndrome (AIDS) related illnesses and particularly from many forms of rejection within family and in the wider community. Listening to many stories, I discovered how a person can find life through facing death: in the midst of suffering hope is often born. In PNG, researchers have given little attention, as yet, to pastoral aspects of care. Continuing to work one day a week, as a pastoral caregiver, at Port Moresby General Hospital (PMGH), in 2005, as a researcher, I designed a further project. Its purpose was to find out how one group of people living with HIV, dying of AIDS-related illnesses and suffering from stigma and discrimination, find meaning and hope in their lives.

*Hope in a Time of HIV and AIDS* is a research project in the field of Ministry Studies. The Ministry Studies program explicitly engages the insights of the social sciences and the resources of the Christian tradition. In this way it recognises the cultures and the contexts of communities involved in Christian ministry and the distinctive role of the Christian minister. Here I draw on the insights of cultural anthropology and the Book of Psalms. The primary focus of the study, then, is on the context and the experience of ministry. The project seeks to demonstrate the integration of theory and practice in my own pastoral ministry.

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4 HIV and AIDS are distinct. The person living with HIV may have no symptoms of illness but the result of a medical test shows the presence of HIV in the blood. AIDS, on the other hand, occurs when the HIV virus breaks down the body’s immune or defence system. AIDS is the condition of being unable to recover from common diseases like malaria, diarrhoea, tuberculosis (TB), pneumonia or meningitis because the body has insufficient defence. AIDS refers to the more visible manifestations usually associated with late-stage disease. The term HIV/AIDS refers to the disease in all its stages.

5 See Chapter 3: Research Design and Methods for discussion of ‘pastoral’.
“AIDS is an unprecedented crisis and poses exceptional challenges.”

Speaking at the 2006 AIDS Summit, UNAIDS executive director, Piot, stated that twenty-five years after a mysterious pneumonia came to be named AIDS, 65 million people have become infected and 25 million killed by HIV. “Today”, he adds, “it is the leading cause of death of women and men aged 15 to 59. Half of all new infections are in young people.”

Discussing advances in HIV and AIDS prevention and care, he notes, that in most countries, there is a reluctance to confront sexual behaviours and drug use. This has led to failure to help people protect themselves from HIV, failure to end discrimination and stigma and failure to provide treatment. But now there is hope that signs of commitment to fighting AIDS will begin to lessen the suffering caused by HIV. The number of people in poorer countries receiving antiretroviral therapy (ART) has greatly increased. In 2005 alone 300,000 lives were extended. Funding for the global response to AIDS has continued to increase. Funding reached $A10.8 billion in 2005. How the global financial crisis of 2009 will affect funding is not yet known.

The problem of turning the tide when there are an estimated 14,000 new infections and 6,000 deaths every day is not easily solved. Severely affected African countries like Lesotho and Botswana are in a state of emergency. Food security is threatened because of AIDS, the lack of service delivery, especially in the rural areas, and the breakdown of the transfer of knowledge in homes and schools because so many children have lost one and often both parents. HIV flourishes in a society where there are unjust structures. Entrenched poverty, the low status of women, stigma and discrimination and an oppressive global economic system are fuelling the epidemic.

Faith communities have often provided refuge for people rejected by society. At the same time, Piot cautions, faith based organizations (FBOs) can also be places that reinforce stigma. “Effective action is paralysed by unwillingness to address the issues men and women are facing in their daily lives.”

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7 Piot, "Desperate Race." 3.
Of those people worldwide who are living with HIV and AIDS, the majority are in developing countries such as PNG. Locally, there can be wide variations in infection levels between provinces and districts, and between urban and rural areas. Despite a growing accumulation of medical data since HIV was first identified in PNG in 1987, research into cultural factors related to HIV began more recently. Cultural factors can facilitate the rapid spread of the virus and may also suggest responses to reverse this trend. Research has also been limited to a small number of the many cultural groups of PNG. Qualitative methods seek to gather data which might help explain why statistics show increasing prevalence. So far, however, a cultural study in Port Moresby has not been reported. Because this disease is often surrounded by a culture of silence, little is known of how it affects people’s lives.¹⁰ In particular, a study that gathers information from those infected with HIV and those affected, is lacking. Therefore, the aim of this study is to create such knowledge. Access to this knowledge may be of help to people living with HIV, their caregivers, to policy makers, to Churches and to others who seek to protect themselves and their families from HIV and to ease its burdens.

### 1.2. **Aim and Scope**

The aim of the project is to develop strategies for pastoral ministry. These strategies are informed by evidence gathered from social research and reflective engagement with the Christian tradition to nurture hope for living. The goal is to help form, sustain and shape communities where faith is expressed in mutual care and support.¹¹ To achieve its aim, the project first addresses the question: What is it like for someone to live with HIV in Port Moresby today?

The project is also designed to develop a sound theological foundation for the Church’s mission in a time of AIDS. The model of theological reflection adopted here proceeds

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through four phases – immersion, analysis, reflection, action. This process addresses the questions: What is happening? Why is it happening? What are the root causes? Then, in the light of Christian tradition: What does this mean for the Christian community? The final question is: What can be done in this situation? What pastoral strategies are called for and how might they be implemented?

The study is based at Port Moresby General Hospital (PMGH). Participants, numbering thirty-five, were in one particular medical ward or clients of the Sexually Transmitted Infection (STI) clinic, 18 years or older, who could communicate in English and were sufficiently stable to participate in an interview. The data were collected over the years 2005-7. Contact with the hospital and with several participants continued until analysis and writing were completed. Having been a pastoral caregiver at PMGH since 1993, I set aside that role for the period of the research.

1.3. Thesis overview

Chapter two provides background to the study. It describes PNG and its people, beliefs about illness and its treatment, current information relating to health, PMGH and Church responses.

Chapter three discusses the research design and methods. The selection of ethnography to study the hospital setting is explained and justified. Procedures for gaining entry, recruitment, how ethical issues were addressed and techniques for ensuring rigour are described. Finally, data collection and analysis are explained. The strengths and limitations of the design and its methods are also discussed.

Chapters four, five and six present the findings of the study around the themes of family, caregivers and meanings. Findings related to the ethics of studying vulnerable subjects and of implementing a research design in a cross-cultural setting are noted. Chapter seven

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12 This reflection may vary when undertaken by other FBOs or could adopt the values of the UN Human Rights Charter.
identifies and discusses some of the issues of pastoral significance and proposes a theoretical framework.

Chapter eight contains theological reflection offering further insights. Ancient prayers of lament among the Psalms are brought into dialogue with the personal stories collected in the study. The thesis then proposes pastoral strategies and ends with discussion of the achievements and limitations of the project, recommendations for further inquiry and conclusions.

All participants’ names are pseudonyms. Care has been taken to mask place-names and other identifying details. By recounting the stories, giving the disease a ‘human face’, I hope to contribute to lessening the climate of fear and shame associated with AIDS and to increase understanding and a commitment to action. Listening to people’s stories begins the work of healing and of building communities where life can be shared and hope can grow for we are reminded, “people’s lives actually depend on being able to put their situation into words, or rather, learning to express themselves .”

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14 Soelle, Suffering, 76.
2. Background to HIV Ministry in Papua New Guinea

We the people of Papua New Guinea – united in one nation, pay homage to the memory of our ancestors – the source of our strength and origin of our combined heritage, acknowledge the worthy customs and traditional wisdoms of our people — which have come down to us from generation to generation, pledge ourselves to guard and pass on to those who come after us our noble traditions and the Christian principles that are ours now.¹

“Papua New Guineans are often misunderstood by outsiders”, writes Yoseph Tumbe Mangi.² Outsiders often assume that PNG is made up of a homogeneous group of black people who have just come out of the Stone Age and who need to be guided along the path of development. How do scholars understand this land and its people?

The aim of this chapter is to position the study in the context of previous research and current developments in PNG. It describes how Papua New Guineans approach life, illness, and care of the ill. It begins with a brief geographical and historical survey followed by description of the people and their culture with attention to structural injustice and the recent rapid rise in the number of people living in poverty. Next there is information relating to health and to Port Moresby General Hospital (PMGH). Finally, it describes some Church responses.

² Yosep Tumbe Mangi, Understanding Our Own Kind: An Introduction to Anthropology (Port Moresby: National Research Institute, 1998), 153. Mangi belongs to the first generation of PNG lecturers at the University of PNG.
2.1. **Papua New Guinea**

a. **Geography**

PNG is an independent state in the South Pacific. It comprises over 600 islands in addition to the mainland which makes up 85 per cent of its land mass. The terrain of the mainland is among the most rugged in the world. Seventy-five per cent of land is covered by rainforest. Significantly, 97 per cent of land (462,000 km$^2$) is held by customary landowners, giving them considerable rights over land use. The country is divided into 20 provinces and four regions. Census figures (2000) show a total population of 5,190,786 - rural 87%, urban 13%. Projected growth is illustrated below (see fig. 1, Table 1).

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**Figure 1: Papua New Guinea: Provinces**

*Source: University of Papua New Guinea: Geography Department*

Geography plays a pivotal role in the identity and growth of a people and a nation. The physical features of the country have considerable bearing on development generally and the prevalence of illness, its treatment and care. Developing effective health services and

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providing access to them is made more difficult because of these physical challenges. Factors such as access to information, health and education, communication, markets and transport services play a significant role in the unabated spread of HIV and an appropriate and effective response to it.

Table 1: Population growth in Papua New Guinea 1966-2020

<table>
<thead>
<tr>
<th>Year</th>
<th>Pop.(mil)</th>
</tr>
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<tr>
<td>1966</td>
<td>2.2</td>
</tr>
<tr>
<td>1971</td>
<td>2.4</td>
</tr>
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<td>1980</td>
<td>3.0</td>
</tr>
<tr>
<td>1990</td>
<td>3.8</td>
</tr>
<tr>
<td>2000</td>
<td>5.2</td>
</tr>
<tr>
<td>2010</td>
<td>6.5</td>
</tr>
<tr>
<td>2020</td>
<td>8.1</td>
</tr>
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</table>

b. History

In the pre-colonial era the people of New Guinea and the offshore islands lived in small, virtually autonomous societies. Trade, marriage and tribal warfare created links. However, most communities remained distinct with no regional government or political organization. There were kinship obligations to local groups; these continue to be very strong. Exchange and retaliation or ‘payback’ were and remain important means of social control.\(^6\) The colonial era, from around 1880 was marked by the Dutch annexation of the western half of the island (known today as the province of Papua or Irian Jaya in Indonesia), then Germany annexed the north-eastern section and Britain declared a protectorate over the southeast. After World War II the existing territories were combined under Australian rule. Finally, Papua New Guinea became independent in 1975.\(^7\)

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Table 2: Three Periods of PNG History

<table>
<thead>
<tr>
<th>Period</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-colonial Era</td>
<td>Before 1880</td>
</tr>
<tr>
<td>Colonial Era</td>
<td>1880 - 1975</td>
</tr>
<tr>
<td>Post Independence Period</td>
<td>1975 on</td>
</tr>
</tbody>
</table>

PNG’s political history since Independence is particularly relevant to this study. Pokawim offers an analysis pointing to features that are producing stability in government such as longer terms of office. The present lack of goods and services for the majority of the people is acknowledged by Government as unacceptable. Solutions have yet to be found. The collapse of health, and to some extent, education services in rural areas, where 87% of the population live, is of major concern.

Political parties and elections show that coalition governments have an average life span of only about 2.5 years, largely due to votes of no confidence - evidence of instability. From 1987 to 2002 no government lived out its full term of office. Frequent changes of government, together with corruption, abuse of power, nepotism, misuse of public funds, lack of allegiance to parties, lack of transparency and accountability have taken their toll. This complex political history forms a backdrop to the present study (see Appendix 2).

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c. Culture

As the white people came into our country and as we lived with them we got ourselves accustomed to Europeans’ lifestyle. We forgot all about our customs. And we used to say where are all our good customs are they hidden or what? This new life came in and spoiled all our societies. Bad things came and good things have gone.\(^{12}\)

PNG is marked by cultural variation. Migrations from Southeast Asia and from the Pacific Islands have created considerable diversity, not only from one region to another but sometimes among close neighbours.\(^{13}\) Contact with traders, missionaries, colonial administrators and now multinational companies, is bringing further dramatic social change.

Recently, the initial findings of policy makers and field practitioners argue for considering the cultural context when designing HIV communication, treatment and care programmes.\(^{14}\) It points out, firstly, that promoting a biomedical approach to HIV and AIDS to the exclusion of social and cultural approaches misses opportunities to engage with local communities. Secondly, consideration of culture is often narrowly interpreted to mean behaviour and in the context of HIV this often means behaviour change. A clear, simple strategy is proposed as a means of containing the spread of the virus rather than building dialogue, participation and empowerment through an understanding and appreciation of local cultures.

Culture cannot be easily defined. One widely accepted definition considers culture as: “not only the arts and letters, but also modes of life, the fundamental rights of the human being, value systems, traditions and beliefs.”\(^{15}\) This holistic definition of culture recognizes that there are many ways of living, being, knowing and expressing identity in word, music and dance. Developing a theology of culture, Gorringe explains human beings as ‘suspended in


webs of significance they themselves have spun. Culture is the name for those webs'.  

He builds on the work of Geertz whose symbolic anthropology views culture as a shared communication network that sends messages along vast and elaborate interconnected routes. Culture is like a web of signs that are bearers of messages and their meanings. The shared symbols, Geertz sees, as a set of plans, recipes, rules and instructions. Considering the work of the Church in the midst of diverse communities, Luzbetak understands culture as a ‘socially shared design for living’ noting the characteristics that have usefulness for theory and practice.

Given the complexity of the term ‘culture’ and considering that PNG has the most complex linguistic composition of any country in the world and hence diversity of cultural systems, working in the nation’s capital city to which representatives of all these cultures are drawn is always going to be an enormous challenge. Spoken languages number as many as 849. Outside the urban context English is rarely used. Police Motu and particularly Tok Pisin are the language of the majority. When patients speak only their local language or have no formal schooling they have limited means of communication. Importantly, each language group has its own distinctive culture, its own symbols, rituals and myths reflecting a world view. And so concepts of health and illness may differ significantly. Some have adopted new ways while others retain traditional thought-patterns.

Kinship is one of the most important aspects of the culture - a system that governs how people should relate to one another. The principle of extending kinship relations indefinitely forms the basis for the wantok system. The expectation that a wantok who belongs to the

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wider group of kin will help in case of illness in the city is today often a cause of frustration. There is a tendency for wantoks to be large in number in good times when there is some kind of wealth to be shared; however, in difficult economic times wantoks who are not related by blood are few in number.

Research highlights that cultural variation is a critical issue when dealing with all aspects of HIV/AIDS. Clear, basic language is essential. Sexuality is a subject linked with taboos. Talking openly about sex is not easy. As yet, AIDS is a disease that has no cure so to talk about it can stir up strong emotions. Sensitivity is required at all times. Traditional understandings of health, illness and treatment will be discussed below (see 2.2.a).

d. Economy

*As our unacceptable income levels and social indicators highlight, the real cost of failed policies is poverty and (lack of) human development.*

Subsistence farming is still the way of life for many today; types of farming are varied. Some depend on paid employment. For Melanesians, resources include land, time, labour, knowledge of magic, past favours and so on. For instance, vegetables may be exchanged for magic knowledge. Moreover, large quantities of wealth are acquired by Melanesians for the purpose of giving them away at ceremonial occasions. It is still this world view of the pre-colonial era that has the greatest influence on modern PNG.

Economic change has brought considerable social disruption. The trend towards individual ownership of land has often created social conflicts. Labour migrations have weakened traditional forms of social organization and control. As the younger generation is offered...
formal education, the elders may lose their traditional authority and respect. All of these
trends contribute to social problems such as crime, alcohol abuse, gambling and prostitution
and the rapid spread of HIV. There are indications of increased permanence of city
residence for urban migrants. However, a circular pattern of migration remains common.²⁵
Rural residents, particularly in Chimbu and parts of East Sepik, are concerned about the
return of urban migrants and their children to a situation of increasingly limited resources.²⁶

Poverty and lack of human development are often the result of failed Government policies.
It is generally agreed by community residents and local leaders, church leaders,
government, non-government and private sector that poverty exists in both rural and urban
areas when people have too little of the following: jobs and cash, land, education, services
such as health care, water supply, transport and roads.²⁷ In addition, people list the
breakdown of the family as a contributing factor to poverty through divorce, use of drugs
and criminal activity. The definition must include both the income and non-income
dimensions of poverty.²⁸ This broad notion of poverty has been adopted.²⁹

Detailed data for understanding poverty is found in a PNG Household Survey.³⁰ These data
conclude that 93% of the poor live in rural areas. Across the four regions 38% of the poor
live in the Highlands, 36% in Momase, 13% in Southern, 9% in the Islands while the National
Capital District (NCD) has 4%. The poor have lower literacy rates and depend heavily on the
agricultural sector for their living. Poverty rates are lowest for the small minority that has
the advantage of a wage earner. PNG has a high level of inequality with the gap between
rich and poor growing; members of the wealthiest quartile earn more than eight times the

²⁶ Allen, "Geography," 59. Note ‘Chimbu’ is spelt ‘Simbu’ by other writers.
²⁷ Asian Development Bank, Priorities of the Poor in Papua New Guinea (Manila, Philippines: Asian
Development Bank, 2002).
²⁹ Department of National Planning and Rural Development (DNPRD), PNG Poverty Reduction Strategy 2003-
377-380. See below for more recent statistics.
income of the poorest. “As a result, the lives of the poorest people have changed little from
the way their predecessors lived prior to colonialism.”

The average annual income is $US510. The kina is the local currency with a value of $US0.30
and $A0.40. Referring to data from 2007, the UNDP Human Development Report 2009
highlights the “very large gaps in well-being and life chances”. The Human Development
Index for Papua New Guinea is 0.541 giving PNG a rank of 148 out of 182 countries. On the
Poverty Index the figure is 121 out of 135.

e. Religion

Describing religious experience and attempting to communicate how a Melanesian
understands the cosmos, Narakobi stresses that Melanesians do not differentiate religious
and non-religious experience: “experience is a total encounter of the living person with the
universe which is alive and explosive.” At birth, the Melanesian is “endowed with a sense of
history, purpose, a set of values, and a vision of the cosmos by which ... life is guided ... given
a culture and autonomy within a defined community territorially and in terms of human
relationships.” Thus, born into a spiritual and a religious order, much of life will be devoted
towards the maintenance and promotion of this order. Death is the end of human life. It is
also transformation. The living shed one ‘cloak’ and put on another as a snake sheds an old
skin. The person is reborn at death and lives on as a living being. Today, Melanesian
knowledge of the universe has been widened to embrace the encounter with Jesus Christ.

Mantovani, as ‘onlooker’, attempts to discover underlying principles of conduct and
behaviour. Value is a reality that possesses a certain quality making that reality desirable,
motivating people to acquire, or defend it. Community, which is understood as the need for good relationships with one’s kin, is most important. With cultural change the desirable qualities and the way they are expressed can drift apart. The expression can continue but the qualities are lost. Traditional values include: community, life, relationships and exchange. All of these come into play when someone is struck down with illness.

The quest for life and participation in the power of life, which find expression in magic, medicine and sorcery, are best seen as expressions of religious systems. MacDonald suggests that these forge links between aspects of human experience by the use of symbols. Images found in everyday speech or in dreams evoke healing and new birth. Life is experienced as cosmic and as communal, in relationships to land, to ancestors and to kin, hence the importance of burial in traditional land. Traditional medicine and healing practices, and their underlying belief system, can help to develop an understanding of the Melanesian world view and how such healing practices may be a valuable resource today for a sik ino gat marasin (a sickness that has no medicine).

Faith plays an important role especially in the lives of women. Research on faith may help understanding of female caregivers’ stories. The Religion of Relating investigates the link between kinship and spirituality. Arguing that elderly Jewish women give religious significance to the mundane relational realities of life, Sared illustrates how religious duties are described in relational terms. Relationships do not consist of a series of encounters but rather form the paradigm through which the women interpret and organize their lives. Religious ritual, including prayer, links relationship with God to interpersonal relationships. This link between kinship and spirituality is relevant to the behaviour and attitudes of caregivers, their spiritual needs as well as those of the patient. A “profound belief in the omnipotence of God [is] combined with an intense concern for the happiness, health and

fertility of [the women’s] extended families ...”\textsuperscript{39} They shape their religious world around behaviours and symbols aimed at safeguarding ancestors and descendents.

Statistics for Religious Affiliation are presented in Table 3 below. Zocca concludes that the historical mainline churches are losing ground in favour of more recently arrived denominations.\textsuperscript{40} Included in the category of mainline churches are Anglican, Catholic, United and Lutheran. ‘Other Christian churches’ include Seventh Day Adventist, Salvation Army, Evangelical Alliance, Pentecostal, Mormon, Jehovah Witness, and others\textsuperscript{41} ‘Other Religions’ include Baha’i, Buddhism, Hinduism, Islam and Judaism.

\textbf{Table 3: Religious Affiliation for Papua New Guinea and National Capital District.}


<table>
<thead>
<tr>
<th>Religion</th>
<th>PNG</th>
<th>%</th>
<th>National Capital District</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christian</td>
<td>4,934,098</td>
<td>96.0</td>
<td>229,662</td>
<td>94.6</td>
</tr>
<tr>
<td>Other</td>
<td>72,406</td>
<td>1.4</td>
<td>7014</td>
<td>2.9</td>
</tr>
<tr>
<td>None</td>
<td>30,733</td>
<td>0.6</td>
<td>873</td>
<td>0.4</td>
</tr>
<tr>
<td>Not stated</td>
<td>103,239</td>
<td>2.0</td>
<td>5,336</td>
<td>2.2</td>
</tr>
<tr>
<td>Total Population</td>
<td>5,140,476</td>
<td>100</td>
<td>242,885</td>
<td>100</td>
</tr>
</tbody>
</table>

In summary, Papua New Guineans are characterized by much variation. Beneath what, at first, may seem homogeneous lies considerable complexity.


2.2. **Health and Illness**

When illness strikes the poorest families have no transport to urgently access medical assistance. Women and children suffer particular disadvantage. Women’s health concerns are closely related to the multiple roles they play. Their social and cultural environments place them at increased risk. Important factors that affect women’s health include their level of education, their treatment in their marriages and their workload. Heavy workloads in subsistence agriculture, multiple pregnancies and extended breastfeeding place stress on women’s bodies. They also often lack an appropriate diet. Nutritional problems are related to education, access to a variety of foods and to money. The high incidence of sexually transmitted infections (STIs) is linked to a lack of relevant information. Every year the number of women infected with HIV increases. Because of gender inequality, women living with HIV/AIDS often experience greater stigma and discrimination.

Unfortunately, in a five-year period, 1995-2000, more than 300 aid-posts providing basic health services closed and this trend is continuing. Statistics indicate that outpatient visits, antenatal care and the rate of supervised deliveries of babies is declining significantly. Births in health facilities number only 13.4 per cent. Family planning is not widely used with less than 20 per cent of women using any method of contraception. The sick in the villages have little help available. Their need for treatment and care forces them to the towns and cities where lack of income, housing and gardens brings further disadvantage. A brief review of literature from a cultural perspective follows.

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a. Explanatory models

Wholehearted conversion to Western medicine is the exception.45

Practices today in relation to illness and misfortune are the outcome of the day-to-day experiences of preceding generations.46 To understand how people interpret their illness and select ways to lessen its impact, it is first necessary to examine the general categories to isolate the range of meanings and their relevance in the case of HIV. Firstly, the terms ‘disease’, ‘illness’ and ‘health’ require definition.

For Lewis, ‘disease’ depends on both biological and social facts; it can be extremely difficult to unravel the exact connections.47 ‘Disease’ covers many conditions - malaria, multiple sclerosis, hernia and heart failure which doctors consider to be medical matters. However, ideas about ‘illness’ are diverse. ‘Illness’ refers to the experience and meaning of perceived disease. Behaviour in illness is the outcome of a complex mixture of forces: biological effects of the illness, local explanations, cultural conventions and responses. It enables a focus on the cultural meaning of the illness and interpretation of its significance. It is the common ground bringing together biological, cultural and social components of illness.48 Discussing diagnosis and the classification of illness he states that people are less concerned about a precise diagnosis than interpreting the personal significance of the illness.

Similarly, people’s attitudes to someone’s illness are influenced by ideas about its cause. This is especially the case of implied responsibility or by the injustice of suffering.49 Some conditions are strongly linked with particular situations. Moral judgments easily arise because some behaviour evokes strong social disapproval and the sick person will bear the

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48 Ibid., 98-99.
49 Ibid., 111.
added burden of stigma. For instance, there are strong moral rules governing sexual behaviour, so STIs are associated with special stigma and shame. Another reason for stigmatizing the sick person may be that the disease disfigures or handicaps. This instance can prompt people to try to make sense of the suffering in moral terms such as rewards for good or evil.

In English ‘health’ has a range of meanings. One component is the absence of disease. However, health is not so simple. Frankel defines ‘health’ in the Huli culture (SHP). A person who has an infected toe or a passing sore throat might still regard themselves as basically healthy. But to be unhealthy, in addition to being sick, is to become sickly. Health, then, is a state of resilience, a state of comparative invulnerability to disease. It is a ‘state of complete physical, mental and social well-being’. This concept of health extends beyond merely adequate functioning and suggests ‘wholeness’. However, Frankel cautions, ‘wholeness’ is a moral more than a medical concept.

In Huli, and some other PNG languages, there is no word for ‘health’. There is instead a constellation of ideas and actions that relate to the concept. To a considerable extent one’s own and one’s children’s health is regarded as evidence of one’s skill and resolve in maintaining health. The absence of health then is likely to be seen as caused by one’s own carelessness or the wrong-doing of others.

Sorcery is given as the cause especially for those complaints that the doctor cannot cure. Studying the Kutubu (SHP) Williams, like Frankel, notes that sickness is often linked with morality. In the Eastern Highlands Glick observes rituals relating to healing. Sickness and its relief are clearly a concern and the underlying beliefs seem to have more in common with religion than modern medicine.

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51 WHO Charter. Quoted in Ibid., 53.
Sorcery is understood to mean that some symbol of the victim is subjected to treatment which represents in symbolic form the sickness that will inflict the victim. The intended result is considered inevitable because of some added supernatural element that is known only to the sorcerer. The ease with which HIV and AIDS can be linked with sorcery can be inferred from this. The urge to inflict harm or death on the suspected sorcerer has lead already to the murders of suspected sorcerers, often marginalized and innocent members of the community.54

Traditional treatments fall into three categories: common-sense, expulsive and placatory. The first includes dressings of leaves for wounds, blood-letting for headache or snake-bite or resting in a quiet and comfortable place. Expulsive treatments are based on the idea of disease as an intrusive element. These methods require special powers in the ‘doctors’ who practice them. An example is massaging the limbs and body, pinching the flesh very hard, rubbing towards the extremities continually removing hands from the body of the patient with what resembles a plucking motion, with a motion of throwing away something. The aim is to locate the sickness or its cause in some portion of the sufferer’s body, to shift it to the extremities and hence cast it out of the body.55 These ideas about illness and its treatment can help understanding of the sick.

Medical pluralism - the coexistence of differing medical traditions - is the norm in all but the most isolated parts of the world. However, the increasing unavailability of health services is likely to also increase dependence on traditional treatments. Added to a range of other Western treatments, antiretroviral drugs have been introduced. How do people, with their own traditions of illness and healing, respond to new theories of disease causation and drug treatments they must observe daily for the rest of their lives? The data that Frankel and Lewis analyse and the questions they discuss under the theme of continuity and change are important for an appreciation of the context into which HIV and AIDS have come.

54 Media reports are collated in Franco Zocca and Jack Urame, Sorcery, Witchcraft and Christianity in Melanesia, Melanesian Mission Studies, No. 5 (Goroka, EHP: The Melanesian Institute, 2008).
While HIV is incurable with present knowledge, people can still exercise some control over the consequences for their lives. They can adopt the idea of ‘living positively’ - maximising their general health, minimising secondary infections and spreading to partners and children and seeking social, emotional and spiritual support. Taking such steps has been shown to be beneficial among groups where the epidemic is more advanced. These steps, adjusted to PNGs socio-economic and cultural setting, may be relevant.

To summarize, PNG societies have never been static. There is little evidence that before European contact, traditional societies’ knowledge of illness and treatment of the sick was a specialized field. On the contrary, care of the sick was a part of family and local obligation. This has important implications when people are living with HIV and dying of AIDS. Religious rituals are a part of this care and ideas about illness are part of a distinctive world view.

b. HIV and AIDS in PNG

In 2002, HIV prevalence rose above 1 per cent among antenatal clients at PMGH signalling a generalised epidemic. Given the limited information it is known that statistics considerably under-measure the actual state of the epidemic. By June 2008 the number of confirmed cases is almost 25,000 (see fig. 2). Estimates put the number much higher.

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57 National AIDS Council Secretariat and Partners, UNGASS 2008 Country Progress Report: Papua New Guinea (Port Moresby: 2008), 10. The doctor at Porgera Mine, Enga (2006) reported that of 646 clients tested, 50 results were positive (8%). Philip Gibbs and Zelia Cordeiro, "Mist in the Mountains: HIV and AIDS in Porgera," (Papua New Guinea: National Catholic Family Life and the Melanesian Institute, 2006). By 2008 a new STI clinic in Port Moresby reported nearly 7% of clients were positive. Maureen Gerawa, "Grim HIV Story," Post-Courier (Port Moresby), September 29, 2008. These small samples are taken in particular contexts; however, they do suggest that HIV may be increasing rapidly.

Though data are incomplete the primary means of HIV transmission in PNG is unprotected heterosexual intercourse. 69 60-70% of truck drivers and military personnel and 33% of port workers report paid sex in the previous year. 60 Unprotected sex between men might also be a factor in PNG’s epidemic. One survey reports more than 12% of young men said they had sex with men. Condom use is rare. 61 Known infections involve almost equal numbers of males and females, but infected young women is the group with highest and increasing numbers (see fig. 3). 62 The number of HIV positive women aged 15-24 attending antenatal clinics in Port Moresby rose from 0.15 per cent (1998) to 0.3 per cent (1999) to 1.07 per cent (2003).
Heterosexual intercourse with multiple partners, in the context of very high rates of STIs, means that HIV affects men and women equally. Data on age distribution and sex show that the majority of cases for which information are available are found in persons aged 20-29 years followed by the age group 30-39 years. The number of persons aged 15-29 years who are infected with HIV has increased significantly. In this age group female cases far outnumber male cases. This is similar to the distribution patterns in other developing countries and underlines the serious vulnerability of girls and young women.

Gender aspects of this vulnerability include: women’s low life expectancy because of health risks posed by childbirth, malnutrition and malaria; a literacy rate about 10 per cent lower than men; limited employment opportunities – women may have less access to medical services, counselling and support; they struggle to survive and to feed, clothe and educate a family. Some trade sex for money or other gains. Men often exercise violent aggression towards women to assert their authority, making them victims of coerced sex in situations that expose them to HIV. The graph also illustrates the pattern of infection in children. Babies are most likely infected due to parent to child transmission. Infection in children raises the question of sexual abuse.
Data collection systems - important for understanding trends and developing policy and programs to provide treatment and care - were established when the first cases were diagnosed but there are still major problems. In some cases, age and/or sex are not recorded, affecting reliability of data and reporting. There are also problems with providing feedback to health workers regarding the information collected and integrating the data into planning and everyday practice. Surveillance traces the trends and characteristics of the epidemic. Combined with surveillance, social science research can contribute to reducing the spread of the virus by identifying cultural factors that may affect transmission.

c. National Response to HIV and AIDS

Efforts to prevent AIDS and to provide treatment and care began more than 20 years ago but many individuals and families still lack basic needs. The National Department of Health (NDOH) and the National AIDS Council Secretariat (NACS) have responsibility to address the epidemic and to coordinate all efforts made by people living with HIV, government, non-government and faith based organizations. The national government’s response includes the creation of the National AIDS Council (1997), the 1998-2002 National Medium Term Plan, and the PNG National Strategic Plan on HIV/AIDS 2006-2010. Also a part of the National response is: the Provincial AIDS Councils (PAC) and their secretariats; the Special Parliamentary Committee on HIV/AIDS; the decision to move the National AIDS Council to the Prime Minister’s Department; and the endorsement of the HIV/AIDS Management and Prevention (HAMP) Act 2003.

The urgency of the present situation has intensified efforts through the 2006-2010 National Strategic Plan (NSP). In an effort to overcome weaknesses in earlier programs there has been a critical evaluation and search for a more holistic and effective response. Much thought has gone into reviewing earlier plans and referring back to the guiding principles enshrined in the National Constitution, in particular integral human development, equality and participation and the distinctive culture of Papua New Guinea. The overarching Strategy

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63 Reid, "Interrogating."
sets the goal of “controlling and stabilizing the spread of HIV by 2015” (see fig 12-13, Appendix 6). The National Response is guided by international conventions and agreements highlighting the urgency of the situation.

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2.3. **Port Moresby General Hospital**

PMGH is a large Government hospital. It was opened at its present site in 1957. It is the major referral and teaching hospital (see fig. 17-18, Appendix 6). The hospital’s annual report states its mission: to provide high quality patient care, associated services to the community and an environment conducive to training health workers. The hospital’s objectives are to afford relief, provide maintenance and the treatment of any disease ... or injury..., to provide facilities for the treatment of public and private patients and to support and assist the local community health organizations ...”

The hospital is located in the National Capital District (NCD).

**a. National Capital District**

Port Moresby, the nation’s capital, is located on the southern coast of the mainland. The majority of residents are Melanesian but there are also people who have settled in the city from countries such as Australia, the Philippines, India, China, Malaysia, Korea and other Pacific nations. Port Moresby is not connected by road to any major city or town making air travel almost the only option. The city attracts thousands of tourists and people with wide ranging interests. But it is a city of stark contrasts. Signs of modern development, a colonial past and traditional cultures create a somewhat disturbing mix. People with money rub shoulders with those who have none.

Approximately 85% of NCD is taken up by the national capital. The remaining areas, belonging mainly to the Motu Koitabu, consist of semi-rural villages – home to some of the study’s participants. Unlike the provinces, where many people are isolated due to lack of transport and communication, people have relatively easy access to transport, communication and other services. Migrants live side by side with the original land owners - the Motu speaking Papuans.

68 The names ‘Port Moresby’ and ‘NCD’ are often interchanged. Personal communication, Roko Koloma, NSO, Port Moresby, 13 June, 2008.
The population of Port Moresby is 254,158: males, 55%; females, 45%. Estimated annual growth rate is 3.6%. The male domination occurs especially in the 45-49 and 60-64 years age groups attributable to the high rate of immigration. The age distribution of migrants differs from the pattern of the total population. Migrants come from all provinces in varying numbers. Central contributes 18 per cent followed by Gulf, Chimbu and Eastern Highlands. Non-citizens number 5,210. NCD occupies 240 square kilometres. This gives a population density of approximately 1,000 persons per square kilometre compared with 800 persons in 1990 and 500 in 1980 - evidence of rapid growth straining limited services.

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70 Ibid.
The ‘disturbing mix’ of people can be seen in a positive light. In an interesting study evaluating development in several of Port Moresby’s settlements, Muke sees Port Moresby as a city with a history of migration and settlements - first settled by the Motu-Koita, then by Australians and now by migrants from within PNG and from overseas. These three groups have made contrasting contributions to the landscape. Skyscrapers and settlements appear side by side as do bustling wharfs and urban villages along the coast. While some favour the signs of modern life and frown on the squatter settlements or the rusty materials of the homes in urban villages, Muke suggests that this contrast reflects the strength of PNG’s diversity and the need for cultural integration.71

At the same time, Chao illustrates the extreme poverty and hardship experienced by some settlement dwellers.72 Her study of life in the 9-Mile settlement identifies the people’s main concerns as shortage of food, money, lack of employment and inadequate housing. To these are added family conflicts due to alcohol or gambling and problems with health and violence from raskols (gangs involved in crime). Gibbs further comments that sixteen years later people’s situation of poverty has seen little improvement.73 Participants often indicated a settlement as their place of residence.

A person’s work status is an important indicator of individual and family well-being. This, however, can change overnight when illness strikes. Since the 1990 census the labour force has become more feminized rising from 27 per cent to 32 per cent. Income generating activities in NCD include selling betel nut, mustard and lime, food crops and cooked food. About 21 per cent are engaged in selling betel nut, 16 per cent selling food crops and cooked food, less than 5 per cent selling fish. Growing food crops and betel nut are the main household activities. The majority, 65 per cent, grow only for their own consumption. Literacy, the ability to read and write a language with understanding, is officially 91 percent in NCD. English has the highest rate at 81 per cent, Tok Pisin followed with 78 per cent, Tok

Ples with 71 per cent and Motu approximately 33 per cent.\textsuperscript{74} However, a more recent study in NCD shows high numbers of school-age children not attending school, and experience in the general hospital suggests that the literacy figures are in fact considerably lower.\textsuperscript{75}

b. HIV/AIDS programs

The Heduru clinic at PMGH opened in 1998 providing care for clients with STIs (see fig.19 Appendix 6). From 2002 voluntary counselling and testing (VCT) for HIV was offered. In 2004 clients began accessing anti-retroviral therapy (ART). By the end of 2005 the staff was involved in clinical training of teams from other sites: Lae, Goroka, Mt. Hagen and Rabaul, the aim being to enable ‘rollout’ of ART. The PNG Strategic Plan set the objective: to make ART treatment available and accessible to at least 10 per cent of infected people by 2005 and 25 per cent by 2008. Heduru clinic’s goal was to treat an additional 500 patients over the next year. An evaluation of the plan is yet to be released.

There has been a steady increase in the number of HIV infections. Of the admissions to PMGH statistics reveal 31% have TB and only 19% of those have HIV tests. Of 400 admissions to the medical ward with HIV/AIDS, most delay seeking help and there is a mortality of 31%, though a recent review conducted at Heduru clinic questioned whether this figure might be higher.\textsuperscript{76} After discharge from the medical ward, only one in three comes for review. This raises the question of the part played by fear, shame and other factors when faced with referral to an STI clinic. Discrimination and stigma appear to prevent access to treatment and care.

Those people who are fortunate to have ART prescribed say that, despite its availability, they do not have enough food, particularly when unemployed in the city. Lack of money or transport to access the clinic and the supply of drugs from their rural home raise further difficulties. To ensure supply of drugs, couples with possibly some of their children may decide to move in with a relative who is living in the city. The epidemic exacerbates the

\textsuperscript{74} Tok Ples refers to any one of the 800 or so PNG language groups.

\textsuperscript{75} The Post-Courier newspaper (2006) recently reporting a study of literacy levels carried the headline: “Half of us cannot read or write”.

\textsuperscript{76} Dr Anne Mijch, Team leader, Monash Medical Centre, Melbourne.
increasingly high levels of poverty of a large sector of society. The next section introduces Church involvement calling for new theologies to understand the suffering caused by chronic illness, particularly in a situation of structural injustice and poverty.

**2.4. Church Response**

Church responses have been many and wide-ranging. Knowing that HIV and AIDS thrive in an atmosphere of ignorance, silence and denial, the Catholic Church has acted quickly in partnership with other churches, with Government and non-government agencies. For instance, it has been particularly active in training personnel and increasing access to VCT services and counseling while introducing drugs that prevent parent to child HIV transmission. Church workers have been trained in awareness, prevention and counselling and are, most importantly, reaching people in the remotest areas.

The PNG/SI Catholic Bishops Conference (CBCPNG/SI), committed to fighting the spread of HIV and AIDS while caring for those who are infected and affected, endorsed a set of objectives formulated by the National Catholic AIDS Board. These include: establishing a Diocesan AIDS Office with an AIDS Ministry coordinator who will liaise with the National coordinator; coordinating work in co-operation with the government provincial body; providing awareness, training in counselling and support services for families and communities; providing support and care of the terminally ill - modelling all efforts on Jesus’ ministry among the poor and needy. Christian faith challenges the community to follow the Good Samaritan (Lk 10:25-37) resisting the temptation to judge and “walk by on the other side of the road” in ignorance and fear. Rather, the Christian response is to reach out compassionately and to offer hope to all who are suffering in this time of AIDS.

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A recent letter to Catholic men from the Bishops, recognizing the role they could play to stop transmission, addresses them as Fathers and Leaders. Written as a personal letter the bishops say: “... you are at the centre of our discussions. You have a special and distinct role as Catholic men, fathers and leaders in the family, in the Church and in society.” Wanting to awaken a desire to follow more closely the Gospel way, this letter served as a reminder of the traditional Melanesian values of the man was the protector and provider of the family.

In the field of Catholic education new teachers’ books have been written and recently published providing resources and teaching methods so that Personal Development courses in schools may address sexual health in a comprehensive, accurate and appropriate way according to the level of understanding of the child or adolescent. Existing Religious Education programmes are being reviewed in the light of the challenges HIV poses. The National Catholic Family Life Office has produced a wide range of resources appropriate to various settings including out-of-school youth, women’s and men’s groups.

The Churches Medical Council speaks for the churches as a whole. However, each church has its own structures that include pastoral care of the sick. This is expressed in different ways within the hospital. Some church groups such as the Revival Churches of PNG preach to the ward and pray over particular patients. They encourage the sick to be baptized by immersion and to surrender themselves to the Lord. Other churches offer pastoral care in the form of visiting and praying with the sick in whatever way might be meaningful for the person. Pastoral conversation gives opportunity for the patient to express worries and concerns that are part of the illness and are compounding their suffering.

Churches work alongside businesses, schools and voluntary organizations visiting the hospital offering support. Food is generously offered. Some organizations donate larger items. Such contributions send a clear message that the community does care. However, the need far outstretches the resources. There is need, too, for pastoral caregivers who can listen to the very personal stories of anxiety, loss, joy and hope.

Summary

This chapter has described some aspects of PNG, its people, their culture and contemporary context. The land’s difficult terrain presents development challenges. Establishing a stable government for a nation independent for just over thirty years is not easy. While the majority of the population still depends on subsistence farming, the Government looks to a future with an economy based on partnerships with multinational companies and the nation’s mineral wealth. Landowners see things differently. Tensions and unrealistic expectations can uncover sickness in a society that has yet to reflect critically on where it is going. Symptoms of this sickness include tribal fighting, protest by landowners, law and order problems, deteriorating health, education and transport systems and HIV/AIDS. These problems are being addressed and PNG’s noble traditional values and the Christian values professed by present generations provide the soil for growth of the common good with health and well-being for all. The challenges this situation presents are great but, as with all crises, there is both danger and opportunity. Constructive responses to this situation include helping raise awareness of socio-cultural processes and future options; helping to promote community cohesion; helping people become aware of their own resources; and challenging their values and priorities.
3. Research Design and Methods

In this chapter I explain my research design and methods. My research question is: What is life like for someone living with HIV in Port Moresby? I have chosen a qualitative approach and ethnographic methods to explore HIV/AIDS in relation to culture.

First I explain the nature of pastoral research and then my research method, justifying and explaining how I use it. Next I discuss the research design - the study group, data collection and analysis. Finally, I explain my theological method.

3.1. Pastoral Research

‘Pastoral’ arises from a religious context. The Latin *pascere* means ‘to feed’; a *pastor* is a ‘shepherd’. Pastoral usually means something relating to the work of a priest or pastor, a church worker or teacher in giving help and advice on personal matters, not just those connected with religion or education. Pastoral care is “that aspect of the ministry of the Church which is concerned with the well-being of individuals and of communities.”¹ Healing, guiding, sustaining and reconciling are identified as four main pastoral functions.² More recently, drawing on broad experience in the developing world, Lartey attempts to capture

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the complex nature of the interaction between people in a multicultural society. He defines pastoral care as consisting of

helping activities, participated in by people who recognize a transcendent dimension to human life, which by use of verbal or non-verbal, direct or indirect, literal or symbolic modes of communication, aim at preventing, relieving or facilitating persons coping with, anxieties. Pastoral care seeks to foster people’s growth as full human beings together with the development of ecologically holistic communities in which all persons may live humane lives.³

Thus, Lartey underlines: the expression of human concern through activities; transcendence; multiple modes of communication; the motive of love and both preventing distress and nurturing life.

Pastoral research involves many factors which add to the complexity of the concept. It has deep roots in a variety of fields of inquiry such as anthropology, sociology, psychology, biblical studies and theology. While not neglecting conceptual development the focus of pastoral research is on the life of the community.⁴ What distinguishes pastoral research is that it is located in a community of faith and, in the Christian context, is concerned that the community continues the ministry of Jesus. The aim of pastoral research is to understand and develop the practice of ministry by developing professional capacity and personal growth in its ministers. It examines the life of the community and reflects critically on both the individual’s experience within the community and the community’s experience within society. It gives a distinctive perspective to the methods used.⁵

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⁵ *The New Dictionary of Pastoral Studies*, s.v. "Research in Pastoral Studies."
3.2. Research Method

HIV is often linked in people’s minds with sexuality and death and thus it encounters cultural taboos, silence and denial. Cultural and contextual factors, such as the unequal status of women and unequal access to goods and services, play their part in exposing some sections of the population to high risk of infection and limiting their access to health services. I adopt a qualitative research method which focuses on meanings and interpretations as the research strategy to understand how, and why, people act in particular ways. Qualitative methods enable me to begin to engage with the complexities of meaning that are often emotionally and politically difficult to challenge. Charmaz offers insights into qualitative health research which are relevant here. She begins by distinguishing two ways of knowing. “We can know about a world by describing it from the outside. Yet, to understand what living in this world means, we need to learn from the inside.” The challenge is to break open the studied phenomena “to make an interpretative rendering from the inside.”

Qualitative methods are also useful when the study necessitates the analysis of complex connections helping to overcome the risk of fragmentation and of paying insufficient attention to contextual factors. Data are collected over a period of time, enabling processes to be observed and providing an overview of the study field. Since many qualitative methods including focus groups and participatory action research are available the following section will explain why ethnography is adopted to gain a cultural and pastoral perspective. Quantitative work in this study is limited to descriptive statistics.

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9 See Meursing, World, 79.
3.2.1. Ethnography: a definition

During the first month or so [the ethnographer] proceeds slowly ... walks warily and attempts to learn as quickly as possible ... important forms of native etiquette and taboos ... often experiences anxieties in a strange situation ... and [is] overwhelmed by the difficulties of really getting ‘inside’ an alien culture and of learning ... [a] strange language.\(^\text{10}\)

Ethnography is “the art and science of describing a group or a culture”.\(^\text{11}\) It is a process of learning about people by learning from them. It has the following defining features: a strong focus on exploring the nature of particular social phenomena; the tendency to work primarily with unstructured data; the examination of a small number of people, perhaps just one in detail; and the analysis of data which involves explicit interpretation of the meanings and functions of human actions. Descriptions and explanations of events are of prime concern.\(^\text{12}\) Ethnographic methods are chosen to study the culture of a village and examples abound in PNG.\(^\text{13}\) However, ethnographic methods can also be applied in contemporary societies and the ward of a hospital can be considered as a cultural group, though not all researchers would agree.\(^\text{14}\)


\(^{11}\) James P Spradley, *The Ethnographic Interview* (New York: Harcourt Brace Jovanovich, 1979), 9. Spradley adds: Ethnography consists of a body of knowledge that includes research techniques, ethnographic theory, and hundreds of cultural descriptions. It is based on the assumption: knowledge of all cultures is valuable.


\(^{13}\) Examples include the classic study of Kenneth E Read, *The High Valley* (New York: Columbia University Press, 1965).

3.2.2. **Theoretical Assumptions**

The theoretical orientation of ethnography is illustrated in the work of Clifford Geertz, one of the most influential interpretative ethnographers. Geertz prefers to define ethnography not by the techniques it adopts but by a particular kind of thinking which he describes as ‘thick’ description. ‘Thick’ description is concerned with detail and with background information. Its aim is to explain people’s culture – their way of life or pattern of living – by describing the patterns of meaning that underlie their actions so as to make these accessible to the reader and understandable. Thus, Geertz defines culture as “socially established structures of meaning in terms of which people do ... things”.\(^{15}\) He adds that according to this approach cultures are never finally mapped out. Such studies are always partial and incomplete ‘guesses’ at explanations. However, there is a variety of theoretical traditions and his interpretative theory is one of several.\(^{16}\)

An example of how interpretative ethnography works is given by Rosaldo among the Ilongots in the Philippines. His aim was to understand the practice of head-hunting. He relates how the people’s explanation that “rage in bereavement could impel men to head-hunt” did not satisfy him as an explanation; he dismissed it.\(^{17}\) In Geertz’s terms, it was too ‘thin’. However, when Rosaldo’s own wife was killed in an accident he began to understand ‘rage in bereavement’ and he could begin to construct a ‘thick description’. His description captures the “powerful visceral emotional states” and the “deep cutting pain of sorrow almost beyond endurance”. In analysing his own experience of bereavement he developed an understanding of the complexity and depth of emotions of the Ilongot men. The resulting detailed description of the intricacy of bereavement and links to cultural patterns of meaning led him to make sense of the practice of head-hunting.

Important points about ethnography emerge from this example. Firstly, ethnography focuses on describing in detail the systems of meaning and emotions that are integral to a

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\(^{15}\) Geertz, *Interpretation*, 12.
\(^{17}\) Ibid., 3.
particular culture and that explain particular actions. Secondly, the pre-existing understanding, experiences and theoretical traditions adopted by the researcher are an essential part of the analysis and description. Rosaldo’s own personal experience of force of anger in bereavement enabled him to describe the experience of the Ilgonots that leads to head-hunting. The researcher as positioned subject, therefore, has important significance and will be discussed in more detail in the following section.

3.2.3. The Ethnographer

As an ethnographer my work would be with people. When interviewing, I would be asking probing questions about a person’s inner life, their achievements and failures or about cultural rites. Like all ethnographers working in this field of human science, I would follow a code of ethics that respects participant rights, designed to ensure that, in seeking to understand the culture of a particular community, no harm is done. I must be careful to avoid any hint of offence. Adherence to the code guarantees respect for the individual person, the common good. Respect ensures effective communication in the field, the integrity of the data and a fruitful, long-term relationship between the people and the researcher. Professionalism and sensitivity demonstrate respect and appreciation of the culture - good ethics and good science. I should be prepared to adjust my position. Ethical dilemmas growing out of the context of the work will be discussed in more detail below (see 6.4).

This study is a type of ‘advocate ethnography’. I am inviting participants to describe their world. I would note their views about desired change hoping to take an active role enabling social change and serving as an advocate. My aim as an educator and pastoral worker is to offer hope for a better future – to influence public opinion and attitude, to challenge those who misuse power and provide relevant information about HIV and AIDS at significant moments in the policy-making forum.

3.2.4. Health Applications

Ethnography, with its emphasis on holistic description and understanding can offer insights when examining personal interactions.\textsuperscript{20} It can serve pastoral workers helping them to examine their interaction with patients, staff and family members. Stein argues that in trying to reveal the complexity of clinical thinking and intervention, ethnography offers a more complete understanding than is often done by medical science.\textsuperscript{21} One successful example of many in the field of public health is a study by Winch and others which aimed at promoting the use of mosquito nets to prevent malaria in Tanzania by explaining risk of illness using familiar ideas about mosquitoes.\textsuperscript{22} Ethnography has many applications in health care settings and may contribute significantly to more effective work with HIV/AIDS.

Studying vulnerable populations, researchers have found that ethnography has high potential in obtaining sensitive information. Rao used the method to find out about the incidence and determinants of wife-beating from women in three villages in southern India. Needing a wider sample to extend his results, he used information gained from ethnography to construct questionnaires and so was able to elicit responses from a further one hundred and seventy women. This quantitative study allowed him to generalise the main themes of his qualitative findings and may point to a method relevant to future research on HIV/AIDS in PNG.\textsuperscript{23}

3.2.5. Advantages and Limitations

Anthropology is a field that celebrates complexity and ambiguity in a world looking for simplicity and clarity. 24

Ethnography shares with other methods of qualitative research certain advantages as well as limitations. I adopt it because it can provide an understanding of people and their lives that is not possible using other methods. In this instance I want to understand the experience of HIV/AIDS with its accompanying fear, shame, acceptance and hope. Ethnography can further understanding by drawing on the participants’ own perspective not from judging behaviour or beliefs in terms of the researcher’s own cultural values and traditions. Practicing reflexivity or critical reflection, as in the case of Rosaldo, can help create awareness of instances where the two are not clearly distinguished. Ethnographic studies are not only concerned with understanding the people and their culture but may also apply the findings to bring desired change. This is particularly relevant to the topic of HIV and AIDS where preventing the spread of the disease and proper care of those living with HIV are major concerns.

Limitations of the ethnographic method can also be identified. Attempting to see the world from a viewpoint which has marked contrasts to my own may give rise to feelings of unease or frustration which could introduce bias. Ethnography is demanding because it requires spending long periods of time in the field. A further limitation is that the data gathered in one medical ward from a relatively small number of people cannot be generalised to the wider population. 25 In summary, ethnography can offer an effective way to gain insight and deep understanding of people - interpreting and presenting findings from a cultural perspective.

25 Pranee Liamputtong Rice and Douglas Ezzy, Qualitative Research Methods: A Health Focus (South Melbourne: Oxford University Press, 1999), 170. See further critiques of ethnography: 19, 22-4, 33.
3.3. **Research Design**

The research design focuses on the problem, the people and the place. It is “the logical and systematic planning and directing of a piece of research.” Qualitative research design provides useful guidelines but needs to be flexible to allow for unforeseen problems. New conditions and connecting links in the data can emerge. It is often necessary to change the plan according to circumstances. Having researched widely in cross-cultural settings, Rice explains, “[M]odification should not be seen as due to the researcher’s poor performance, but as an integral part of rigorous qualitative research.” I discuss below, especially in relation to recruitment and to informed consent, how modifications were necessary.

3.3.1. **Study Group**

   a. **Location**

The study is twofold - to both answer the research question and develop ongoing methods of critical reflection and practice in ministry. I have selected Port Moresby General Hospital (PMGH), my place of regular pastoral work, because I want to investigate my own practice. While the city has an increasing number of private hospitals and clinics, PMGH is the country’s major referral hospital, and, in 2004, was introducing Anti Retroviral Therapy (ART). HIV positive patients are found in almost every ward of the hospital, but the medical ward is chosen because of established relationships with staff and familiarity with its functioning.

It is common practice for data collection to take place where the participant feels most comfortable, usually in the home. However, these participants are familiar with the hospital and its staff and generally feel comfortable there. This location also provides confidentiality for those whose family members do not know of their positive HIV status or are ambivalent about it.

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27 Rice and Ezzy, *Qualitative*, 222.
b. Gaining Entry

Heroic literature is replete with tales in which the hero must pass a series of tests and questions before [being] admitted to gain the prize. A similar experience, though less ritualized and unaccompanied by operatic music, awaits the sociologist in the hospital.  

Ethnographic research requires considerable preparation. I must obtain permission from the ‘gatekeeper’ who decides if the project has merit and is in the best interests of the community. Gatekeepers in this study include the Chief Executive Officer, his Director of Medical Services and the Chair of the PNG Medical Research Committee. Permission to carry out research and to access medical records and reports is granted in a letter circulated to Department Heads. I must also consult the Officer-in-Charge of the STI clinic and the Chief Physician. Without exception all these people seem willing to offer their help and often add that this kind of research is urgently needed.

Good rapport with the community and informants is essential. Sincerity and readiness to give reassurance about the purpose of the study might be an issue in some settings. However, I do not find people unwilling to involve themselves or to perceive the study as any kind of threat. Because I have been a part of the hospital community for more than ten years most people trust me. In fact, it is likely that they share my interest in the stories of people living with HIV and concern for their well-being. Later discussion of recruitment will describe the role of nurses as ‘gatekeepers’. Taking time to obtain approval leads to easier access to participants and potentially a higher level of trust in the interviews.

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31 Several years later Heduru clinic placed limitations on researchers due to the small size of the clinic and staff and because it was thought that research at this location may become a burden to staff and clients.

c. Sample Size

Initially, the number of participants chosen is fifteen, an appropriate number for conducting in-depth interviews. However, the Human Research Ethics Committee (HREC) recommends that the research sample would probably need to be larger to provide for greater cultural diversity and flexibility. So the sample could expand to include at least thirty. According to Rice the sample is large enough when the researcher is satisfied that the data are rich enough and cover enough of the aspects of the research question.\(^{33}\) Because the analysis is qualitative, the criteria for the sample size are also qualitative. The number of participants is less important than the richness of the data. Charmaz, for example, began with a sample of thirty-five people who had a serious chronic illness. This sample was derived from referrals from doctors. She was concerned that the doctors had been selective. Therefore she sought additional participants from other sources, including those who might have avoided the medical system. The final number was ninety. It is not the number that is important here but the rationale given by Charmaz for her sampling technique which relates to theoretical criteria. Her sampling strategy was purposive.\(^{34}\)

d. Criteria for Selection

The criteria for selection are as follows: participants will be English speaking and Pidgin speakers who had sufficient English language skills to communicate well. They will be aware of the implications of their HIV positive diagnosis and willing and able to talk about their experiences. Patients who speak a language other than English and those who have symptoms of dementia or for some other reasons are limited in their capacity for communication are excluded. The age range is 18 years and over.

\(^{33}\) Rice and Ezzy, *Qualitative*, 46.

e. Recruitment

The recruiting process is guided by the principle of justice that requires that “within a population there is a fair distribution of the benefits and burdens.” Recruitment as approved by HREC involves preparation of various information sheets for nurses and participants and an individual consent form for those who agree to participate (see Appendix 3). The process used to recruit the participants involves doctors who identify eligible patients. Nurses with first-hand knowledge of the patients assess eligibility in the course of their normal work and invite a patient to participate in the project. Patients are then freer to either accept the invitation or to refuse than might be the case if I approached them. Difficulties in implementing this process will be discussed below (see 6.4).

f. Withdrawing

Before data collection begins patients are given the opportunity to withdraw. The information sheets explain that staff and patients are free to take part or not. The information sheet for patients explaining the initial ward observation explains that if a patient does not want any action noted in which they are involved then they can let the nurses know. They can fill in a brief tear-off section at the bottom of the information sheet simply indicating their bed number. This indicates that they do not want to take part in my observation of the ward (see Appendix 3.6). As stated on the consent form and explained orally, the participant can withdraw at any stage and withdraw his or her data up to one month later with no consequence for treatment or care (see Appendix 3.5).

g. Potential Harm

As noted above, ethnographers need the trust of the people they work with if they are to complete their study in a satisfactory way. With a bond of trust established, I can learn more about the deeper layers of meaning in the community. Trust is built on a foundation of openness and honesty and this is communicated both verbally and non-verbally over a period of time. Trust is built through presentation of self and general demeanour. Physical posture including handshakes, smiles, moving towards a person and other non-verbal cues

35 National Health and Medical Research Council, “Statement”.

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help me establish and maintain trust. My guiding ethical principle is respect for persons, that is, regard for the beliefs, religious practices, welfare, rights, perceptions, customs and cultural heritage, both individual and collective, of participants. Respect comes before research interests whenever the two appear to be in any kind of conflict.

Ethnographic practice requires that power in researcher/participant relationships be examined. Ethnographers typically adopt a passive rather than an active role and are highly dependent upon the willingness of participants to speak about their concerns. I identify the inequality arising from my previous role as pastoral caregiver. Because of this relationship recruitment takes place through a third party. As a researcher, I am intentional in my work setting aside my role as caregiver.

### h. Informed Consent

Informed consent is not always easy to obtain. Providing information to participants about the research, its purpose, methods, potential risks and benefits so that they can understand and choose whether to participate raises many challenges. While working within the guidelines for human research ethics I am also guided by the experience of researchers who have worked with vulnerable subjects. When one researcher attempted to gain informed consent for a study on sexual abuse of women with learning difficulties concepts like ‘research’ or ‘methods’ did not have much meaning for them. A very simple explanation was given: “I am talking to women about sex, so I can learn more about it and to try to make sure women get the help they need. I might want to talk to other people and write about what I learnt, but I won’t tell them anything personal about you or use your name.”

Detailed evaluation of in-depth interviewing of vulnerable subjects provides insight into this issue. Verbal, as well as written, explanation would be necessary in most cases.

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i. **Confidentiality**

Confidentiality is observed at all times. At recruitment I assure participants of anonymity. Pseudonyms are used as a simple way to hide the identity of informants and protect them from potential harm. Similarly, disguising place names ensures there will be no harmful criticism of a community. When field notes are stored, they are coded to avoid any misuse of information. In some instances pseudonyms are not sufficient because those who have some knowledge of the research setting can make informed guesses but pseudonyms protected individuals from a wider audience.\(^39\) This section has discussed the study group; the next describes data collection methods.

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3.3.2. Data Collection Methods

The ethnographic method requires participant observation and usually in-depth interviews. In addition, I would collect data from documents such as participants’ medical records and hospital reports (see Appendix 3.5). Key informants, people with particular expertise, would provide additional, relevant information and help to make connections. My data collection methods are discussed below.

a. Participant Observation

Describing ethnography’s basic research approach as ‘participant observation’ refers to the ethnographer’s disciplined study of what the world is like for a particular group of people.40 Usually the setting is not known in an intimate way so that awareness of difference is heightened.41 My researcher’s role differs from my caregiver’s role and so offers a new perspective.

Taking part in the daily routines of the medical ward, developing relationships with people and constantly observing what is happening, I write what I observe and learn in note form, in a regular, systematic way. “These two interconnected activities comprise the core of ethnographic research: firsthand participation in some initially unfamiliar social world and the production of a written account of that world.”42 Assuming that observed behaviour can indicate hidden values and beliefs revealing significant aspects of the person, field notes contain not only systematic description of events, behaviours and other relevant details but also perceptions and interpretations of the events. Using methods of self-observation I attempt to give not only a passive account but to also record an active process of finding meaning and relationship, including feelings and interpretations of what I experience.43 Van Maanen sums this up succinctly: ethnography is “the peculiar practice of representing the

42 Ibid.
social reality of others through the analysis of one’s own experience in the world of others”.  

The field journal is an internal dialogue making conscious the writer’s unconscious. I describe everything that comes to mind including descriptions of personal struggles. Writing helps me to hear my inner voices and recognise my own position in the situation in the midst of the research process. Field notes provide me with opportunity to examine my own assumptions. Through note taking my skills in observing, interviewing and interpreting develop. Re-reading and assessing the field journal later functions in an important way enabling me to begin to comprehend the complexity of the meanings hidden in the evolving text. In order to capture vivid impressions of incidents in the ward I write up my field notes as quickly as possible.

**Advantages and Limitations** Participant observation has advantages. It can record actual behaviours. People may say what they think, but that is not necessarily what they will do. On the other hand, it has limitations. People’s responses may be influenced by the presence of other people. The following section will discuss the second data collection method: in-depth interviewing.

### b. In-depth Interviewing

At the end of the interview, I left with ‘the data’ and the interviewee was left with the memory of a conversation. However, several people explicitly commented that they found the interview useful and worthwhile because it helped them to understand and come to terms with some aspects of their experience.

In-depth interviewing enables me to explore the complexity of meanings and interpretations of the participants’ lived experience. Mishler sees in interviews the negotiation and reformulation of meanings. Interviewers are not passive and distant but actively involved in encouraging the respondent to talk, to converse about the question

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under discussion. Brooks emphasizes that this negotiation of meanings implies that “the relation of teller to listener is as important as the content and structure of the tale itself.” As a consequence allowance is made for the influence of the interviewer on the outcome of the interview. There is a stark contrast here to structured interviews where emphasis is placed on administering questions in the same way every time because it is assumed that a consistent form of questioning is required for reliable responses.

The in-depth interviews are guided by a theme list (see Appendix 3.8). I begin with the invitation: “Tell me a little about yourself and your family.” This approach draws a wide range of responses as well as providing demographic data. The data are important to enable a comparison which shows similarities and differences across cases. Using a theme list rather than structured questions leads me to the realization that often what I want to know is different from what the interviewee wants to tell. In these interviews I use brief responses, verbal and non-verbal, probes and questions allowing the stories to develop beyond what might be only a brief response.

When interviewing an ethical question arises as to how far the researcher can probe participants. Barnard discusses this issue in the light of her research with vulnerable people. She explains how important this area is because of its impact on the information collected. Her experience has led her to believe that if the participant is willing to disclose events that are painful, it is likely that the researcher could continue to probe, asking for more details. At the same time she argues that there is a limit with researching a sensitive issue, for example, in the case where the participant is distressed by an experience. However, Barnard felt strongly about asking the parents in her study to elaborate on the impact of a possible drug problem on their children. While choosing to stop the tape recorder and not ask any further questions, as time passed, the focus of the interview “shifted to a much greater

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concern with understanding the overall dynamics of the problem”. Thus, she made special attempts to balance the interests of her research with the welfare of the participants. A similar tension is present in this project. Prior arrangement is made with the Director of Social Work, PMGH, for counselling of participants following an interview, if needed, and this information is passed on to participants (see fig. 24 Appendix 6).

In-depth interviewing involves conversations of about an hour with each participant. A tape recorder is used to record some interviews but, at other times, I choose to allow greater freedom to continue a conversation that may have started in a noisy environment. The intention is to provide more scope and depth in the conversation. No payment is offered; a small gift such as fruit, biscuits or soap acknowledges the help given to me.

Advantages and limitations In-depth interviews have the advantage of providing more detail about an individual’s understandings and experiences than can be gained by other methods. People’s responses are less influenced by the presence of others and they may be more prepared to discuss sensitive matters such as sexual practice or strong emotional responses which they would not otherwise talk about. In-depth interviewing takes time because understandings are developed and experiences are unfolded over time. It requires considerable skill in communication, persistence and sensitivity to the complex process of interpersonal communication. Overall, the advantages outweigh these limitations. The third method of data collection, using documents, will be discussed in the following section.

c. Documents

Documentary material that might be relevant to the researcher takes many forms. It exists along a continuum with ‘informal’ at one end and ‘formal’ or ‘official’ at the other end. At the ‘informal’ end there are ‘lay’ accounts of everyday events and personal experiences. Formal or official documents relevant to this study include the PMGH Annual Report

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containing statistics for the year, comparisons with former years, details of personnel, and so on.

Demographic data relating to the participants are available from hospital records. For example, the ward admission register indicates such details as place of residence, province of origin, date of admission, previous admission(s), religion, diagnosis on admission and cause of death. Data collected in this way are limited to these categories. Due to constant movement of patients in and out of the ward and the likelihood that each interview would need some degree of analysis before continuing with the next, the demographic data collection is ongoing. “The ethnographer who takes no account of [written documents] ... ignores at his or her peril such features of a literate culture.”53 Heeding this advice I would routinely read both the doctors’ and nurses’ notes, in addition, the entries in the Admission Registrar, the Death Registrar and other records kept by the clerk of the ward. There are also rosters of nurses and a sign-in book helping me keep ongoing contact, various circulars relating to drug supply, meetings and other events. These details contribute to a ‘thick description’.

Advantages and limitations Using written records is non-disruptive. Having obtained permission through the hospital’s ethics committee and from participants this method is safe for the researcher and for the participants. Other researchers may crosscheck re-examining the data for reliability and validity. However, using documents such as medical records can reduce the possibility of understanding people. The written records may be distorted or selective due to biases, either to create a particular impression or hiding some information in keeping with cultural practice, reducing accuracy. This section concludes with a brief consideration of methodological rigour.

53 Ibid., 143.
d. Rigour

Rigour refers to issues raised by the terms ‘validity’ and ‘reliability’. Validity is to do with strategies that produce data that are accurate and that measure what is intended while reliability is the consistency and dependability of the measuring instrument. While these are important in qualitative research, the core of the problem is the relationship between the observer and the observed.

Triangulation which involves the use of a combination of methods, researchers, data sources and theories is employed. Different results are obtained by using different methods. Different researchers, informed by different theoretical traditions, may reach different conclusions.\textsuperscript{54} Triangulation addresses this problem allowing a complex picture to evolve which might not occur if only one method were used.\textsuperscript{55} This study uses two types, data source triangulation and methods triangulation. The procedure is limited by not employing, in addition, either researcher triangulation or theory triangulation. It draws on one theoretical perspective, namely ethnography, while acknowledging that a combination of perspectives could further inform the research. Similarly, only one researcher was directly involved in the project. A variety of researchers could bring different perspectives to the study, as illustrated in a similar study of women living with HIV/AIDS.\textsuperscript{56} My own personal perspective or bias is acknowledged. It is not possible to eradicate or control bias; triangulation is one way of managing it.

The combined approach to data collection enables a balance between closeness and distance. It incorporates a degree of subjectivity through observation and participation in the field, through the use of field notes, and a degree of objectivity by collecting naturally occurring data, such as written records combined with interview audio-recordings. Data, such as documents, exist independently of the researcher’s intervention. These data have a

\textsuperscript{54} N K Denzin, The Research Act (Chicago: Aldine, 1970), 298.
degree of objectivity because they are not ‘researcher evoked’. In these ways bias is managed and rigour heightened. The combined approach may shed light on the tacit and implicit which would otherwise be taken for granted.

Finally, Charmaz’s reflections are a reminder that a person’s story may differ markedly from an ethnographer’s recording of the events. She cautions and draws attention to the topics discussed in an in-depth interview which may be sanctioned in other settings. For example, others can silence the stories of the person and discount their suffering but, “[w]hat they are silenced about may be among the most important things to learn from them. Silences are significant.”

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58 Charmaz, "Premises," 979.
59 Ibid.
3.3.3. Data Analysis Methods

Interpretation is an art that cannot be formalised.\(^{60}\)

The aim of qualitative data analysis is to discover new facts and their relationship to existing knowledge by means of immersion in the data. Initially, I attempt to answer the research question and to gain understanding of the field in this way. Though confused and chaotic, this step is in fact, ‘calculated chaos.’\(^{61}\) The data drawn from interviews and from participant observation are complex and offer the possibility of exploring multiple interpretations. However, there are established procedures and methods for analysing qualitative data. In this section I discuss the methods I select for the analysis.

a. Grounded Theory

The techniques and procedures I adopt are those associated with developing grounded theory - a particular way of thinking about and studying social reality that places importance on going into the field to discover what is happening there. Grounded theory appreciates the relevance of theory, grounded in data, to the development of a discipline and as a basis for social action. It recognizes the complexity and variability of phenomena and of human action and believes that persons take an active role in responding to problematic situations acting on the basis of meaning. Meaning is defined and redefined through interaction in the midst of unfolding events. There is an interrelationship between conditions, action and consequences.\(^{62}\)

Grounded theory, one of the methodologies commonly used in qualitative health research, is consistent with the provisional and inductive approach of this project. It argues that theory can be built up through careful observation of the social world:


[A grounded theory is] derived from data, systematically gathered and analysed through the research process. In this method, data collection, analysis, and eventual theory stand in close relationship to one another ... the researcher begins with an area of study and allows the theory to emerge from the data. Grounded theories, because they are drawn from the data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action.63

While Strauss and Corbin fear that pre-existing theory could “hinder progress and stifle creativity”, Gerson demonstrates that grounded theory does make use of pre-existing theory and criticises the view of Strauss and Corbin as an “absurdly restricted and inadequate vision”.64 Theory building can occur in an ongoing way between pre-existing theory and new insights generated as a consequence of empirical observations.

Coding is central to this process. The three main coding procedures are open coding, axial coding and selective coding. Coding involves sorting and organizing data in a way that is understandable to others. Open coding involving a process of comparing events, actions and interactions is the first step. I begin by doing a line-by-line analysis (see Appendix 3.9). I am searching for differences or similarities between events, actions and interactions. I then apply conceptual labels to these differences or similarities. I identify pieces of text and collate all those that are coded in the same way. This enables me to group them into categories.65

Deciding units of analysis is guided by previous research on this and related topics and the uses for which this research is designed. In the hospital ward examples of units of analysis are: illness and its meanings, encounters with family members, health workers, religious practice, narrative structures and lifestyles.66 Having identified possible units of analysis I question the data trying to find evidence of each. I am able to code the texts generated by interviews, participant observations and other sources of information as the review progresses. The codes are not pre-determined as is the usual approach of content analysis. Instead, a thematic analytic approach is adopted where the codes are found in the texts.

63 Ibid., 12.
65 Strauss and Corbin, Basics of Qualitative Research: Grounded Theory Procedures and Techniques, 63.
66 Lofland and Lofland, Analyzing, 71.
The second type of coding used is axial coding. When the initial categories and relationships are developed, the next step involves specifying these codes more rigorously. The data are put back together in new ways by making connections between a category and its subcategories. As coding continues, sometimes, one of the codes or variables needs to be broken down into two or more sub-categories. For example, ‘caregiver’ gives rise to subcategories: sex, age, relationship to patient, competency.

Finally, selective coding is applied. This process attempts to take all categories and unify them around a ‘core’ category. The process is similar to the preceding one but at a higher level of generality. The overall aim is to tell a story about the interviews, observations or other data that has been collected from the perspective of participants. Data gathered from them are the primary source. Scope and depth are added by the addition of data from other sources.

Miles and Huberman describe this process as ‘noting patterns and themes’ and ‘making metaphors’. An example of such a metaphor is identifying illness with a quest, thus suggesting a new way of thinking about personal responses to the suffering experienced by a person during illness. This metaphor and others that Frank employs reminds us that metaphors suggest the richness and complexity of the experience. Miles and Huberman go on to explain how the metaphor works. It is a data-reducing device summarising several different aspects of the experience. It is also a pattern-making device suggesting new relationships as a result of this new image. Metaphors are finally centring devices providing a different perspective and they suggest different questions about the data. They are inherently ambiguous but they are useful because they allow qualitative researchers to avoid the temptation to understand human experience using laws. Metaphors cannot be easily quantified yet they are a powerful means of understanding relationships and everyday life. Metaphors such as journey are applied to this study. Also, the idea of mining is appropriate because there is a search for something of value.

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b. Reflexivity

As part of the process of analysis I practise reflexivity - developing the capacity to reflect on my own actions and values when collecting and analysing data and to view my own beliefs in the same way as I view the beliefs of others.69 Reflexivity is a characteristic of the ethnographic imagination and establishes the researcher’s integrity.70 Arbor discusses the principle and practice of reflexivity; several points are relevant to the present research. Her focus is the practitioner as researcher and what that means for the data collected. She discusses the feeling of being an ‘insider’, a practitioner, as well as the feeling of being an ‘outsider’ and how such moments were revealed to her. I was guided by her discussion about feelings, emotions, tensions that can occur in the researcher attempting to keep to a marginal positioning on the boundary between practitioner and researcher identities and how this tension is resolved in the lived experience of the research.

Memos are small pieces of analysis that spring from the encounter of the raw data with the creative imagination and the skills of the social scientist.71 The writing of memos is a technique used to further investigate ideas and processes that appeared in the data. Keeping these kinds of memos enables me to analyse and interpret and to report on the findings of the project. Using research memos is noted by Charmaz:

Throughout the analysis, I wrote memos to define and examine implicit ideas and processes that I saw in the data. These memos helped me to synthesize data and to define patterns within it. As the research ensued, my memos become more conceptual and abstract.72

Another form of reflexivity is theological reflection which will now be discussed.

71 Lofland and Lofland, Analyzing, 135.
72 Charmaz, Good, 276.
3.4. Theological Method

The method I use in this study to speak about God is central to both classical theology and to contemporary theologies. The mystery of God comes to life in contemplation and in the practice of God’s plan for human history. Contemplation and practice can then move to reasoning and speaking in a way that is relevant to a particular culture and its present situation. The first stage is silence; the second is speech:

Contemplation and practice feed each other; the two together make up the stage of silence before God. In prayer we remain speechless; we simply place ourselves before the Lord. To a degree, we remain silent in our practice as well, for in our involvements, in our daily work, we do not talk about God all the time; we do indeed live in God, but not by discoursing on God ... The time of silence is the time of loving encounter with God and of prayer and commitment; it is the time of “staying with him” (Jn 1:39). As the experience of human love shows us, in this kind of encounter we enter depths and regions that are ineffable ... we do not speak; we let an object or gesture speak for us ... symbolic language is the language of a love that transcends words.  

Theological reflection is the process of seeking meaning that relies on the heritage of Christian tradition as a source of wisdom and guidance. It presumes that God is present in human lives, caring for people and that human experience is a source of deepening knowledge of God and people. The reflective process is a movement toward insight. This movement explains how we come to new understanding of living, leading to new ways of perceiving and acting. Drawn to find meaning in life every human society reflects when something happens. Are the insights valid and reliable? How can they be tested? How does a particular standpoint or world view influence the outcome or meaning found?

The standpoint taken markedly influences the insights gained. The answer to the question of what causes illness differs markedly from one culture to another. Standpoints like certitude and self-assurance also block the process of reflection and yield less significant insights. A standpoint of exploration encourages reflection that may lead to creative thinking and transformative understandings. One definition of theological reflection is:

74 Patricia O’Connell Killen and John de Beer, The Art of Theological Reflection (New York: Crossroad, 1994), xi.
a discipline of exploring our individual and corporate experience in conversation with the wisdom of a religious heritage ... a genuine dialogue that seeks to hear from our own beliefs, actions, perspectives, as well as those of the tradition ... respects the integrity of both. [It] may confirm, challenge, clarify, and expand how we understand our own experience and how we understand the religious tradition. The outcome is new truth and meaning for living.\textsuperscript{75}

One of several models of theological reflection is proposed by Killen and de Beer. Figure 5 (below) shows the relationships which exist between four sources of theological reflection: Narrative, Tradition, Culture and Position:

![Figure 5: Four Source Model of Theological Reflection](image)

\textit{Adapted from Killen and de Beer}

Theological reflection, in this instance, creates a dialogue between the experience of living in a particular cultural context and the prayer of lament, a rich though often neglected Christian tradition. Theological reflection can feed the silence of contemplation and practice.

\textsuperscript{75} Ibid., 51.
challenging personal beliefs, attitudes, values and ensuring the reflection bears fruit in action.76

The narrative is constructed by focusing on one aspect of experience and describing it so that it becomes a living narrative. Lived narrative includes a series of actions and the thoughts, feelings and perspectives accompanying the actions even when awareness hardly exists. I work with stories or events that came from participants’ lives. Extended narratives constructed in the early stages of the study are provided (see Appendix 4.2). These and other often brief narratives are central to my theological reflection.

The tradition I select is from the Psalms, in particular the Psalms of Lament. They offer another aspect of experience. Other parts of Scripture, doctrine or history could be selected but lament is particularly appropriate in times of trouble and when help is urgently needed. The psalms are human cries; a dialogue between the believer and God. Melanesians, whose culture continues to value its spiritual traditions, can also draw on these to enrich their theological reflection.

Culture has been described as ‘weaving webs of significance’ which support living. It encompasses symbols, values, artefacts, assumptions, ideas and philosophies. It also includes social structures and patterns of organization within groups – the structures of a society’s economy, politics, law, education and health. The dialogue between faith and culture, the process of inculturation, ensures that the Gospel takes root in the lives of people. Culture is an important source for theological reflection. In addition to lived narrative, tradition and culture is my own position including the attitudes, opinions, beliefs and convictions that I hold and am willing to defend. Position includes my understandings of roles, values, politics or religion and plays a vital role in my reflection.

Thus my four sources of theology are: lived narrative, Christian tradition, culture and position. All are aspects of experience – the interaction between an individual and the

people, places, events, situations and cultural factors that are a part of a person’s identity. Pieces of experience can be taken and relationships with these sources explored. This way of reflecting theologically can be represented visually as a prism whose lines represent the dynamic relationship between the sources. The meaning of any particular event is revealed only when attention is given to all four sources and their mutual relationships.

Using these sources the process of theological reflection unfolds. First, I focus on living with HIV and its associated experiences. Second, I describe the experience in such a way as to identify the core of the experience, for example, distress, helplessness, courage or faith. The third step is to explore the core experience in dialogue with the lament psalms. Finally, this dialogue may lead towards the goals of pastoral practice offering new direction and meaning for both pastoral minister and people.

Summary

Beginning with an explanation of how I understand pastoral research I have described my qualitative, ethnographic research method then explained the research design. Reasons are given for making each selection and for how techniques and methods are implemented. Data collected can offer information leading to knowledge which, in turn, may yield insight and wisdom through applying a theological method which is briefly outlined.

Data analysis leads in Chapters four, five and six to a presentation of the findings of the project. From the categories identified through coding, themes emerge and fall into major categories – those related to testing for HIV, to responses to the reality of HIV and to actually living with HIV. Further subdivisions reveal themes related to immediate and extended family, the role of caregivers and matters of purpose and meaning.

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This section will present process and findings. Data relating to the Study Group are provided in Appendix 4.1. Appendix 4.2 contains extended narrative texts of Manoko, 30 years old, married, office worker and Cally, 25 years, single, currently unemployed. The narratives contribute to an understanding of living with HIV and provide a background for comparative analytic information. Themes related to living with HIV emerge: illness, death of a child, testing for HIV, disclosure, marriage, family of origin, extended family, in-laws, children, spiritual beliefs, traditional practices, employment, poverty, health services and death. The following chapters will present the findings related to Family, Caregivers and Meaning. Given the small sample the chapter is descriptive and makes no generalizations. However, the knowledge gained may be useful and suggest questions for further investigation.

In the majority of cases transmission is by heterosexual intercourse directly affecting the family. Illness, death of a baby or of one or both parents has long-lasting effects. This chapter begins with the stories of two young married men. Though both have had bouts of illness, their health improves with antiretroviral therapy (ART) and they are living with and being supported by their families. My aim is to highlight some related issues. Underlying the accounts are questions of male identity and sexuality in a changing world and the risks faced by married women. Both common and contrasting elements emerge. Background information illustrates how cultural and contextual factors make a difference. The experience of testing for HIV, of disclosure and facing the reality of HIV are presented. Then findings related to marriage and children follow and, finally, the part played by spiritual
beliefs as adapted and practised. Italics are used as a means of emphasizing that there is a human face behind every story.

4.1. **Family and Village Culture**

Lamana, 34 years, and Stanley, 37 years, are two young men in Port Moresby. They both grew up in remote villages. Both completed primary education in the village and secondary education in the district. In Lamana’s case his early schooling gave him a very hard time because teachers didn’t turn up. He seemed to repeat a grade twice before he completed Grade 6 and was among the privileged to be selected for high school. This high school required a 1-2 days’ walk at the beginning and end of term, but his father paid his fees, so all was well. Instead of going back to the village, sometimes during the term break, Lamana would find a truck going to the city and he would spend his holiday with his older brother thus exposing himself to city life. He graduated with a Grade 10 certificate and returned to the village. *From being a schoolboy I became a village man helping Dad to build … gardening, fencing, hunting, preparing for feasts. I was happy. These activities overcame my disappointment when I could not continue my schooling.*

Stanley is the third child and second son of a family of seven. He mentions that his mother was his father’s second wife. No details are offered as to the location of his father’s first wife and their children. Stanley’s parents were *divorced* when he was still young, after his father married a third wife. His mother took the children to her own village giving up full-time employment as a nurse to care for them. Stanley also remembers: Our *grandmother cared for us; she shared her wisdom and passed on her values*. Speaking of this formative period of his life, Stanley reflects on his family situation: *there was no male present*. His elder brother died as an 8-year-old child. At that time health services in the village were poor. The family held to traditional beliefs, *kastam*; they believed sorcery played a role in the death of the child. Stanley himself now believes that the death was probably due to malaria. His elder sister is married and a health worker in their home province. Stanley’s younger brother died as an adult, and he says he saw ‘renal failure’ on the death certificate. *I don’t know what caused it*, he adds. His youngest sister is completing her training as a health worker, and the older sister’s salary is being stretched to meet the fees to ensure
graduation. [My mother] cared for me when I was sick and my sister supported me while I studied. We learned as kids to use every opportunity. This was because of our Christian upbringing. Traditional belief and values also played their part as seen in the strong sense of mutual obligation. Stanley completed his secondary schooling with a Grade 12 certificate and was selected for tertiary where, after four years, he graduated with a diploma. As a public servant he worked for some years in a remote coastal area of his home province.

Although Lamana had experienced life in the city, his heart was still in the village. He came alive when he spoke about his childhood experiences: the cultural ceremonies with their singsings. One village would invite another village. Everyone would dance with kundus (drums). We decorated our bodies with paints, reds and yellows. We used clay and fruits. Our headdresses were made from bird’s feathers. We used flowers like hibiscus. We had grass skirts made of pandanus grass. Life in the village was normal village life: gardening, feasting at bride price, marriage ceremonies and when someone dies. Sometimes we would go for parties in neighbouring villages. Some villagers left their home to look for jobs in the city. Some found casual work or were employed as labourers. Some returned to the village. Some found success in the city; others were lost.

Stanley’s cultural experience was different. His father had three wives, but they and their children certainly did not live as one polygamous family. His mother took her children back to her own village and her mother supported them. No male present, Stanley underlined. Describing his mother as a Christian woman, he spoke with pride of her training and qualifications as a health worker and her full-time employment in the early years of her marriage. Her qualifications were gained in the city when PNG was under Australian administration. Her lecturers would probably have been well-qualified expatriates bringing an alternative culture to their students and offering new possibilities. That a Papuan woman would leave her husband and return to the village of her clan with all her children appears to be a departure from the norm.

Stanley’s schooling took him away from the village. Later, though he worked in a rural area there were regular visits to the city. When unemployment began to worry him he realized that returning to the public service was not an option, because of his forthright manner and
attitudes to authority. So he studied newspaper advertisements. He hoped to retain his reasonably high salary. His attention was caught by new companies promising bright futures. He prepared his papers with the intention of applying. Except when he was sick, Stanley’s higher education and desire for paid employment kept him near the city.

4.2. HIV Disclosure and Treatment

Following a traumatic and near fatal accident resulting in concussion and multiple broken bones in a fall from a coconut tree, Lamana was flown in a company plane to Port Moresby for medical attention. After the painful ordeal of walking to an aid post nursing two broken arms, he explained: next day ... that was my glorious day ... the health people arranged transport. They put me on a chartered plane with my wife and small boy and I came to the hospital. After discharge, he returned to the hospital for medical reviews. Health workers suggested a blood test including a test for HIV because I was sick. The circumstances of Stanley’s test were different. He explained: After I had the strong cough for two years, my eldest sister prompted me to go for a test. I felt I had the [HIV] virus. I used to come to the city and stay in hotels. I was an evil man, drinking, womanizing ... I had a ‘don’t care’ attitude. I wasn’t surprised by the test result.

Their reactions also differed. Lamana expressed deep feeling: When I came back to the hospital they told me: you are HIV positive. I felt like crying ... It is very hard to explain ... I was crying in my heart. Stanley, on the other hand, chose to go to a non-Government Voluntary Counselling and Testing (VCT) clinic. He described the event with no apparent emotion: They told me the result. I was positive. On reflection Lamana added: HIV – I didn’t know about it. Had heard about it. That was all but didn’t take it seriously. Thought it was like other diseases [I would get better] whereas Stanley commented: I had heard of HIV/AIDS but I had the attitude, ‘It won’t happen to me.’ And he added that AIDS awareness is low both in the village and in the field where he was employed. However, having attended a tertiary institution, and coming to the city at regular intervals, Stanley was likely to have often been exposed to awareness messages. Testing for HIV is conducted in a wide range of circumstances with different responses as the following accounts illustrate.
Leo, 52 years, had been tested positive for HIV four years before his admission to the ward. He described the experience: *I was confirmed HIV positive by the doctor. I was surprised, shocked. My waters (tears) ran down. Knowing me well the doctor became emotional too. So I went home to the village in case I died. They said, ‘fully-blown AIDS’. I was very sick. I believed I would die. I wanted to see my first-born son. He would look after me.* Like Stanley, Leo was a university graduate. He had travelled widely. In his workplace, much attention was given to HIV awareness and to testing and counselling but ART was not yet available.

Referring to a visit to his village, Leo commented: *I got an OK from the village leaders. The elders are good people.* The nature of this meeting is unknown but clearly it was important and approval and support from these men was remembered when Leo returned to the city. With advice and support from the clinic nurse, Leo *started on herbs. I won’t die,* he said, *the mind and heart play a big role.*

“There is no cure for AIDS” is often interpreted as “nothing can be done” so just staying in the house may make sense. When Joy, 35 years, first got sick she *just stayed in the house.* Her husband had died less than a year ago, *sik bilong ples* (sorcery), according to his family. Her youngest child, 2 years, had been recently admitted to the hospital: *he was given TB treatment.* Her diagnosis on admission to the ward was HIV/AIDS. Joy resisted her family’s efforts to return, as her husband had done, to the village but instead wanted treatment in the hospital. She talked around the topic of HIV infection but how much she understood about her own and other family members’ possible HIV infection was not clear.

In contrast, when Meggie, 43 years, did not respond to treatment for recurring diarrhoea both she and her husband, Ron, were advised to go for blood tests. They had not been long married and had no children. Ron who was about the same age as Meggie reported that his HIV test was negative; hers was positive. *People generally feel this sickness is dangerous but I have no fear of this illness because the Lord sees the heart. I have faith in the Lord. I fear the Lord.* Meggie’s mother died in childbirth. *Mi no lukim Mama* (I never saw my mother). *Auntie lainim mi long gaden* (Auntie taught me how to make a garden). *Skul nogat* (I never went to school). She was happy for Ron to take the lead. He explained that he made up his mind to provide all the care that Meggie needed and he did that to a remarkable degree.
A different story was of Patricia, 15 years, not married and with no steady boyfriend. She went with her aunt to be tested at a clinic where pre- and post-test counselling were routinely conducted. She was given the result by the friendly nurse who added advice on how to keep healthy. *Mi bin go long klinik na sekim blut. Na mi gat HIV. Mama* (auntie) *na mi wantaim i stap insait. Ol nus long klinik i helpim mi.* (I went to the clinic and checked my blood. I have HIV. My auntie was with me. The nurses were helpful to me.) Her matter-of-fact report may be explained by a good clinical experience and family support. Thus, she was adjusting to treatment and living positively.

Stanley’s wife, Winnie, was 40 years old. Fearing she might die, her family brought her to the city. Her three sisters took her to a VCT clinic. The HIV result was positive. Winnie was devastated. According to one of her sisters, *Winnie almost gave her life away. Her spirit left her. She said: I don’t want to eat ... I want to die ...* As her sister explained: *she felt so guilty.* Her sisters encouraged her: *It was not you. It was your husband.* Before Winnie was tested, her husband had already ‘confessed’.

The findings presented above provide a range of examples. Each person faces the reality of HIV in their own unique way, and it is likely that their response mirrors learned responses to crises. A positive result brings varying measures of distress; a supportive family brings some comfort.

Lamana shared the result of his HIV test with some of his friends: *It’s nothing to hide.* He told them: *You’ll be going anywhere you like and you end up sick. I mainly told my relatives ... my older brother.* Stanley did not include details of his disclosure, but one of his in-laws described the setting. The family were gathered together. He *confessed his sin* in front of everyone because the prayer leader told him he would get better if he ‘confessed’. Lamana added that disclosure has not brought change: *My relationships still remain the same. There is no discrimination. People know how HIV is passed on. This sick comes from unsafe sex. That’s the way. I don’t believe in sorcery.* Apart from his older brother, it is unknown how

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1 Patricia, because she was under 18 years, was not selected to be a participant. However, in the process of observing activities in the ward and from data gathered from informants, Patricia’s story unfolded.

2 Winnie, too, was not a participant. She was too weak, speaking only a few words at a time. Her story was told by her sisters and brother who were eager to share it. Her husband, Stanley, added some details.
many others he told. Having ‘confessed’, Stanley’s relationships with his in-laws became strained, his in-laws preferring to take charge of the care of their sister. On discharge, she went to live with them.

Both Lamana and Stanley could talk freely about their situation, but the majority of patients were guarded about disclosure. It was rare for any patient or guardian to speak of HIV. It was far more common for a patient to say that the doctor had diagnosed TB and commenced TB treatment. There were some exceptions. Leo agreed to an interview with an overseas media team who were making a documentary on HIV/AIDS (see fig. 26 Appendix 6). For his own reasons, he decided to share his experience on international television.

After diagnosis Lamana’s and Stanley’s lives took a sharp turn. Lamana was distressed, but the doctor said: Don’t worry ... there are drugs that will help you stay normal. You won’t die ... so they directed me to the STI clinic, to the specialist. The doctors did help a lot ... they encouraged me to think positively, to have good health, to be faithful to the ART drugs. The nurses ... they encouraged us too. At the clinic I started reading pamphlets. I was thinking if I knew I wouldn’t get infected. Before I was tested I didn’t go deep into it. In the beginning I was worried. Now, no more worries. Doctor told me not to worry. Worry leads to trouble, including other diseases. Don’t underestimate your brain power or you might be an AIDS victim. You have to be positive. Now I am feeling OK.

As noted, Stanley was very matter-of-fact. They referred me to the STI clinic and I went for an ‘education’ session and started ART. He wasted no time reporting there. If you value your life you do it quickly. Like Lamana, Stanley was eager to learn all he could about this virus which he now knew had serious consequences. No doubt he read. With highly qualified and experienced health workers among his family members, he had people close at hand who could help him to understand the medical aspects of the virus and of the ART treatment. My CD4 count was 136. If you are less than 200, that is low. The doctors put me on medication. I asked for two months supply because of travel to and from the village by road and by sea. It is so difficult to travel. Stanley talked a lot about drugs. He was grateful that donors have made these drugs available and they were working for him. He had to come to the city regularly for review. Like Lamana he summed up his story: I am thinking positively. Though

Family

Chapter 4
similar statements were made by patients and guardians in the medical ward, it was less common because admission to the ward often meant serious health problems.

Since beginning ART Lamana and Stanley were trying to maintain a positive outlook. As Lamana said, I go back to the clinic now. The doctor checks me ... that’s their work. Checks blood pressure, sees if my body is functioning normally, checks weight. He asks me: Are there any changes? Stanley explains: I have learned about CD4 cells from the doctors and from family medical books. I’m infected so I need to know how to take care of myself. I share my knowledge and I explain to people who come to visit. I’m strong now. I have a little problem with breathing. I’m on medicine. Now I am in the ward looking after my wife. I give her medicine at 7am and 7pm.

Traditional herbal medicines interested Stanley: now I am drinking herbal medicine. Not to cure but to make the body strong. It is mushroom tea. On Thursday I felt breathless. After drinking this mushroom tea I was OK. A woman, a highlander and a church member, gave me these medicines. She lives here in the city. The drink is full of vitamins.

4.3. Marriage and Children

Lamana was married at 25 years. He explained with pride that he chose his own wife. She was from another village; they met at a funeral. Only later did his parents accept her. Bride price was not mentioned. He built his house close to his parents’ home and started a family. Stanley may have been a little older than 25 when he married. He and his wife just started living together. There was no customary marriage, no bride price.

Another participant, Nenge, 37 years, had rarely been happy. The couple had no children. Although they shared a common cultural background, she summed up her discontent: He was a drunkard. He didn’t go to church. He would go and get drunk and come and bash me up. Three times he bashed me up. But, I stayed with him for ten years. I went to church and prayed to Jesus. Finally, she decided: I can’t handle this. I ran away. Her husband came after her and there was another violent attack, resulting in serious injuries. Six years later she was in the ward.
Marriage for Gordon, 38 years, appeared stable but employment had involved long periods away. His wife sat by his bed, quietly attending to his needs, observing activities in the ward and regularly returning to their home in the city to care for their three young sons.

Several of the male patients described themselves as ‘divorced’. Leo made the point: *I have been divorced a long time.* Clearly expecting a response to this statement he raised his voice saying: *I said ‘divorced’, did you hear me?* Then, after a pause during which there was silence, he added quietly and with feeling: *I have no one to care for me.* As his story unfolded over a period of time he explained: *My family mostly live in Moresby. With HIV I deserted my family. Chaos in my family. I became more segregated. It’s all gone now.* Seemingly speaking to himself he whispered: *Be strong. Firm heart.* Divorce brought a sense of loss and grief to Jack, 45 years: *I have no one to stay with me or to visit me. I would very much like a radio to be my friend. Can you find a radio for me? I would like to listen to rugby.*

The children of the participants were affected by their parents’ infection in a range of ways. Stanley’s eldest daughter had discontinued school and was at times sharing the care of her mother in the ward. She had had a fall some time ago. Sometimes she wrapped a cloth around her upper arm, but when it was not covered the bone was clearly out of place. Brief reference to her injury suggested that the little girl did not like doctors or was she afraid to show anyone her injury and talk about the pain? Her mother was in hospital and bedridden, her father only just managing his illnesses. Her mother’s sister as primary caregiver was expending all her strength providing for her seriously ill sister and herself in the crowded ward for nearly a year, leaving her own husband and children to fend for themselves. The little girl’s mother’s family were struggling to provide shelter and food in the city for their large households. Her father’s family were living far from the city.

This little girl would play under the bed when she was not assuming adult responsibilities, such as collecting food for her mother from the hospital kitchen at lunch-time, and running messages for her mother or her aunt. Because of the remoteness of their home, they received some food from the hospital, though barely enough for all three. Other family members had little food to spare, nor the money for bus fares or time to visit regularly. Sometimes this lively little girl would hold a pencil and make some drawings around pictures
in an old newspaper. When asked about school she said she used to go but the teachers often didn’t come. Her outgoing nature and animated conversation suggested that she might have had a bright future. Hers was a family where there were several members on both sides who had had broad experiences including overseas travel and tertiary education. Lamana said little about his children. In response to enquiries about the little one who was in the city with him and his wife, he would reply simply: He’s fine.

Like Winnie’s young daughter, Gordon’s son, who attended a city primary school, would sometimes stay with his father in the ward. His mother managed all necessary care. But clearly there was conflict for the child. He and his younger brother were happier to be with their father, but attendance and participation in school activities suffered. The younger brother, Grade 1, came one morning with his mother. He was dressed in his school uniform, ready for sporting activities. He told his mother he wanted to see his Daddy and could not be persuaded to go to school. He stood close to his father as his mother went about her daily routine of care. Both parents were concerned for their children’s education and future. They expressed their wish that the children speak good English. But for children with a sick father school was not a priority.

John’s wife revealed her concern for their children and how she felt about the previous 2-3 years. I’m feeling sorry for him ... for myself ... for the children. The children are still small - 3 and 7 years old. The younger one had only known her father as a man with recurring illness. Admissions to the hospital and clinic visits had become a regular part of life. The wife’s sister was caring for the elder child and enabling him to commence school. The younger one was in the wife’s village.

Joy left her four children in her mother’s care. The eldest two, 8 and 6 years attended the village school. The younger two were still at home. The youngest child who had been admitted to the children’s ward was now in the village. No details of the child’s HIV status were available. In this case the children stayed together, the elder ones attended school. In the village, the economic strain was eased.
Among the children involved in this study, Patricia calls for attention. Her HIV diagnosis had occurred some time ago when she was less than 15 years of age. Her illness began at a time when she was going to dances, drinking beer and enjoying city life. *Sik i painim mi taim mi raunim danis, dring bia, mi bin bikhet* (I got sick when I went dancing, drank beer and was disobedient). She was born in the village but insisted that she had lived in the city for a ‘long time’. When she left her mother, she came to the city with ‘nothing’. *Mi no gat wanpela klos. Mi kam nating* (I had no clothes. I had nothing). Her uncle provided for her needs. In the ward she appeared to have more than enough - stylish teenage clothes, finger nail polish, attractive bedding, carry-bag, fancy radio and ear phones providing popular music for her entertainment. She was clearly a very independent young woman. While she spoke openly about being infected with HIV by a man at a nightclub, *danis ples*, she did not mention payment for sexual favours. One nurse commented that she was neglected by her family. Patricia mentioned in one breath that her family didn’t visit, in the next that her auntie had brought food. The absence of a full-time guardian might be equated with ‘neglect’ but Patricia’s own description of herself as disobedient might also explain that she often chose to go her own way, ignoring the guidance of her uncle and aunt. After her diagnosis, she was scorned by former friends. Her aunt offered support and practical ways of coping. Her uncle took extra care to provide her with a healthy diet.

As these examples show children are affected in many ways. They can suffer from lack of adequate care and are vulnerable to physical, emotional and sexual abuse. Although parent participants describe arrangements they or their family members have made for the care of their children, there is no way of observing the situations in which the children are placed. There are examples of children separated from their siblings. In fact, this seems to be a likely outcome in order to reduce the burden of care, especially in the city, where costs are high.

Analysis of the data identifies the following children infected or affected by HIV. There are three age categories - pre-school, primary, secondary. The family categories highlight the effect HIV can have on the availability of relatives to care for children (*see Table 4*).
Beyond the family the wider community provides both support and challenges. The following section describes living with HIV in the city, where medication and clinic visits become a regular part of life but there is little money for essentials.

Table 4: Children infected and affected by HIV

<table>
<thead>
<tr>
<th>Age of children</th>
<th>Total</th>
<th>0-6 yrs</th>
<th>7-13 yrs</th>
<th>14-18 yrs</th>
<th>Unknown age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother died</td>
<td>3</td>
<td>2</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Father died</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Both parents died</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother ill</td>
<td>3</td>
<td>2</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Father ill</td>
<td>10</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Both parents ill</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family breakdown</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Parents on ART</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Sibling ill</td>
<td>2</td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Grandmother carer</td>
<td>7</td>
<td>4</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death of Children</td>
<td>6</td>
<td>4</td>
<td></td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Food is here in the city, Lamana explains, but how can you get it [without money]? There is similar stress for Stanley: I am in the ward looking after my wife, sleeping here and trying to find food for her. She is not able to eat the brown rice that the hospital provides. I try to feed her with bread, milk, meat, egg. I have a big problem. I need to buy these things. My sister comes every two weeks but at the moment she is paying school fees for our younger sister. Yet, he adds, I am thinking positively. Employment opportunities are clearly limited. We can sell betel nut, Lamana explains, but looking for a job is very hard. He has given thought to the employment situation in the city and observes: friends find jobs ... casual ... or with security firms or offices ... with Government departments ... depending on knowledge ... A Grade 10 certificate places Lamana in a relatively favourable position. His English language and other skills would be considered satisfactory for many positions. Yet, it is likely that
there are other obstacles in his path, for example, not knowing how to apply for work or overcoming perceived nepotism. And so, he concludes: *I get some cash from selling nuts and scones. I don’t know how I can find a job.*

### 4.4. Spiritual Beliefs and Practice

In describing the religious rituals in his family Lamana spoke within the framework of the Catholic Church which was *the first to come along to the village* long before his birth. European missionaries brought their European style of Christianity. Having first evangelized the coastal areas they moved up into the mountains. They built a church from bush materials in the vicinity of the village. They also built roads and bridges, schools and clinics. They brought a community of Sisters, religious women, who also brought their culture, its values and customs, along with their health, education and development projects, which were welcomed by the people. While Stanley stresses how his mother lives her Christian beliefs, and how his sister is also a strong support to him, he sums up his own concern: *I value my life.* His actions suggest that he also values the lives of his family and the good of his people. He welcomes time to reflect on his life and appreciates conversation that allows him to explore his own hopes and fears. In contrast to the Christian practice of his mother and grandmother, Stanley says: *I don’t have strong faith. I know there is a God. I know about Jesus. I lack motivation. I stay with the wrong people. I was ignorant. I thought God was so big. One minute you say you are a Christian and next minute you are backsliding. Once you accept Jesus it is for life. Right now, I cannot say I am a good Christian.* Describing his faith in this way may suggest it is already under review. Spiritual beliefs and practice will be presented in more detail in Chapter 6.
Summary

Families living with HIV face a series of challenges.

- Living between two cultures: rural and urban, both in process of change
- Coping with limited access to goods and services
- Facing the crises posed by positive HIV results, the associated emotions, decisions
- Preventing spread of HIV to others, within and outside marriage
- Negotiating stigma and discrimination
- Finding caregivers in time of illness
- Accessing medical care for supply of drugs and review of health
- Generating family income
- Providing adequately for the needs of children
- Drawing on community resources

The strong sense of mutual obligation in the extended family is one resource where support and care may be accessed and hope for living found. Participants report moving into the future with at least some degree of confidence as will be discussed below. The following chapter will present findings on caregivers illustrating in more detail the continuing important role of the extended family as a source of hope. It will also describe the situation of patients who have lost contact with family members.
5. Caregivers

Learning to be an effective and compassionate caregiver is of primary concern to me. This chapter presents findings related to caregivers who in most cases are close family members. With HIV, recovery from other illnesses is usually slower and the illness more serious, sometimes leading to untimely death. In a large ward, after attending to treatment nurses have limited time for other aspects of care. Thus, the role of caregiver is critical. For parents, facing the chronic or terminal illness of a child often an adult child, HIV can mean a crisis; future hopes are threatened. Similarly, when a spouse is confronted by the HIV infection of a partner there is not only the question of caring for the sick but the threat to one’s own life and future well-being.

This report considers the caregiver’s relationship to the patient. In the cultural context, the former expectations within the relationship are important. When a patient has no guardian, perhaps not even a family member or friend to visit, the role of caregiver is often taken up by volunteers. Finally, care of the dying is described.

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1 ‘Guardian’ is the commonly used term for a relative who stays with the patient in the ward often for the full term of admission and assumes the role of caregiver.
5.1. **The Extended Family**

PNG cultures possess many familiar and practical ways of dealing with illness and other crises (*see 2.1.c and 2.2.a*). The extended family functions as the most important resource for material, social and emotional support. The idea of the extended family is to facilitate the survival of the family as a whole so it can continue to support and enhance the well-being of its members. Survival of the family is central to survival of the individual hence exchange, mutual assistance and cooperation become the central values. People who live in a self-centred way, who refuse to support other family members or simply put their own interests ahead of those of the family are likely to suffer rejection. They are often described as ‘proud’ and lacking ‘proper respect’ and may even forfeit family support altogether. Family members, particularly elder siblings or those in paid employment, are likely to feel a strong sense of obligation in addition to a genuine concern for the welfare of a loved one.

Philip, 35 years old, was living with HIV and word reached his elder brother who was working in a provincial town some distance away. The brother on hearing the news sent a large sum of money and an airline ticket so Philip could return home to his family.

According to custom, to ensure peaceful cooperation, the rights and responsibilities of each family member are clearly understood through participation from childhood in communal living. However, migration from the village along with social change weakens traditional values and customs. Not everyone who is sick has family to provide care; volunteers are much needed and welcomed by hospital staff and patients alike.

5.2. **Volunteers**

Volunteers, particularly church workers, often take a particular interest in ‘neglected’ patients. These patients often reveal that their marriage has ended; that employment took them away from home for long periods or that unemployment, homelessness, chronic illness, imprisonment or other experiences create distance between themselves and family. The research found that neglected patients are both male and female in approximately equal numbers. Their ages range from 30-50. The majority are originally from the central Highlands region; some are from the Southern region particularly from the remote,
mountainous inland areas. While some have no ‘city residence’, most indicate they are living in an area of poor housing and lack of services. Almost all have been married. With these common factors, each story has its own special features including abusive relationships, family conflict, rejection by family or rejection of family.

Burdened by rejection as well as illness, neglected patients tell their story which is often marked by complaint of unfairness and associated hurt and distress:-

Jack had been married once and had two adult children. His wife had married another man. He had been tested HIV positive the previous year and believed he had been infected two years before that by a lady he met. Brought to Emergency he was left alone. In the ward, he lay on his bed with an intravenous drip in his right arm, his eyes closed. When greeted he responded, Mi pilim pen (I feel pain). Since his admission at the start of the year no relatives visited until one day, according to a nurse, his wife pushed him to the shower in a wheelchair. Jack, however, continued to say that no one came to see him and that he had been rejected by family and wantoks. He complained he had no shirt, no trousers. He enjoyed talking to anyone who was willing to listen. He was given ART and laughing at his improved health exclaimed, ‘Could this be ART magic?’ ‘Have you got a car?’ he asked, ‘we could go for a drive when I get better’.

Missing in the conversation is talk of family. Companionship emerges as a deep longing. It had been experienced in the ward a short time before through the kindness and thoughtfulness of one young man who came to offer help and could meet Jack’s need for spiritual nourishment. Shades of this narrative appear in most stories told by neglected patients, especially males who expect to be looked after by a faithful wife. In some cases explicit mention of conflict within the family suggests that participants, for their own reasons, walked away from a family situation of conflict.

a. Rejection of Family

In Philip’s case, his elder brother responds generously. However, Philip goes out and sells the airline ticket, adds the money from the sale to the cash gift he received and “spent the lot on alcohol” as reported by a former classmate. His health deteriorates quickly. He is admitted to hospital where, soon after, he dies alone. Rejection of family involves factors linked together in complex ways. Family conflict is a part of many stories. In some cases, it seems that the conflict has left gaping wounds - the situation leading to increasing alienation.
b. Guardians helping other families

Guardians who are with their own sick ones are often sensitive to the needs of others in the ward. Having reported that she and her daughter were alright, one guardian, Regina’s mother, related the events of the previous night when the 50-year-old patient in the opposite bed died. The experience still fresh in her mind, she told of her involvement in supporting the family – the wife and the sister of the dying man. Her relationship with the women had developed as they greeted each other, passing in the ward and standing together washing plates or clothes.

Listening to such stories made one wonder if, rather than simply following a rule of life as adopted by a Christian believer, there was not something deeper at work, rooted in a common humanity. The sight of suffering, particularly in the poor, the needy and helpless, arouses pity and desire to help. Many instances of helping the ‘stranger’ were noted.

5.3. Family Support

While it might be expected that a woman would care for her husband, there are in fact times when the number of men (8) as primary caregiver for their hospitalized wives outnumber the wives (3) caring for their husbands. Not only are mothers (6) there in the ward but fathers (3) too, though perhaps in not such large numbers. Then there are both daughters (5) and sons (3), daughters tending to be a slightly larger number. Caregivers who are the brothers of the patients are considerably larger than the number who are sisters (M= 6; F=1). The extended family are present too in the role of primary caregiver. There are brothers-in-law (2) and a sister-in-law, an uncle and a daughter-in-law. These findings suggest that the role of caregiver, as observed in the ward on one particular occasion, is not restricted to either sex (M=23; F=17). Husbands are in the largest numbers (8) followed by mothers (6), brothers (6) and daughters (5).

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2 Data were collected during one particularly overnight observation period in the ward when patients and guardians were preparing to sleep and movement in and out of the ward had ceased. There were more male patients in the ward (M=32; F=24).
a. Family Support for teenagers

Family support for teenagers differs as the following stories illustrate. Christine’s father was constantly at her side for several months ready to encourage her and to watch over her treatment.

Christine, 17 years, was from the Southern region. She had been a primary school student. A close bond was evident between father and daughter. Reading the Bible each day he drew inspiration. “I know where I am going ... and my daughter too. I know she will get well again. Every day I pray.” He himself had been a patient for more than six months with serious back and leg injuries. His understanding of hospital routines and hierarchy was obvious and often prompted him to critically evaluate the situation. Obvious, too, was that he had a heart for the needy.

While Christine’s present needs were met, other concerns, such as her future, were not openly acknowledged. Young women are expected to marry and become mothers. How Christine and her father imagined her future is unknown. Her continued illness and treatment for TB appeared to be the focus of concern and the past and the future seemed to be put aside. There was no mention of boyfriends or sexual relationships. Her father’s concern with poor staff performance in the ward and his trust that God would heal may have kept him from facing some of the difficult issues related to his daughter’s illness. Her father at her side, Christine appeared to have minimal contact with others.

A second example presents a very different picture. Though only fifteen years, Patricia enjoyed time alone with her radio. She spoke openly (See 4.3). She recovered temporarily from illness and on discharge appeared to be a healthy young woman. She woke early, washed, put on clean clothes, washed her plates, straightened the bed and swept the floor in spite of the fact that, unlike most patients, she had no guardian; she had run out of food and was feeling hungry. But, she was expecting her relatives would come and take her home. Patricia was a confident and articulate teenager, happy to have opportunity to come to the city and enjoy city-life. Little is known of her family and her childhood with a brief mention of Grade three schooling.
b. Young, never-married men and women

This group were frequently found in the ward, the majority of them women. Most had support from family members. When she became sick Alice, 21 years, was living with her parents close to the hospital though the family came from a coastal village in a neighbouring province. She was a Grade 10 student when she ‘dropped out’ of school. *My father doesn’t work. My mother does marketing in front of the house. She sells betel nut and smokes and she sometimes comes to visit me in the hospital.* Meanwhile, Alice had a young female guardian about her own age - cheerful and attentive, not only to Alice, but to the patient in the next bed as well. Alice was well enough to enjoy the company.

Noteworthy in Alice’s story is the context in which sickness enters the life of the family. She has ‘dropped out’ of school; her father doesn’t work; her mother, employed in the informal sector, provides for the family. Time away from selling to visit Alice may significantly reduce the family’s income for that day. Alice’s young guardian may also have been a student. Both young women are confident, self-reliant and willing to help others. Elements such as these recur frequently in the descriptions of the context of the lives of city dwellers that have only one or no family member in paid employment. Out-of-school youths are often under-employed and, at times, despondent.

Unlike Alice, Bonnie, 21 years, and her family are unfamiliar with city life. Both parents sit at the bedside along with several younger siblings. The family enjoy each other’s company - talking and playing cards. Apart from the clothes they were wearing they seem to have few possessions. They accompany Bonnie in a wheelchair to the STI clinic. They create a sense of home. Referral to PMGH, where a family must often fend for themselves, can mean considerable stress due to shortage of food and money. The family’s living space is suddenly reduced to the tiny area around a hospital bed. Extra family members may be threatened by security staff - only one guardian is allowed. Money may be demanded to cover cost of water used for washing. Yet, being together may mean survival in the city.
Social concerns affecting the family and the village community may be voiced:

Sarah, 20 years, grew up in a coastal village, attended primary school and finishing after Year 7 because her mother had no money for school fees. Now, her mother was always at her frail daughter’s bedside. Her father was serving in the disciplinary forces but had malaria. ‘PNG men, you know, (leaning forward and speaking confidentially) they chew buai and smoke - eyes are open. No buai, no smoke - they sleep! Whisky – eyes open; no whisky – they sleep!’ She laughed. Her husband’s brother, also in the disciplinary forces, came to visit and had much to say. Concerned about life in the village he wanted awareness programs on topics like sexual abuse. In almost the same breath he added ‘I am not happy with my brother (Sarah’s father).’ Other family members of the family visited. Sarah’s father made a brief appearance. Sarah’s sister was a welcome visitor - the young women exchanging stories with knowing smiles and laughter.

Surrounded by family members, concerned and wanting to see her well again, Sarah was unlikely to feel lonely. Her mother also had support and the possibility of sending and receiving messages from the village. Sarah had been working selling food at an Asian Kai Ba (Food Bar). When the usual medication for malaria had no effect, her mother took her to PMGH thinking that the illness came from eating tainted food; Sarah’s symptoms included diarrhoea. Food, her mother said, should be eaten while it is still hot. Another idea her mother put forward was that the sickness came from going around with girls and sharing food (she did not mention boys).

However, the story also had its dark side as she and her brother-in-law talked about the social ills that have beset the villagers. Not far from the city villages have retained some aspects of their traditional way of life. Missionaries have brought change in the form of Christian faith in God and the rituals of the Church. Education has also brought new ideas. Paid employment has attracted family members to travel sometimes far from the village and for extended periods of time. Roads have brought connection with the city and access to markets and other aspects of city living. Change has been a mixed blessing.

In contrast to these young women and their caregivers, Cally a 26 year old male needed support and encouragement to take care of his health but his father lacked the resources to offer help. He did, however, visit at times and showed concern for his ailing son (See Appendix 4.2).
c. Family Support for mature, unmarried men and women

Sometimes the marital status of patients was unclear. Medical records could skip over that question perhaps not giving it importance or because ‘married’ may be variously defined. Unmarried could mean never married, widowed, divorced or separated. The following patient’s sister was at the bedside.

Henny, 32 years, had no visible signs of illness. He was sitting up cross-legged on the bed and spoke about being discharged soon. Fully dressed, able to look after himself and walking around outside the day before he had his sister there. He was happy and felt that his family was looking after him well. They were cooking food for him and bringing ‘fruits’ to the ward for him. He had been in the ward for nine days and was eager to go home.

In contrast, suffering from AIDS-related meningitis, Barry, 32 years, needed family support. He was a big, strong man but restless, unable to converse or to look after himself. At times he became distressed. The floor surrounding his bed was dirty and smelly. On one occasion, his father made a brief visit and handed over a small supply of store goods. A young well-dressed man, another relative, came too. Though she was sitting on the floor as far away as possible from the bed, the sister-in-law of Barry’s father was the assigned guardian. But later she explained that she was not washing the patient because he is a grown man indicating that the situation was an embarrassing one for her. She hoped that nursing staff would come and attend to him. Her brother-in-law spoke to her in their local language. She frowned.

d. Family Support for stable married couples

At least five of the participants were married men whose wives were at their bedsides almost constantly. These wives cared for their husband’s physical and emotional needs. At times this was at considerable cost.

Gordon, aged 38, (see 4.3) was a high-achieving person, who had travelled widely. Having graduated with a Grade 12 certificate at a time when this was not common he went on to further training. He wanted to be a pilot but found some aspects of the discipline too demanding so decided that he would be a ship’s captain. He succeeded in his studies and began his apprenticeship. He clearly enjoyed his work and the people and places he visited. His eyes were opened when he travelled internationally experiencing other cultures and cities of the world. Though brought up in a Christian environment his life on the sea meant a
break from church membership. This first experience of illness brought with it worry, anxiety and fear. His wife was supportive, faithfully seated at his bedside for much of her time.

Gordon’s wife had previously spent time in the ward as guardian to her nephew who had been suffering from TB and died in the ward the previous year. Strangely, her husband was not aware of this but his work took him away from home for long stretches of time. His wife’s experience of illness and life in this particular ward provided her with knowledge which helped her face her husband’s illness and an unknown future. She sat at his bedside quietly, calmly occupied with bilum-making.\(^3\) Gordon seemed to appreciate her support at a time when he was feeling anxious about his illness and the pain which persisted even after draining an accumulation of fluid from his chest.

Other married men indicated that they were well cared for. Alfred, 32 years, had his wife at his side most of the time and a continuous stream of visitors. They would bring the newspaper and discuss matters together. Luke, 38 years, spoke quietly. His wife was looking after him. He had already spent six or seven months in the surgical ward now he had been transferred to the medical ward.

The findings so far presented in this section relate to the group of married male participants who mostly fall in the 30-40 year age group. Some have a background in well-paid employment. Others are struggling to sustain themselves and their families in the informal sector usually marketing small goods or they rely on relatives. All have children, some of whom are still very young, who are cared for by wives or relatives. Strong family support assists their recovery from illness and their ability to manage HIV infection. Prospects for long term care and support need further research. The situation for a wife and mother who is hospitalized raises somewhat different issues.

Rob had no paid employment (see 4.2). How he made ends meet remains unclear. But what was known of Rob was that he was a most extraordinary caregiver.

There was an extraordinary quality to the relationship of Rob and Meggie. Rob’s love for his wife never wavered and was always expressed in action. This involved nursing her through a critical period of meningitis when she was very seriously ill, restless and totally dependent.

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\(^3\) A bilum is a traditional PNG string bag but often made of wool today.
on him for all her personal needs, washing, toileting, feeding and laundry. Rob was an active member of the Mormon Church. However, his church involvement could be traced back to his work as a Sunday school teacher. He explained, ‘I started Bible study as a very young man.’ He acted on the belief that, ‘Serving others brings blessings.’ That was how he lived his life taking Christ as the perfect example of service. ‘I have faith. I have no fear. The Lord sees my heart.’ This conviction enabled him to do remarkable acts of kindness.

Having made an amazing recovery to health with her husband’s devoted care they returned to their humble dwelling where his wife’s small dog was waiting. However, illness returned and Rob gave all his attention to the home-care of his wife until she died some months later. The response of the Mormon Church and friends in offering support and practical help when Meggie died indicated the high regard in which they held Rob. Since then Rob has involved himself in an organization of caregivers and is continuing to support those in any kind of need. Another married woman, Winnie’s story has already been told (see 4.2).

e. Support for divorced or separated women from family and in-laws

Divorced or separated women seemed to have little support. Nenge had run away from a violent relationship.

Nenge, 37 years, was brought up in a Christian family and as a member of the PNG Bible Church. She went to Sunday school and learned Bible stories. Her favourite was Jesus crucified and suffered. ‘I was so sad.’ Later, at school, ‘I came close to Jesus.’ Marriage was difficult. If she wanted ‘devotion’ in the house her husband demanded K1 for buai (betel nut) or cigarettes. Finally, she arrived in Port Moresby trying to find her sister. Not having a guardian seemed not to trouble her unduly but gave rise to a fruitful experience of solitude even in the setting of a crowded ward.

The desperate situation of Mary was temporarily relieved when a ‘stranger’ came to her help and brought her to PMGH. Little is known of her story:

Mary was 44 years old. Her ‘Good Samaritan’ reported that Mary had been left seriously ill and unattended for about six months at home. Taken first to a clinic then referred to PMGH, the referral mentioned a name that differed from the one used in the admission register and described the patient as ‘Known retropositive’. A note was added and the ‘alias’ provided. Pulmonary TB was her admitting diagnosis but what left an indelible memory was that all her skin was covered with thick fungal growth. Doctors could not find a vein suitable for an intravenous drip and finally decided to connect it through a vein close to the surface of her shaved head - a frightening picture. Attending the clinic 6 months earlier with a chronic cough she began TB treatment. Three months later, as noted in her medical history, treatment was stopped ‘due to not drinking medicine properly’. Within a short time Mary died in the ward.
Explaining that her husband had married a new wife, Peggy told how her in-laws had brought her to PMGH but, once admitted to the ward, she had no guardian, despite her desperate need.

Peggy, 21 years old, was wheeled into the ward with an intravenous drip in her lower arm and a baby on her knee. Soon after she was helped on to a bed the baby began to cry and Peggy was unable to comfort it. She was sitting cross-legged on the high bed her left arm attached to the IV drip, the baby lying on the bed in front of her. With one free arm she was trying to change the baby. She had removed the large safety pin from the wet towelling nappy and was doing her best to remove the nappy with her free hand. Meanwhile the baby’s crying continued unabated. Peggy was exhausted after spending many hours in Emergency (see Appendix 6: fig. 21). Caring for the baby was beyond her strength. Hearing the baby a volunteer, who was visiting the ward, went to assist and picking up the baby found him easily comforted. Though in size he appeared to be less than a year old, Peggy said he was two years old. There were some small cartons of milk in her bag which her tambu (in-law) had provided. The baby drank eagerly and later ate small pieces of a bread bun while Peggy ate a piece of orange.

Later Peggy added some details to her story. The baby was not her first-born but her second-born; her first child died. The baby could sit on the bed but was unable to stand. The Sister-in-Charge collected medicine for the child and the volunteer donated Bumbums (disposable napkins). According to Peggy all her family members les long stap long wod (were unwilling to stay in the ward with her). The reason was not given but the family lived some distance out of town. Two weeks later Peggy’s mother had come and taken the baby with her to the village and an uncle had visited leaving Peggy with a packet of potato crisps. A rash had appeared on Peggy’s face and she thought it had come from her medication. Illustrated, in these examples, is the minimal or lack of support from family for ‘divorced’ women.

**f. Support for divorced or separated men from family**

While confined to the ward, men who were divorced or separated often struggled to find ways to meet their needs. Jack longed for company (see 5.2). One day, a young overseas student was among the volunteers and he was eager to be helpful and to be a support to the neediest patients. He approached Jack and greeted him warmly immediately forging a relationship with him. The young man asked, “Jack would you like a drink? Milk? Juice?” The young man went down to the canteen and brought back a large carton of milk and gave it to Jack. Seeing him struggling to free the straw and insert it into the carton, the young man
helped him. Appreciation poured out from Jack: You are not like the others. They (other volunteers) come and leave food on the bed and continue on their way. You are different. You asked me what I needed. You went and found it. You came back and gave me milk and you stayed with me and helped me to drink.

Being divorced had significance for Leo, 52 years, though he expressed that in indirect ways (see 4.3). He was married and had five grown up children. He had five grand-children but rarely received a visit from a family member. Four years ago I was confirmed HIV positive by the doctor. I wanted to stay with my first-born son but he said, Papa yu go long Mosbi. There are not enough drugs here (in our place). Arriving in the city Leo’s married daughter met him at the airport and took him to the hospital. She had his welfare at heart but she had a family to care for and full-time employment. Her time was limited but her care for her parents was apparent.

Michael, 46 years, used to be a Lutheran but ‘now Revival’. He was going to church, fellowship, bible study, he said. A recurring theme in his conversation was ‘the body counts for nothing. Scabies, sores, earthly pain counts for nothing. In heaven all will be well.’ He is estranged from his sons and daughter. The absence of his sons who live close to the hospital makes him feel belhat (very angry) but he prefers not to think about it. Rather he thinks about Man antap (God in heaven). Son doesn’t visit. Misin tasol. (Only visitors are ‘mission’, church people.)

Michael’s memories bring laughter. He remembers well his childhood in the Highlands. In 1975, he was in Grade 5. Celebrations at the time of Independence are vividly etched on his mind. Sometimes the experience of rejection by family was resolved. In the case of Terry his acceptance of rejection was summed up simply: ‘God is my wasman (guardian, shepherd)’.

g. Support for widows from family and in-laws

When a husband dies, the support of in-laws for the widow can disappear. In PNG a widow is at risk of losing her home and her children who may be claimed by the husband’s clan. Her financial security is often threatened. This situation existed before HIV but now a wife can feel even more at risk of being blamed for bringing HIV into the family. Her protestation of innocence is likely to be of no avail. A climate of denial, stigma and discrimination means that the consequences can be devastating for the widow and children.
The wife of Thomas, 32 years, took preventative measures as soon as she knew of her husband’s HIV infection. Her husband who was diagnosed with TB and meningitis lapsed into a coma and she cared for him with devotion. She insisted that the doctor not disclose the test results to his family. Thomas’s father could not believe that his son could deteriorate so quickly having been ‘walking around in good health’ so recently. His anger and frustration drove him to hound the doctor for some explanation. The doctor was observed doing everything possible to avoid meeting the father. Thomas’s wife, a professional woman, continued to work every day returning to the hospital to sleep at night. Her mother-in-law and sisters-in-law cared for Thomas during the day until his death four months after admission.\(^4\)

\(^4\) McCarthy, “Bikpela”, 54-58.
5.4. Terminal care

This section ends by describing care of the dying which has a complex set of rituals related to the on-going concern and care of family members. The setting of the ward places some limits on these rituals as relatives who have close relationships visit. Death calls forth other rituals associated with paying respects to the dead, offering comfort to the grieving family and often arranging burial in the home province.

When Brian, 30 years, became very ill his older married sister could see that she would not be able to manage her own family and care for her younger brother as well and began planning to travel with him to their home province in the Highlands. He was not a talkative person but one day he was much better and clearly was happy to share his news. “I’m fine”, he declared, “I’m going to fly home tomorrow. I’m going with two wasman (guardians). I’ll see my brothers and sisters, my parents too. I’ll be happy to see them. They will be happy to see me too. I’ve got my ‘supply’. I’ll get further ‘supply’ from the hospital there.”

Brian’s recent hospitalization had stabilised his condition enough to make air travel possible. His parents, siblings and extended family lived in the village where fresh garden food was usually plentiful. The village, according to his story, could access a hospital that would continue his ART treatment. His family could find the necessary money for the travel.

Far more common is for terminal care of the patient to be provided in the ward. Advantages are that professional care is available. Home care in the city could be supplied by relatives and alternated with hospital admissions. Supportive organizations are available though support for home care is limited. Housing and finance in the city are often inadequate for the care of a terminally ill patient. Care in the city might give access to resources but is often unrealistic unless the family has necessary resources. Thus, many died in the ward.

Vincent, 36 years, had never married; however, he had an adopted daughter. She was about 10 years - confident and capable, very attentive to her father and content to stay at his side for long periods. Vincent came from a traditional village close to the city. As his condition deteriorated various family members stayed with him and at the end he was surrounded by many of his very large, extended family. “We owe it to him. He always cared and generously provided for us.” His family described Vincent as a businessman who travelled overseas and, perhaps, actually lived there for some time. When first admitted he looked a particularly fit and healthy young man in bright, colourful dressing but suffering from a large abscess on his lower leg. He often expressed his desire to pay a visit to his Motuan village. “Just a visit,” he added, “my in-laws have a vehicle.” He intended to return to the ward. He was a friendly
person with an easy-going relationship with the nurses and others. But within a month he lay weak and seriously ill. Female relatives sponged him. They propped up his bed with pillows. They applied cold water to cool his hot skin supporting him physically and emotionally. Nurses adjusted the supply of oxygen and when unable to eat attached an IV drip administering drugs simultaneously. Very tired and weak, he would open his eyes only momentarily. He welcomed someone who could pray with him. His large number of married brothers and sisters and their children would come in turn and surround the bed assuring him of their care. The loving concern of his family and the staff of the ward surrounded him until the end.

Summary

Caregivers, family in most cases, provide support and care. The quality of the relationship that existed before the illness and the resources of the family are some factors determining what can be offered. Most families are burdened by the high cost of living and limited resources. Female patients seem to encounter more problems and have less support and care. This may reflect the double standards concerning sexuality and women’s inferior status. The continued or renewed dependency of a woman and her children on her own family can be a cause of tension. Women are expected to be supported by their husband and in-laws.

Caregivers, including volunteers and church workers, often bring unique gifts and build around them caring communities where hope is nurtured. Most families demonstrate their care of the sick by making at least one person available for care of the patient. In some cases that guardian has support from other family members. On the other hand, patients without a guardian often experience hardship, lack of basic needs, loneliness, and a painful sense of inferiority and rejection. In one instance, a participant reported that solitude led into a time of spiritual growth and a deepened sense of peace and well-being suggesting hope for living her life to the end. Finding meaning and purpose in life, as she did, is the subject of the next chapter.
6. **Meaning**

Recording the findings, this chapter reports the theme of meaning-making associated with illness, its treatment and care. It begins with the causes of illness - categorised as traditional Melanesian beliefs, religious beliefs and health science, then describes how people seek help from prescribed drugs, traditional healing and Christian rituals. Finally, there is brief reference to burial and to stigma and discrimination. My aim, again, is to put a human face on this disease and to identify what sustains people with hope.

6.1. **Cause of Illness**

Cause of illness is presented in three categories: traditional Melanesian beliefs; religious beliefs associated with Christian churches and health science.

a. **Traditional Melanesian beliefs**

Traditional beliefs related to sorcery are evident in the following two accounts of young women. Both were employed in the city. Not long after both became ill and later died.

Regina, 27 years, was married with one child. Her mother described her as a strong, healthy baby, first-born of six children. She found employment at a large hotel which catered for tourists and business people. She brought her pay home and gave it to her father. She was a good girl. Soon afterwards she married a white man who worked for a resource company. Her mother was happy about the marriage but her mother’s clan who were known for their strong views did not like the idea. Regina gave birth to a healthy baby, but her husband kept little contact. Four years later, she was umpiring a game in the village. A village man put something on the whistle. Though she drank plenty of water, Regina’s mouth was dry; she
began vomiting and developed diarrhoea. As the illness continued her mother brought her to the hospital where her blood was tested. Tests were negative, her mother insisted. *Driman i lukim meri na pasin banana lip.* (A sorcerer watched the girl and used banana leaf to put a spell on her.)

Sally too was working in the city. She was living with her husband’s family and it was her husband who brought her to the hospital. Her mother’s responses as told by her son-in-law are revealing.

Sally, 26 years, second-last born in a family of six children, was very seriously ill when her young husband brought her to the ward. She died two days later. Her husband was caring and concerned. A university student, he was eager to tell Sally’s story. A quiet person, she had completed Grade 10. Her mother was from the Southern region, her father from the New Guinea Islands. Sally was employed at a retail food outlet and many *wantoks* would come, especially on pay-day, and ask for money. Her father married another woman from his own place; her mother married another man from hers. Sally’s stepfather was a pastor whose wife had died but people said he was a sorcerer who killed his wife. Such things puzzled Sally’s young husband who was from the Highlands where, he said, sorcery was not widely practised. Though Sally and her husband had lived happily together for four years, they had no children and she began getting sick soon after moving in with his family. This coincided with Sally’s mother’s marriage in the village. Her mother said the sickness was sorcery worked by her stepfather.

In each case the mother’s beliefs and responses play a determining role in selecting treatments as will be described below *(see 6.2).*

‘Witchcraft’ and a ‘ghost’ were thought to have been associated with illness in other cases, too. Noreen spoke of ‘witchcraft’, and the story had much in common with the previous stories of ‘sorcery’. She linked her story of a husband who went to the village and had many girlfriends with stories from the past. When she was still a child her younger brother became ill with a fever and died in less than a week. This, she explained, was because her *auntie did something to her in-laws. So her in-laws did witchcraft on her baby brother.* Then, as an adult, she herself got sick. Again, the cause was ‘witchcraft’; the reason: her in-laws were jealous of her.

Ellen’s treasured photos of her family were a source of pride but also carried the burden of sorrow *(see 1.1).* When fire destroyed the upper part of their home, the family moved into a makeshift ‘shack’ on the property, which was damp and dark inside. She recalls a frightening experience wondering if it might be linked to the baby’s ill-health. Sometimes, at night she
would hear knocking on the door of this ‘house’. Was it a ghost? Was someone working ‘kastam’(sorcery) on the baby?

Sorcery is also briefly mentioned in association with place of burial. Leo from the Momase region where sorcery practices are still feared today, as in the past, expressed his fear briefly in reference to burial. He wanted to be buried in the city, because in his village his bones might be used for sorcery.

b. Religious beliefs

Religious beliefs associated with some of the churches, for example, Pentecostal churches, make a direct link between immoral behaviour and HIV. Sam explains the onset of his illness: *Sik gat mi* (Sickness got me), conjuring up an image of illness hunting down and finally catching its prey. Life in the village was happy. But, he admits, *I was a bikhet. I did not finish my Grade 10. I was smoking marijuana.* His illness, he believes, is the result of his bad behaviour. Similarly, Cally explains his illness: *I got sick because I followed the wrong road. Smoking, drinking, pamuk pasin* (‘risky’ sexual behaviour). *God was punishing me* (see Appendix 4.2). Other Christian churches see HIV differently, as a disease, and the sick one needing unconditional care. Perceptions of God’s punishment will be considered below (see 8.3).

c. Science

Lamana and Stanley both claim that sorcery plays no part in their lives. Instead both explain their illness in the language of health science. Lamana explains: *this sick comes from unsafe sex. That’s the way. I don’t believe in sorcery.* His commitment to regular clinic reviews and ART is consistent with this explanation. Stanley’s case is similar; he relies on his family and clinic and the health science they offer. Differing understandings of illness are linked with differing treatments, as described below.


6.2. **Treatment**

a. **Drugs**

The participants were all under the supervision of a medical doctor, and all had been prescribed drugs as treatment. Manoka was among the first to have ART prescribed. Though she initially suffered side effects, with her doctor’s advice she continued to benefit from ART. Three years of treatment restored her health. Weight gain and positive outlook came with family support in addition to drug treatment, enabling her to sustain full-time employment and to enjoy life with her children (see Appendix 4.2).

While in the ward Cally was prescribed drugs. These were distributed by nurses at regular intervals, but it appeared that he had little interest in the medication. Whether his Church visitors influenced him, advocating ‘faith healing’ as was sometimes reported, is unknown. Discarded tablets were found around the bed. Lack of supervision and encouragement suggest that he was unable to care for himself and possibly benefit from medication.

Stanley and Lamana began ART more recently. Stanley had been on the programme for less than a year; Lamana less again. After doctor-consultation they were each ready to use ART which, they hoped, would enable them to ‘live normally’; they were already enjoying better health. Medication, however, often lacked the supplement of a healthy diet. Lamana’s frustration, arising from a situation of poverty and dependence on his brother in the city, was likely to limit the drugs’ effectiveness. Stanley, too, was resolved to live positively, but tension with his wife’s family and a remote family home were some of many obstacles. However, he understood how the medicine worked and the importance of strict adherence.

Details of many of the patients and ART are unknown and call for further investigation. Limited privacy when interviewing may have been a reason for this, but, once discharged, as outpatients, participants spoke more openly.
b. Traditional Healing

Often complementing prescribed drugs are various forms of traditional healing, particularly herbal medicines. Traditional healing rituals also continue to take place in the village. City dwellers may return to the village to find a cure, particularly when medical doctors find none. Joy’s father wanted her to return home, but she was adamant that she would not go.

As recounted in Sally’s case, her young husband noticed that, when the mother married a second husband, the daughter got sick. Her mother thought that the step-father may have been unhappy with his step-daughter and her husband. Actually, the issue was probably money, because she was in paid employment, and the girl’s husband, still a student living at home, may not have paid bride price. Whatever the reason, the mother’s response was to seek reconciliation with the step-father. She left the city and went back to the village seeking reconciliation by cooking food for him. Perhaps she also arranged some payment to him as his share of the daughter’s bride price. Then she and her daughter were happy. Sally got well again without seeing a doctor or taking any medicine.

However, the sickness recurred. Her mother, finding out that there was a ‘witchdoctor’ in the city, took her daughter there. The witchdoctor removed some ‘bad blood’ and ‘hair from her stomach’ telling the sick girl: You will get well again. There was no mention of payment but in most cases there is a charge perhaps K50-60 ($A25-30). In the city the following is likely to occur: the witchdoctor says to come at a particular time and has the leaves and herbs prepared. Putting the mouth on the sick person’s stomach, trying to suck from the stomach, then, pulling out blood and dropping a stone may say: this stone has been in your stomach for a long time. Now you will get well again. You pay this amount. If you get sick again come back. Some people, it is reported, have recovered after treatment from witchdoctors.

Another form of traditional healing is herbal medicine. Stanley supplements his ART with herbs not to cure me but to make my body strong.
c. Christian Beliefs

I thank God for this sickness. It has brought me closer to God. When I am alone there is peace in my heart.¹

Prayer was a lifeline for Nenge who had been subjected to violence and whose physical pain, restricted movement and absence of a guardian could have made for an impossible burden. Instead she expressed how she feels supported by prayer, her own and the prayers of her cousins and friends. Her sense of peacefulness in the midst of suffering was evident.

All participants in the study claimed association, at least, with a Christian church. Most churches combine medical treatment with prayer, song, Bible reading, counselling, communal worship, confession of sin and healing rituals. Pastoral approaches vary widely among churches. For example, most churches encourage patients to cooperate with health workers and to follow their advice; some do not, proposing instead faith in God’s power to heal directly. Some Pentecostal churches offer hope for a cure for illness in general and, in a few cases, for AIDS specifically (see Appendix 4.2).

Christian rituals are frequently followed. When medicine from the clinic did not cure Regina’s illness, the family sought help from their Church. The pastor prayed and gave them ‘water’.² Churches, such as the Catholic Church, offer rituals of healing which include prayers and anointing with blessed oil, individual confession and absolution from sin. Holy Communion is brought to patients who express the wish to be included. Other denominations gather around the bed and join in rituals of prayer for their sick. Rituals follow the traditions of particular churches or are traditions particular to one person or family. In addition to Bibles, rosary (prayer) beads, statues, holy pictures and prayer leaflets are used in rituals observed in the ward.

Personal prayer is mentioned by most participants. One mother sums up her story, stating quietly but strongly: *Mama igat bilip long Bikman. Nogat bilip long HIV.* (I believe in God. I

¹ Nenge, a participant in this study, confided that despite terrible suffering from a severely disabling cancer she was at peace.
don’t believe in HIV.) She turns to God and prays: *God help me, heal my daughter. I put my faith in God,* she declares, *if you believe, then God will look after you.*

Another mother explains that her parents were deacons in the Uniting Church. The family has strong faith. She put it simply: *when I face trouble I turn to God in prayer.* So, confronted by her daughter’s illness, she said, *I prayed inspired by the woman who reached out to touch Jesus’ cloak believing that Jesus could heal her and he did heal her.* She adds, *I remember Lazarus. He was dead and Jesus raised him to life again. Mary and Martha had faith. So I keep praying that Jesus will heal my daughter.*

Winnie’s sisters gave assurance: *OK. We will leave it in the hands of the Lord. We will pray. Our prayers will be that she will come back to life. Lord, it is your problem. We give her life to you. All of us will pray. We lost an older sister; we do not want to lose you. Life and death are in God’s hands. We trust in the Lord. We prayed with faith. We are sure God will hear our prayer and will answer.*

There were times when someone who knew me as a pastoral worker asked me to pray with them. When death was imminent, my response tried to express something of the mystery of living and dying. I would ask myself, for instance, what words I thought Vincent needed to hear at that moment. I wondered what the God of love would want to say to Vincent. I prayed in simple words, in thanks for so many precious gifts, for life, for family, for friends. I prayed for healing for body and spirit. I spoke to Jesus, the Good Shepherd, who leads us through dark valleys to places of refreshment. “I have no fear for you are with me. I shall live in the Lord’s house forever” (Psalm 23).

Christian prayer of intercession is frequently encountered in the ward. When I was walking from the ward one day, a young man took the opportunity to talk of his and others’ experiences and prayer:

> I am a guardian. My mother is sick and I have stayed with her in the ward for three weeks now. I help her with anything she needs. It is not my first time to stay in the ward. I was a guardian once before. I see many things happening in the ward. I make notes of the things I see. Sometimes, at night, patients will be crying out in pain. They will sing out in their own language calling on God to help them. This is the kind of thing I write in my notebook. Then,
when my mother is discharged – it might be today – when I go home these notes I have made, I will use them for my prayer points. I will pray for the ones who are in pain.

With most of his face covered by a mask, the kind usually worn by a health worker, it was difficult to guess his age. He appeared only a young boy, but he spoke with confidence, maturity and deep faith.

Daily Bible reading supports many of the patients and their guardians. A guardian father explained that when he was a patient: Mi pre strong long Bikman (I prayed hard to God). Reading his Bible and reflecting on how God is present in his life, spiritual thoughts came to mind about how God sees the heart. The feelings that arose in him gave him strength to get well again. Now continually at his daughter’s bedside for many weeks, he testified: Every day I pray. My daughter will not die. She will live.

Similarly, Ron’s life gives witness to his beliefs. He takes time each day for Bible study. When his wife, after many months of treatment and care, was able to sit up and had strength to do small things, he would write a sentence for her to read and guide her hand as she wrote a word. He taught her God loves me and I love Jesus. Never having attended school, she took delight in this novel activity. When able to temporarily leave the ward, they used a wheelchair to rejoin their Mormon community and returned to the ward renewed.

Baptism in the Spirit was promoted by the very active Revival church which was preaching, admonishing, praying, healing and taking patients out of the ward to Ela Beach for baptism, stressing the need to be ‘born again’. Being reborn is linked to moral reform. ‘Backsliders’ are not tolerated nor any member who associates with another church. ‘No compromise’ is the rule. Medical records indicate that, in some cases, the denomination given on admission is changed and ‘Revival’ written, indicating ‘conversion’.

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3 While the Sister-in-Charge in her morning notices cautioned all patients and guardians that if a patient wanted to leave the ward before the doctor gave a discharge then they must sign a paper before leaving the ward. Em samting bilong yu (It is your decision/your business. The hospital will not be responsible for your welfare if you choose to leave the ward without the doctor’s permission.)
Moral reform is associated with the belief that illness is caused by immoral behaviour, so a response must involve change of heart and a ritual to mark conversion.\(^4\) Believing that God was punishing him, Cally took the road offered by the youths of the Revival Church. *Now I have given up all these things and turned back to God. Now I am well again. The Revival Church in the city has many, many people. Lots of youths. People of all ages – young and old.* Healing from illness, he was told, depends on a person’s faith and turning from sinful ways. The Church also offers a large and impressive Sunday gathering of people giving testimony to the works of God. The presence of a large number of energetic and Spirit-filled youths was a welcome and encouraging experience for Cally. In addition, an elder from the church came, laid his hands on Cally’s head and prayed over him. Cally liked to pray in tongues. He felt that, because he was talking straight to God, his prayer would be answered immediately.

### 6.3. Stigma and Discrimination

Stigma is the feeling of shame and of being unacceptable to the community. It is the suspicion or knowledge that others have a judgmental attitude and may be rejecting. Discrimination is when someone is passed over in favour of another because of some supposed weakness. Discrimination occurs when people are not treated equally. The judgement is often based on personal prejudice.

Some examples of stigma were described. For example, Patricia, 15 years, talked of how she would go to the large market near her home. People would look at her and talk about her. It was very embarrassing. Some would sing out: *Sik meri i kam.* However, *Mama bilong mi em i tok: Yu no ken pilim sem. Yu mas pilim amamas. Na bai yu stap hevi olgeta taim. Dring marasin.* This kind of encouragement from her aunt enabled her to say: *Nau mi amamas na mi stap gut.* (The sick girl is coming. Her aunt told her, you don’t have to feel ashamed. Feel happy. Drink your medicine ... now I feel happy and I am well.) Fear that HIV could be spread to other family members also led at times to discrimination in the home.

\(^4\) Eves, "Moral Reform."
Lamana claimed that he never suffered from discrimination. However, he spoke only to his brother and to some close friends. With his brother he claimed this had no ill effect. Stanley disclosed his status to his in-laws, who were distressed to learn of their sister’s infection and suffering, distancing themselves from him.

The issue of stigma and discrimination was not addressed directly by the study. The culture of silence was, however, often noted, suggesting shame and fear.

### 6.4. Ethical Issues

Chapter three has described my research design and methods. This section presents my findings related to the research process and, in particular, to the ethical issues involved.

**a. Sampling**

Once in the ward, I found I was seeing particular types of people – those who were so sick that they were admitted to the hospital. I began to seek additional participants from other sources. I found these by spending time in the STI clinic, which caters for clients who have never been admitted to hospital, or who have become outpatients. Three more participants were added. The failing health of many of the original participants meant that the research proposal needed to be modified to obtain reliable data.

Regarding recruitment, firstly, participants told me they had not previously been involved in a research project, and so the burden of research did not fall heavily on them. Secondly, the process I originally planned was not realistic (*see Appendix 3.2*). Often, because of their work load, nurses were not available, so I became more involved. It was essential, however, that I stay faithful to the intent of the design.

**b. Informed Consent**

Similarly, obtaining informed consent presented difficulties (*see Appendix 3.4, 3.5*). Ideas such as ‘research’ and ‘methods’ and the potential risks and benefits were unfamiliar. When I found it necessary to simplify the consent form, I consulted with experienced PNG researchers. In a recent study of HIV/AIDS in Porgera, a mining town, Gibbs and Cordeiro
made a video promoting discussion in the community. The consent form contained a simple statement and provided space for the participant’s signature or thumbprint: *Mi givim tok orait bilong mi long ol ken yuusim wanem kain toktok mi givim taim ol i wokim dispela video film long mi* (I give my permission for you to use my words when you make this video). The local realities and the expectations of the ethical committee in Australia created some tension, raising the question: what methods are both ethically and culturally appropriate? Living among the people, Church members qualified and experienced in research are well placed to offer guidance. Regarding confidentiality I judged each case, and, where there might be risk of harm did not include that information in either notes or thesis.

c. **In-depth interviewing**

Though the theme list appears relatively simple, many times the story-teller warmed to the invitation to share personal experiences. My encouragement meant that each theme was developed in such detail that the interview was long and exhausting. I was able to develop skill at taking notes after an interview. Conversations that are not recorded, for example, because of high background noise levels, still yielded valuable and accurate data.

Some study participants indicated that the interview helped them to understand their personal situation. My experience of interviewing allowed me to see a gradual freeing of spirit and evidence of hope in the eyes of the person, where previously the burden of suffering was evident. My experience was similar to Karp’s, who interviewed people suffering with clinical depression noting, “Nearly everyone expressed gratitude for the chance to tell their story, often saying that doing the interview gave them new angles on their life.”

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6 Booth and Booth, "Depth Interviewing," 418.
d. Documents

One document I used in this study was a handwritten account by one of the guardians, a personal journal, written in an exercise book containing reflections on the experience of caring for his sick wife. Made in the light of faith and including texts from the Bible, the reflections offered an insight into the beliefs that sustained him in what, for other people, might have seemed an impossible burden of care.

Summary

Traditional belief systems accompany migrants to the city. Sorcery and witchcraft are in evidence - as the cause of illness and as a means of regaining health. Some more readily adopt a scientific explanation. With understanding of their situation, desiring to maintain good health, they enrol with ART - daily medication, regular (often monthly) clinic review and collection of a free supply of medicine. Many make sense of their illness by interpreting it in the light of Christian beliefs. A few churches interpret HIV as punishment from God for immoral behaviour; healing is associated with turning away from sin and conversion to the teachings of the church and its particular interpretation of the Bible. Other churches interpret the Bible differently, stressing respect and acceptance for all, challenging the community to offer support and care. Such Christian beliefs assist the sufferer to accept illness and to take the necessary steps to maintain a healthy and positive way of life, taking care of themselves and their families, and taking all possible steps to prevent the spread of the virus. Prayer, Bible reading, healing rituals, community worship and other activities are a means of nurturing hope in individuals and communities.
7. Discussion

In this chapter I first discuss my process of identifying integrating themes in the data as a whole. Then I discuss pastoral issues, in association with the four major categories: cultural world view, cultural response to HIV, health services and personal response (see Appendix 5: fig. 11). Comparisons are made with the global epidemic and with other PNG studies. Relationships between the themes are examined and a framework proposed. I suggest that the framework may serve as a basis for ongoing critical reflection and research. The discussion ends with recognition of the pastoral needs arising from these findings.

7.1. Integrating Themes

In chapters 4-6, I describe what it is like living with HIV, arranging the data to highlight critical issues for the individual, family, community and pastoral caregiver. The purpose of constructing narratives is to illustrate how HIV progressively affects individuals. Charts are used to illustrate life before and after HIV testing (see Appendix 4.2: figs 9, 10). These narratives also show how data gathered in each case are collated so comparisons between cases can be more easily made. With this background, the data as a whole are analysed and arranged according to themes selected for their pastoral significance: Family, Caregivers and Meaning.
HIV brings considerable disruption not only into the lives of individuals but also their families. Traditionally, caregivers are family members who, for the most part, willingly and capably provide for the needs of their loved ones, but when the caregiver is also the sexual partner he, or most often she, faces not only the immediate burden of care but is also threatened by an uncertain future – her own HIV status and, probably, untimely death. The needs of children can be overlooked or there may simply be insufficient resources available for their care. Some patients are neglected, which raises concerns for hospital staff and pastoral workers about immediate and long term care. Overall, these findings point to the need to strengthen the capacity of communities to respond and to offer support.

As described, I follow a Grounded Theory approach. Firstly, the process of identifying ‘concepts’, open coding, is applied to the data breaking them into discrete parts (see Appendix 3.9). This technique involves naming the data collected from interviews, observation and documents. For example, labels include ‘informal marriage’. This label recurs as all thirty-five interviews are coded. Other labels related to marriage are ‘approved by parents’, ‘stable/unstable’, ‘small children/adult children’, ‘divorced’, ‘widowed’, ‘looking for a new husband/wife’.

The concepts are then examined and compared. The range of potential meanings is explored by questioning and comparative analysis, aiming to open up the text. Memos, records of thoughts, interpretations point to the need for further data collection. For example, examining the idea of marriage I note that, in one text, Lamana says, “No customary marriage ceremony” and adds, “Nothing in the church”, pointing to changes in marriage customs. How widespread this is is checked in subsequent interviews and by re-reading data already collected.

When marriage takes a new form what are the consequences? ‘Informal marriage’ implies that parents approve of the marriage after some time has passed. In the village ‘building a house’ seems to precede ‘starting a family’. ‘Getting married’ and ‘first-born child’ seem to happen simultaneously in Lamana’s case. How does Lamana understand sexuality? How does that translate in practice? How is he vulnerable to HIV? These questions are not
answered by the data and leave gaps in the story. Choosing ‘marriage’ as a category is a logical description of the group of concepts identified in the data and listed above. ‘Sexuality’ as a category is chosen as a logical description of another group of concepts that are not necessarily related to marriage: ‘taboo’, ‘safe/unsafe’, ‘heterosexual/homosexual’. The events, actions/interactions, objects that are conceptually similar in nature or related in meaning are grouped into more abstract concepts or ‘categories’ (see Appendix 5: Table 10).

To reassemble the data, axial coding follows, relating subcategories to categories by examining the properties and dimensions of each category in Table 10. The intention is to explain contrasting experiences. The categories in the left-hand column of Table 11 (see Appendix 5) are regrouped to highlight pastoral issues, including HIV test (a turning point for each participant), context (including the categories of family, education, employment, gender relations, knowledge of and protection against HIV), religious experience (including faith, God, church membership), healing (including health services, pastoral care and traditional treatments) and hope (relating to attitudes associated with moving confidently into the future and possible resources). These larger categories facilitate the tabulation of contrasting individual experiences. In this way Table 11 evolves from Table 10.

The next stage of coding is to integrate and refine the theory. The four major categories are colour coded and formed from groups of existing categories in Table 10.¹ The first is ‘cultural world view’, the second is ‘cultural response’, while the third relates to ‘health services’. The final major category includes those concepts related to the individual ‘personal response’ of the participants. This category illustrates that, although situations may seemingly be similar, different people respond differently (see Appendix 5: fig.11).

¹ The four categories are adapted from a study on palliative care in a cross-cultural context. Kevin Y Woo, "Care for Chinese Palliative Patients," *Journal of Palliative Care* 15, no. 4 (1999): 70-74.
My choice of a central category or theme employs a set of criteria used in Grounded Theory. Criteria require that: all the major categories be related to the theme; the theme appear frequently in the data; the explanation that evolves by relating the categories be logical and consistent; there be no forcing of data; the concept be able to explain variations, and so on. ‘Finding Hope’ was found to match these criteria. All four major categories provide resources that nurture hope. After a tentative choice of this central theme, each narrative was tested to see if its major categories could be related to ‘Finding Hope’. Where physical and spiritual resources were unavailable or in short supply, the participant’s search for hope was limited. This integrating theme was chosen to cover all the stories studied, including any that were contradictory in some way.

### 7.2. Cultural World view

Belief in a spirit world permeates the PNG way of thinking (*Noreen, Leo, Sally*). In illness, spiritual concerns outweigh material ones. Cultural beliefs, related to sorcery and witchcraft, are reported both as a cause and as a means of finding a cure. This is consistent with the traditional explanatory models of illness and treatment (*see* 2.2.a). Participants explain illness in terms of strained relationships (*Noreen*). Jealousy, which might include envy or resentment, is often given as the reason why sorcery was used to inflict illness when, for instance, marrying a ‘white’ husband (*Regina*) or not receiving a share of ‘bride price’ (*Sally*). When someone has more or better land, garden, employment or store goods, the end result is that someone else is offended and relationships in the community become strained, leading to accusations of sorcery. The resolution of disputes is required before a cure for illness can be found. On the other hand, some claim sorcery plays no role in their illness. They know HIV comes from unsafe sex (*Stanley, Lamana*).

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2 Strauss and Corbin, *Basics*, 147.
Sorcery continues to benefit some but threatens others; it is deeply ingrained in the culture. The sorcerer gains power and status in the community and charges money for ‘work’ done on behalf of others. Sorcery is associated with fear, threat and bullying. It develops in a climate of distrust and contributes to further negative attitudes and behaviours. Parents warn their children of danger from certain people or places, passing on to them fear and distrust. Sorcery discourages people from taking initiatives that could improve the well-being of the family or community. Fear of being different, of giving another cause for jealously, is a powerful deterrent. Sorcery, then, has pastoral implications calling for action to address fear and hostility in individuals and to strengthen mutual trust in communities.

Christian beliefs can nurture hope for living, promoting trust and confronting fear. Churches in PNG and the small interfaith groups have not yet worked together to produce a joint statement of the underlying principles that guide their teaching and response to HIV/AIDS. It is likely that they could reach agreement on the importance of the following: respect for the person made in the image and likeness of God and hence the value of each human life; a sense of right and wrong which enables responsible personal choices; concern for compassion, solidarity and practical response in times of need; acknowledgement that the earth and its wealth belong to all and must be shared fairly and protected for future generations. These basic religious principles and human rights declarations have much in common and so make possible common projects which embrace all. PNG Christian Church leaders have begun work together, symbolised in an HIV awareness poster depicting the leaders holding hands and speaking with one voice; they continue to work cooperatively.

Participants express belief and confidence that life is God’s gift, God will provide in every need and is more powerful than all else that may threaten. Some guardians put their faith into action, accepting responsibility and caring for any brother or sister who is in need, thus expanding the cultural notion that concern for others resides within a kinship group (Ron, other guardians). Christian beliefs often overlay traditional beliefs without displacing them. The degree to which traditional beliefs have been modified is seen to differ widely in the study group.

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**Values** Some traditional values are very much in evidence. For most, one’s place, *places*, remains a strong attachment and is often described as a setting of great beauty with mountainous terrain, fast-flowing streams or expanses of beach, a familiar and simple lifestyle. It is the place to see before one dies and at all costs the place to be laid to rest (*Philip, John, Brian, Vincent*). Appreciation of places of beauty suggests openings for pastoral ministry.

Contributing to the welfare of the community is expected of all members. So the person who is ill, weak or disabled feels badly about the situation and perhaps fearful of the present and future regard of others. Good health enables members of the community to fully assume their responsibilities for leadership, decision-making and provision of care. A strong sense of mutual obligation exists. When someone is in need, help must be given because later the situation may be reversed and help will again be needed (*see 2.1.c*). These cultural values work to strengthen communities.

Children are valued as those who will carry the traditions of the clan into the future and who will care for parents in old age. They will inherit the traditional land and its resources. These concerns have pastoral implications; they support the idea of building a future with better access to health and education services. This value comes in conflict with others at times, as will be discussed below (*see 7.3*).

**Rituals** express the life and aspirations of the community. Understanding ‘marriage’ as it exists today is important when heterosexual HIV transmission is the most common pathway for HIV transmission (*see 2.2.b*).  

Participants frequently mention their marriage situation. It appears that often marriages among the young or following a divorce are informal arrangements. Poverty in the city may limit the capacity of families to retain traditional bride price ceremonies; migratory patterns may limit negotiations between the family and future in-laws. The pastoral implications of informal marriages for families and the

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5 Wardlow, "Extramarital Sex," 1006-1014.
community require study to find out if the support of the extended family is reduced when they no longer play a role in the marriage ceremony.

*Traditional healing* by means of witchcraft was described in one case (*Sally*). The massaging method seems to be similar to that described by Williams (*see 2.2.a*). The human need for rituals that use symbol and gesture to make visible an inner healing, as this example illustrates, is a further challenge for churches. It calls for the intimate transformation of authentic cultural values through their integration in Christianity and the insertion of Christian values in human cultures, a process of inculturation.

*Burial* ceremonies are common in the city where many skilled workers are employed. In the case of an employee’s premature death, the funeral can be elaborate, the employer playing a major role in meeting expenses, including flying the coffin to the village. Traditional values such as respect and concern to maintain good relationships, *gutpela sindaun*, are played out in these rituals. Attendance at the residence to mourn, *haus krai*, is expected of family, friends and work associates along with donations of money, food or vehicles. Mourning may extend throughout the night, even over several days. On the other hand, the bodies of the poor are increasingly left in the city morgue, making regular mass burials by charitable groups common. The pain of losing a loved one, often prematurely, is compounded by the inability to follow customary funeral rituals. Evidence suggests that Christianity has brought little change to ideas about death and dying. Recent studies on sorcery suggest that illness, its treatment and care are dimensions that have yet to receive detailed study leading to more informed pastoral practice. Christian and traditional rituals of healing are examples of where faith and culture might dialogue. It is into this cultural web that HIV has come and from within that web that a constructive and lasting response may also come.

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6 Williams, *Orokoiva*.


8 Street, "Diagnosing", 41.

7.3. **Cultural Response**

Traditionally, Melanesians relied upon their own resources in times of crisis. In the case of illness they had their own health care systems with healers, herbal treatments, and healing rituals and techniques. Some of these are still employed today (see 6.2). The advantage of this situation is that care of the sick is culturally integrated into the people’s way of life. Treatment is relevant to the perceived cause of illness. In addition, self-reliance and human dignity are respected. Modern medicine, in contrast, forces families to rely on strangers, who are part of a system which many people do not understand nor feel they can control (*Regina, Gordon*).¹⁰

**Care** of the sick is generally provided by family but there are some who are neglected, even rejected (see 5.3). Although it is often in the family that HIV is contracted, in PNG’s patriarchal society cultural practices favour men over women. For example, the cultural practice of bride price is still widely understood as giving a man unlimited access to his wife for sexual relations. She is powerless to defend or protect herself. Any request for a condom creates suspicion that she has been unfaithful and can easily lead to violence. The main prevention strategy advocated by both Church and Government agencies misses this point. Women are not in a position to abstain nor to demand faithfulness of their partner.¹¹

Access to healthcare and education coupled with social and cultural change are required to prevent the spread of HIV, where many women have no status or power. The Church, the government and civil society groups must expose the consequences of traditional cultural attitudes and practices. Similarly, the effects of stigma are usually more severe for women than for men living with HIV and women are more at risk of rejection by family. Thomas’s wife, a professional woman, insisted that his diagnosis and the cause of death be kept strictly confidential for fear that their marital home would be lost to her and the children.¹²

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¹⁰ Brian Schwartz, “’Take up Your Bed and Walk,’” in *An Introduction to Ministry in Melanesia*, Point Series No. 7 (Goroka, EHP: Melanesian Institute, 1985), 245.


¹² See Thomas’ story, McCarthy, “Bikpela”.
Since the introduction of Prevention of Parent-to-Child Transmission (PPTCT) programmes, more babies have been born to HIV-infected mothers without contracting the virus. Many women do not have access to prenatal HIV testing or, when needed, to the required drugs, supervised birth and postnatal care (see 2.2).

Rejection of a family member seems to rarely occur among the cultural groups whose ‘land’ is close to the city but is sometimes found among other groups who migrate to the city. The time migration occurs seems also to be a factor. Long time residents adapt to city life and find ways to survive. Recent migrants come to the city looking for paid work but find none or poorly paid work, insufficient to provide for a family. Those migrants who bring business and agricultural skills often gain an economic foothold and can sustain their families. However, conflicts of all kinds arise and rejection results.

Caring takes on particular characteristics where the extended family is the norm. Kinship and reciprocity are highly valued and practised. One relative explained: “We owe it to him, to care for him well, because he always cared for us and was generous with his gifts” (see 5.4). It appears that this sentiment was shared by all his family and there was an evident eagerness in the way visitors approached his bed and delighted in caring for their ‘brother’. This example is not an isolated one. Kinship bonds often remain strong when clans live on their ancestral ‘land’, including villages built over the sea. A strong sense of cultural identity and the associated practices of care seem to prevail. This situation differs from other cultural groups who have migrated to the city and, in the process, may have lost some sense of identity and the cultural practices associated with the sick. Or, the struggle to survive in the city may leave them with little available resource.

Talk Patients and caregivers are usually open and friendly towards pastoral caregivers and volunteers who visit, recognising them as willing and able to help in various ways. Apart from the very sick and weak, most are quick to talk about themselves, their family or their illness. Some simply seek companionship; others have weightier concerns and welcome someone who is willing to share their burden.
Silence Responses to an HIV diagnosis are influenced by attitudes to HIV that prevail in the community. Though awareness campaigns began before 1989, they often lack effectiveness. There is limited support from community leaders, unwillingness to discuss sexual relations or an attitude of unconcern. The campaign still lacks reliable statistics and relevant information such as prevalence. Secrecy and stigma hamper access to knowledge about the disease.\textsuperscript{13}

Stressing confidentiality may have added to the idea that this disease is associated with shame. Although attempts were made to involve persons living with HIV, one of the first television documentaries concealed the face of the person who was interviewed, thus emphasising difference. Awareness campaigns stressed no cure existed, thus creating fear. The ABC method of HIV prevention (Abstain, Be Faithful to one partner, Always use a Condom) was often interpreted as meaning that HIV is spread by those who are not faithful to one partner. PNG publicly professes Christian values, so the message also carries overtones of immoral behaviour. That babies, children and people receiving blood transfusion could be living with HIV and dying of AIDS received almost no attention. Stigma and discrimination developed helping to explain why patients rarely speak openly of HIV.

Shame is often associated with HIV. In a letter to the editor, Jacob Sekewa states his belief in uncompromising terms. “HIV/AIDS is a self-inflicted disease. It is spread by people who practise multiple sex and these are people who are prepared to step out of the normal human and moral boundaries.”\textsuperscript{14} Religious beliefs associated with some churches, for example, the Revival Churches, make a direct link between immoral behaviour and HIV. And so a positive test result brings intense feelings, including shame: “It was so difficult to accept. It came as a shock. I was married. I felt shame and regret ... I was so worried” (see Appendix 4.2).

\textsuperscript{13} For a similar situation in Zimbabwe see Meursing, World.
\textsuperscript{14} The National (Port Moresby), September 6, 2004.
Shame plays a significant role influencing people’s behaviour in all areas of life.\textsuperscript{15} With reference to her sister’s infection, one woman explained the meaning of shame:

> It is something like feeling guilty. It is when we want to kill ourselves and die because [bad] news about us has spread. People in the village know what has happened [even when we live in the city]. The family is shamed. It was like when our older sister was pregnant. She planned to die. She killed herself. She wrote a letter to our sister. She said, ‘I’m going away ... It was all because her husband called her pamuk meri (prostitute). He said, ‘The baby is not mine.’ When she died it took our heart away. We felt very sorry. We could tell she felt shame by the way she was acting. She died of shame. There was the same strong feeling of shame when we knew our sister had HIV (Winnie’s sister).

**Anger** is described in the narratives, especially in the case where a married woman is certain that her infection has come from her husband’s extramarital sex. With later insight into earlier events, one woman described how angry she was and how she would never miss an opportunity to ‘pick a fight’ with her husband. One way of dealing with anger is to seek help in prayer as described simply by one woman: “Lord, help me. Take this problem from me.” She believes prayer will overcome this problem. Another married woman described her anger towards her husband and how she reacted strongly, finally running away. At this point, out of anger and frustration, some women turn to prostitution, often increasing the risk of spreading HIV.\textsuperscript{16} In others, anger may not be expressed but give rise to passive aggression. Loss and grief associated with the death of a child, a parent, a partner or one’s own HIV diagnosis follow similar trajectories of loss and grief. Coupled with shame and anger, emotions may be even more painful (*Manoka, Ellen, Maura*).

**Burden of Care** Inability to cope with the illness of a loved one is sometimes faced with all honesty. The burden of care is expressed powerfully by the older sister of one patient:

> The day I brought her to the clinic she excreted on my body. She had changed in appearance. She went into a stage of not recognising us; just lying there ... She didn’t know what was happening. I couldn’t look at her when she went into the ward. I vomited. Our other sister cares for her.

This competent and capable widow with well-paid employment and a strong and practical commitment to social justice heads a family of thirteen, of which she is the only bread-

\textsuperscript{15} A L Epstein, *The Experience of Shame in Melanesia*, RAI Occasional Paper, No. 40 (1984); Street, “Diagnosing”, 44.

winner. The household are mainly children – her own four, the eldest at university, and their cousins, including the eldest daughter of her hospitalized sister. She feels unequal to the demands of nursing her sick sister. The demands on the family caregivers can be “enormous”.  

On the other hand, Ron made light the burden of care. HIV was not a problem for him. It was meningitis and its distressing symptoms that called for his attention and care. Caring had meaning and came from his daily Bible reading. Serving others was a blessing. Ron’s care drew attention. Repeatedly, women in the ward would comment to him, “I see how you look after your wife. I wish my husband was like you!” This contributed to a sense of pride and achievement. In a humble way he delighted in undertaking helping tasks. Finding meaning creates a balance between the cost of caring and personal reward. Involvement beyond the family is one way to keep HIV in perspective and is often motivated by a reaction to attitudes in society as well as being altruistic.  

**Care of Children** The number of children in PNG who have lost one or both parents is unknown. However, the increasing number of deaths among parents of young children indicates that the number of orphans is steadily increasing. There is some evidence that children are cared for by the extended family (see 4.3). There is also evidence showing how children are affected when HIV enters the family. This happens in a multitude of ways as shown in studies of communities elsewhere (see fig.6, below). Children identified in this study are disadvantaged in their access to education and healthcare. Long periods in the hospital ward limit their opportunity to play. Though a maturity beyond their years may be one outcome, they can miss opportunity for guidance from an adult carer. Food in the ward is limited and one participant explained the struggle she had to provide food and other

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![Figure 6: Problems among children affected by HIV and AIDS](image-url)
7.4. Health Services

In the hospital ward designed to support a biomedical model of diagnosis and treatment, doctors move from bed to bed interviewing patients, taking blood to be tested or referring a patient for an X-ray. Results are placed in each patient’s medical file. Following diagnosis, treatment begins. Follow-up visits are often brief with the patient’s progress noted and few words spoken by the doctor, who cannot afford more time. Street explored the kinds of relationships patients experience in a PNG hospital. Interactions between patients and health workers are the source of intense anxiety. Patients express confusion about what they are expected to do and worry that doctors are neither interested in them nor consistent in helping them get well.

Relationships within the hospital differ from other relationships. In the hospital much is concealed. Patients are reduced to bodies and diseases at the cost of their social identity. The ward round, X-rays, blood tests and transfusions, drug taking and so on can appear to be ordering or normalizing a disordered body (Lamana). However, like Street, I observed that patients’ exposure to medical technologies seems, sometimes, to offer opportunities to interact with health workers and to develop relationships that would favour a speedy recovery (Vincent). Some patients and their guardians overcome the strangeness of the doctor-patient relationship and make it work in their favour while many remain confused and alienated. All PNG doctors have been trained in Western medicine. They understand cultural attitudes to illness, treatment and care but at work most adopt the Western model, drawing information from medical tests and recommending standard methods of treatment.

Nurses push a trolley around the ward at regular intervals dispensing drugs as prescribed, replacing an intravenous drip or a urine collection bag. All are local nurses who have been trained in Western approaches. However, they are more likely to encourage supplementing their drugs with more traditional treatments, for example, herbal medicine such as ola vera. One patient mentioned drinking mushroom tea “full of vitamins” (Stanley). Nurses also at

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22 M Foucault, Power/Knowledge (New York: Pantheon, 1980).
times add a prayer along with the medicine and offer simple words of advice or encouragement. Some take time to talk with patients, building up a picture of the person and their situation, and to do small acts of kindness during their regular shifts. Street’s study also provides detailed analysis of nurse interaction with patients. She notes the reference to ‘holistic care’ and the role of the whole family in patient care, including decision-making. Street quotes the Sister-in-Charge: “We try to take the culture of the patients into account.”

Relying more on intuition and personal experience than on formal training, many nurses are in tune with the spiritual as well as cultural needs of their patients. The nurse is there with the patient and is constantly observing all the interactions that go on throughout the day and the night. For example, the nurse may be aware of signs of an inner spiritual force, which motivates and nurtures hope, directing the person to re-build a life that had recently been facing threat of illness or death. Nurses may help a patient to salvage what is left from loss and grief, directing the person towards the values of love, truth, beauty, trust and creativity.

Doctors trained specifically to administer ART work most of their time in the STI clinic, and clients report that they are happy with the care they receive on the ART programme. Reference has been made to personal experiences of medical care (see 4.2, Lamana and Appendix 4.2, Manoka). The initial ‘education’ session begins to introduce terms like ‘CD4’ and ‘viral load’. Some clients coming to collect their ‘supply’ can very soon use scientific names for their drug. Some literate clients, determined not to let HIV become a roadblock to their future, study the details provided on the paper inside the bottle. Some continue their research, using the internet or questioning a medical professional. Typical of people finding hope for living is to hear that the doctor or nurse is giving encouragement: “Don’t worry” and “the drugs will help you stay normal”. Studying HIV-positive patients and the doctor-patient relationship, McCoy found that participants looked for concerned doctors

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23 Street, “Diagnosing”, 85.
who take time to talk with patients in a way that recognizes them as people, not as the “embodiment of a disease”.  

The biomedical model aims to cure the sick. Death can be considered failure. Helplessness faces the doctor when, rather than recovering health, the patient is described as ‘going down’. For some doctors this is not an easy situation to manage giving rise to unease, even fear, which may be observed by the patient and the family. Some doctors try to explain what is happening in a language the patient can understand, but barriers to communication exist such as: language, anxiety and lack of familiarity with Western medicine.

Most doctors are aware of the limitations of their work. They are unable to control their working environment. Guardians are constantly at the patient’s side; sellers wander around the hospital with a tray of food or a bag of toiletries or other goods; a preacher will start shouting in the middle of the ward calling sinners to conversion. The family may invite a witch or sorcerer to visit, particularly if doctors have not found a cure. Doctors understand this cultural context and have little choice but to negotiate the space where they work. The situation is not new and, for the most part, partnerships are formed between doctors and all others who visit the ward. This culture of negotiation surrounds the care of the sick in the public hospital.

Health services become a part of life when the sick come to the hospital seeking help. Professional care is offered as a means of living positively with HIV and finding hope. Frequently, commencing ART brings sudden improved health. ‘ART magic’ is a term which makes an interesting association of health services and traditional healing. The demand of twice daily medication is considerable for some people living in unpredictable circumstances. The reasons for defaulting are many and understandable in the difficult living situations of the city, especially when compounded by poverty. Drugs require a healthy diet and lifestyle. When these are missing the possible benefits of ART are lost.

26 Alice Street, "What’s in a Hospital?" PowerPoint Presentation, Port Moresby: National Research Institute, 2009. For a more detailed discussion see Street, “Diagnosing”.

Discussion

Chapter 7
7.5. **Personal Response**

Within a shared cultural world view with its broadly defined cultural responses in time of illness, individual participants responded in a variety of ways (see Appendix 5: Table 11). The reasons for differing personal responses would require further research. The table shows some individual responses documented in detail. The following section is explanatory.

When a positive test result is totally unexpected, then the crisis is likely to arouse particularly strong emotions such as fear, anger and shame, which persist for varying lengths of time. When family members offer support and encouragement, the infected person is more able to develop a positive attitude and to take all possible steps to enhance health and well-being. A young mother is likely to accept and adjust to her situation, when she is supported by family and wants to reclaim her role as mother, become economically independent and secure her children’s future (*Manoka*). When participants have suffered from recurring illnesses which had not responded to treatment, they seem to respond with some relief that the diagnosis is made and there is treatment to help manage the infection (*Stanley, Maggie*). Rejecting help from family may be a sign that all hope has been lost (*Philip*).

Other factors which may help someone to accept and to adjust to living with HIV include level of education, financial security, familiarity with health care services and the methods of diagnosis, treatment and care. However, individuals who lack these resources can also accept and adjust to their situation. Mothers who gave birth in PMGH and who perhaps had experience of antenatal care and visits to the clinic for immunisation or illness in children seem to adapt more easily to the procedures associated with HIV treatment and care. On the other hand, a female patient may find difficulty in speaking with a doctor, the majority being male. While education may open opportunities for employment and alternative ways of thinking about life and about illness, attitude seems to play a more decisive role than knowledge.

Untimely death is a common event when HIV is the underlying infection. More than twenty of the thirty-five participants died during the study (see Appendix 4.1). Death is often
accompanied by distress, loss and grief, more so when life is suddenly cut short. Derrickson describes the ‘spiritual work’ of dying including review, reconciliation, remembering and reunion. 27 These activities were observed among the participants, for example, life review is frequently encountered in the data as when Michael told an entertaining story of his childhood, including his memories of one major event - the declaration and celebration of PNG’s Independence in a rural setting. This event was about PNG’s transition to self-government and the birth of a new nation, but it also served to explain the transitions in his life. Despite the hardship which accompanied his time in the ward, in the telling of the story the pieces of Michael’s life seem to somehow fit together a little better. Reconciliation and letting go of past hurt was also observed. The visit of Leo’s ex-wife and her “Sorry” was reconciliation for him. Revisiting places, in fact or in imagination, after the manner of a pilgrimage and recalling memories is one of the rituals of dying in the Melanesian context vividly described as part of a “truly noble death”. 28

The sharing of memories, of hopes and fears by someone facing death and the experience of being heard and accepted can be a means of finding hope (Jack, Sally’s husband). When weakness prevents speech, being present and communicating through touch and gesture can reveal hope in the eyes of the dying (Vincent). Touch can communicate care in a way that words cannot. Participants did not include those beyond the reach of words. However, care of these patients was observed. Guardians sat close to their sick relative and offered reassurance by holding a hand.

Transcendence refers to such experiences that are beyond what can be seen or heard or touched. It recognizes that goodness and grace are at work in hidden ways as a person’s life unfolds and recognises that there is mystery at the heart of life and of death – the final stage of life. Transcendence is often experienced through relationships. Vincent’s relationships with his family offered a strong sense of intimacy and belonging.

I was left wondering to what extent the family caregiver was able to ‘walk with’ the sick and in particular the dying person and facilitate moments of grace. Barnard demonstrates this quality of commitment when he reflects on “the promise of intimacy and the fear of our own undoing”. His insightful analysis of the relationship between the carer and the patient is a reminder of the possibility of intimacy. He adds that it most often springs up unexpectedly. Such intimate encounters hold enormous promise and are often accompanied by fear. This fear in the caregiver arises at the prospect of entering fully into the agony of another person and being overwhelmed by the suffering and disintegration. In a powerful way he explains what it can mean to walk with another person, how their suffering needs to be spoken - “if people cannot speak of their affliction they will be destroyed by it …” and how compassion means “sharing the same suffering, / the same agony / accepting in my heart / the misery in yours, o, my brother (sister) / and you, accepting me”.

Some participants and other patients observed in the ward responded positively when faced with illness. This raised for me the question of how they do that. Is there some relationship which becomes a source of strength? Reflecting on what it means to be in relationship or to ‘walk with’ another person, Michael Kearney recalls Nietzsche’s words ‘Someone with a why can bear any how’ and suggests that one might describe the task as enabling the sufferer to recognise their unique and individual why, to recognise the meaning that ‘connects’ for them, knowing that this has the potential to transform their pain. Then he asks the important question of how the carer might facilitate the process. The first helpful step is to spend time listening to and getting to know the person in pain. In this process and using language sensitively, the person may move towards the recognition and accurate naming of the pain which may in itself be liberating. Only this individual can recognise his/her own meaning. The carer’s task is in an attitude and a quality of presence. These can be enabling because it is in waiting in the experience that healing and transformation may come. What

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30 Soelle, *Suffering.*
the carer can do is the necessary groundwork and preparation required to build and hold the space wherein the miracle can happen.33

Interviewing as a form of conversation also has the potential to nurture hope as does other uses of language. One seriously ill man valued his opportunity to voice his thoughts. He insisted: “I want to give you some stories for your book” (Cally). Spirituality and language are important partners.34 Already there is mention of the carer’s use of sensitive language and the desperate need of the sufferer to find words to express what is happening. The idea of language as the means of reaching a depth of reality is explained in a way that makes very clear the meaning of walking with another person. Stanworth explores the potential for patients to express spiritual needs and anxieties so they can be identified and ameliorated. Metaphor extends the boundaries of our language and knowledge, and so the carer must be trained to understand the significance of the metaphors of patients as gateways to their spiritual reality for it is possible for us to say more than we ‘know’.35 What is particular to nurturing hope is accomplished through conversation.36

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33 David Finlay. Quoted in Kearney, 54.
36 A Lester, Hope in Pastoral Care and Counseling (Louisville, KY: John Knox, 1995); Anssi Perakyla, "Hope Work in the Care of Seriously Ill Patients," Qualitative Health Research 1, no. 4 (1991): 407-433.
A Personal Reflection and Personal Process.

At times I feel distant from the experience. While living in Port Moresby I continue to visit patients in the ward to keep alive the experience and challenges. I recall that my friendship with “Manoka” has grown out of the research. She trusted me with her story. She has leaned on me for support from time to time, and I have leaned on her for an understanding of what happens when one is diagnosed with HIV and how the multitude of challenges that follow are managed. I have learned from her courage and her openness and have been inspired by her faith and her hope.

Other participants whose situations have been rather desperate because of homelessness, rejection, or incapacity have been unable to tap available resources. This shows me how great can be the human suffering when there is no one to lean on. The project has exposed me to the stories of people trapped in hopeless situations because they have often been made poor and vulnerable by unjust societal structures. Some seem to have lacked guidance and the capacity to make decisions. Rapid social change has caught people unprepared and left many disoriented.

My response has been to listen to individual stories and to reflect on what they reveal of human suffering and of hope. Sometimes there are small ways in which I can help. Above all I want to work with others as an advocate through education and through all other pastoral strategies to prevent the spread of HIV by strengthening communities. Working with others who share similar goals is important, because anything I might do is small compared with the challenges that are faced. Responding to HIV requires a corporate effort. Everyone has a contribution to make and shares responsibility to create a supportive community.

Initially, my intention was to update knowledge of my field, to gain new skills, to be better equipped to work in education in PNG. I did not intentionally choose to become a researcher; I was not fully aware that I would need to become one. Looking back the process of becoming a researcher was an evolution. As I became involved I learned from experience. By working among researchers and by regular attendance at the National
Research Institute I served a kind of apprenticeship. Over two years I attended the presentation of the work of many researchers and several International conferences in Port Moresby. All of this exposed me to the value of research and its demands.

I was often walking in the dark, feeling my way. I am grateful to the many people who have guided me. The research method I adopted, Ethnography, had immediate appeal to me. It involved an appreciation of the culture of people who have a different world view from mine, different beliefs, values and customs. I think the method has served me well; I had many ethnographic studies of PNG cultures to guide me. Implementing the method in my usual workplace was not too difficult. Much more difficult than collecting the data has been the analysis, the writing up and the general organisation of the findings.

I can recognize other roles such as ‘teacher’, ‘pastoral worker’, ‘missionary’, and from a cultural viewpoint, ‘stranger’ interacting with my role as researcher. All of these played a part and influenced my decisions. I was born into a Christian family where religion was practised. I was raised and educated in a Western society, attended a Catholic Girls’ College where women where encouraged to be leaders and to pursue education. My training as a teacher led to wide-ranging assignments. Theological education ran alongside teaching practice. Twenty years in PNG and teaching adult students in a cross-cultural setting helped me to develop some degree of cultural sensitivity. However, this knowledge did not enable me to understand what it is like for someone to live with HIV. As a researcher I was journeying into unknown places.
7.6. **Finding Hope**

Having discussed the study's findings with the purpose of reaching some conclusions, I propose a framework that illustrates the links between the themes emerging from the data. The over-arching theme: living with HIV and finding hope is shown in the figure below in relationship to the cultural world view of the participants, the cultural response, health services and personal response. The framework draws attention to the critical role of culture in understanding what it means to live with HIV. It shows that hope is derived from several sources simultaneously. While family and clan remain in most cases the primary caregivers and means of finding hope, health services and the response of the individual have important roles to play.

![Diagram of Living with HIV: Finding Hope](Image)

**Figure 7: Living with HIV: Finding Hope**

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**Discussion**

**Chapter 7**
Hope is the capacity to move into the future with confidence. Death was near for more than half of the participants; still the final steps of life’s journey could be taken with confidence. ART when supported by a healthy diet and lifestyle can make possible a longer life span and renewed strength to fulfil life’s goals. Hope may mean that life beyond the turning point of HIV diagnosis may be a far richer life than ever imagined. Quoting from Maura’s poems:

“I look at this life as an opportunity,
an opportunity to leave the world
a better place than when I came into it.
AIDS is not going to steal that opportunity
away from me.
That gives me the courage to go on.
I am living my life positively,
And I will continue to contribute my bit
in this struggle against AIDS.
That is my hope of living.”37

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37 See Appendix 1.
7.7. **Pastoral Needs**

So far, the discussion has identified questions of identity through detailed reference to the cultural world of the participants and what happens when a person’s sense of identity is threatened by illness and, perhaps, untimely death at a distance from other family members. A second question has been about meaning and purpose in life when illness takes a person away from familiar work and life within the family. Finally, discussion has included reference to religious belief and practice characteristic of most PNG people.

Pastoral ministry and HIV pastoral ministry in particular occur within mutual human relationships. Human relationships provide a companion for the journey of life. The role of the guardian in the ward has been described and is highly valued by the sick. Ordinary relationships and events can become opportunities for finding meaning and hope in suffering. Pastoral responses include listening attentively and with empathy to people’s stories of joy, hope, grief and anxiety and responding with feeling, thus offering needed support. In a cross-cultural situation pastoral listening involves recognising the other person’s cultural beliefs and values, noting those symbols and rituals that have meaning. When words are not spoken ‘listening’ means interpreting signs and responding with caring gestures or simply ‘being there’. Respectful listening may uncover the need for a ritual to mark a stage in life’s journey. A missed opportunity to celebrate an important relationship led one patient to request a marriage ceremony that was prepared and celebrated around the hospital bed. More often someone asks for a ritual of healing or of reconciliation or wants to confide a wish concerning burial (*Leo*). Responses are respectful of the needs expressed by the person.

Pastoral needs are often revealed in ordinary conversation in which an experience is shared – the joy of returning to the village, fishing in the nearby river, making a generous catch of prawns and of preparing and sharing a meal with family. The simplicity of the scene, the beauty of the fresh water, the nearness of family and clan and the fishing net, a familiar handmade cultural symbol of work, open onto sharing life’s meaning. Fishing in the shallows of the river is the work of women, and so it is with other women, old and young, that this
event occurs. The time of silent expectant waiting for the fish may provide opportunity for reflection and for opening to a spiritual world.

Pastoral needs include the need to gather in larger groups. Traditionally, the village gathered to celebrate harvest times, marriage and death. While funerals continue to bring together whole communities and their neighbours, even people from further afield, rituals that celebrate life are declining in many places. With young people moving away from the village for education and employment, initiation ceremonies are not common. Similarly, as the data have demonstrated, marriages tend to be informal (Stanley) and the elaborate and often meaningful rituals of exchange integral to the marriage ceremony are seen less often. Pastoral workers should be alert to opportunities for the community to gather and can assist with planning celebrations. A communal feast or anniversary can mark days that hold special significance for the community.

Sorcery is practised and should not be denied. Trying to convince someone that their fear is unfounded is unlikely to succeed. New events disrupt the flow of life in the village such as the advent of development projects, (Stanley) land issues, drugs and alcohol and HIV/AIDS. Discussions among the men or the women as they gather for work or for relaxation continue, and community meetings are gaining acceptance as the way forward. ‘Community conversations’ have been introduced in some places. These can give a voice to each community member including women and youths in a way that is new and welcomed by many.\(^{38}\) There is a deep need to work, to pray, to celebrate life together which is seen particularly among the women guardians, who often talk with others as they wash dishes or clothes or clean around the bedside (Regina’s mother). This developing relationship finds expression at times with two or three gathering in the small area between beds to pray, to sing or speak in tongues, to read aloud or to study the Bible.

Pastoral needs in the context of HIV/AIDS include securing access to health and education for children, youths and adults who have missed opportunities (Stanley, Gordon). Training in self-reliance, non-violence, advocacy and teamwork may be needed. Understanding the

\(^{38}\) Reid, “Engaging Communities”.
links between vulnerable children and the spread of HIV calls for cooperation within communities, so that needs are recognised and communities are supported as they try to address them. At times, the need will be for advocacy springing from the stories of disadvantaged women, children and youths. Sharing the findings of research with communities, especially leaders who can form and implement policies, is an ongoing challenge and a part of HIV pastoral ministry.

Pastoral ministry in a time of HIV is confronted with the need to develop a culture of sexual responsibility founded on values that are life-affirming: respect, mutual care, justice and honesty. Developing a culture of sexual responsibility requires reflection on questions such as: Who am I? To whom do I belong? In response to a prevailing morality that is often judgmental and can promote stigma and discrimination pastoral needs include faith formation and developing capacity for reflection and responsible decision-making. Pastoral needs include speaking out at all times for justice and peace with the understanding that unequal distribution of power and goods in society creates the climate where HIV can spread. Within families and communities change can begin.

The study found that most of the sick found strength in prayer. Recalling stories of healing in the Gospel was a way of deepening faith in the power of God over illness and death. Guardians developed a strict daily timetable which ensured that all tasks associated with their role as caregiver were attended to along with time for rest and prayer and Bible reading. In this way the mind and heart were clearly focussed and fear of sorcery was less likely to gain a foothold.
The four categories discussed in this chapter have overlapping elements and interrelationships. The categories all bear a relationship to the central category: living with HIV and finding hope. Figure 7 illustrates how the findings may be conceptualised. The diagram aids understanding of the many related categories identified in the research and may also be useful in diagnosing where a person’s needs lie, suggesting how best to offer an effective response.

Chapter seven has discussed the findings of the research question and concludes that, in the face of enormous challenges, many individuals and families through mutual support and faith in God are finding hope. The following chapter will reflect theologically on these conclusions, seeking further understanding of what it means to live with HIV.
8. Lament

How long, O LORD? Will you forget me forever?
How long will you hide your face from me?
How long must I bear pain in my soul and have sorrow in my heart all day long?
How long will my enemies be exalted over me?

Hurt, anxiety, bewilderment, betrayal, anger, shame, fear, hatred, guilt, anguish and despair accompany the threat of AIDS. Many people, including many living with HIV, suffer injustice and are excluded from sharing in, building up and enjoying a more just and equal society. Victims of human structures that are unjust, oppressive and dehumanizing attempt to voice their cries for rescue, but these are often too deep to find expression. Similarly, in their effort to survive exile, oppression and injustice, the people of Israel voiced their strong emotions, seeking help from God. Their Psalms of Lament testify that faith and prayer deal with and are shaped by such emotions.

In the midst of suffering the sick turn to the prophet Isaiah, especially the vision of hope found there, drawing from the hymns and poems comfort and strength. Surrounded by the threat of warring nations, Isaiah sees the events of his time as signs from God. The cause of Israel’s troubles is social injustice. God is perceived as punishing the people. Hope for

restoration at the end of the Exile is expressed in the hymns about the Servant of God who suffers for the people. But it is in the Psalms that Israel’s response is so clearly articulated in the larger context of Israel’s historical traditions. These traditions surround God’s intervention in Israel’s history and the promise of new beginnings. Through these events God revealed God’s self to Israel as LORD. The Psalms are frequently encountered in the New Testament and in the Church’s liturgy. Their rich spirituality is rooted in the fact that prayer is an encounter with the living God whom the psalms address as “My God” and petitions cry: “Hear, O LORD”. Because they have much in common with the stories contained in the data I select the Psalms and, in particular, lament psalms, as my source of Christian tradition. What makes the lament psalms particularly appropriate is that they deal with “real life, honestly and in dialogue with God”.

When these psalms appear in the Church’s liturgy as the Responsorial Psalm following a Scripture reading, or in the Liturgy of the Hours, certain verses or even whole psalms are excluded. Psalms expressing strong negative emotions are avoided. Hence, people’s familiarity with these prayers is limited, along with opportunity to pray communally these powerful dialogues with God. Personal and communal prayer, preaching, guided reflection and Bible study seem not to realize the full potential of these prayers. Rarely are they used in the Church’s liturgy in the form found in the Book of Psalms.

In this chapter I argue that the Psalms of Lament are a valuable resource for pastoral theology and HIV pastoral ministry. My aim is to amplify the discussion of the previous chapter and to offer a new perspective on hope. In the first section I will discuss how people need to find a voice in a situation of pain; then I address the issue of God’s justice in an unjust world and the vexed question of how God defends the poor and punishes the evildoer. Finally, I argue that Lament is a prayer form that testifies to the power of God to transform suffering, offering hope and new life. I select individual psalms as examples to explain what lament is and how these psalms are appropriate to situations of extreme distress.

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3 E.g. Ps 109 titled a prayer for vindication and vengeance (NRSV) is excluded, as are verses Ps 139: 19-22 voicing hatred, loathing and killing. However, Ps 88, with its note of despair, has been included in Night Prayer.
8.1. **Giving voice to pain**

Lament is a valuable resource for theology and ministry because it provides a vehicle for the voicing of distress. It reveals a God whom one can challenge, and yet, whose love is steadfast and faithful. The lament psalm offers ‘appropriate’ words in the face of suffering. ‘Appropriate’ words are right in a given situation; they strengthen relationships, ease pain and offer hope. Lament expresses the thoughts and feelings that arise in times of distress, expressing what is deep within the mind and heart, including the longing for rescue, healing and hope. This is important for both the sufferer and for pastoral ministers. The sufferer asks, how can I express what is happening to me? Is there anything I can do to ease the pain, the fear, the loss? The pastoral minister searches for answers to similar questions.⁴ The psalms suggest a way of praying and offer words arising out of a situation of trouble and pain:

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Hear, O LORD, when I cry aloud,       Psalm 27:7
be gracious to me and answer me!
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As noted in the Introduction, to have no voice, especially in a situation of pain, is death; words that express what is happening are needed.⁵ I have attempted to illustrate how people who are facing disruptive events in their lives long to share with someone both the events and the accompanying emotions of anxiety, fear and hurt. When the opportunity is offered in the form of pastoral listening or an interview, many people welcome someone who will listen and respond.

**Psalm 13**

The Psalms of Lament testify that Israel’s God listens with empathy and responds. Psalm 13 is one example of an individual lament. It illustrates how structure throws light on important identifiable elements - address, complaint, confession of trust or assurance of being heard, petition and vow of praise.⁶ The lament is always a dialogue, the speaker assuming a

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relationship of trust and addressing God as ‘my God’, ‘my rock’, ‘my helper’, ‘my rescue’ and other similar forms. Thus, the lament is a personal prayer. Israel believed that, in the dialogue of prayer, understanding of what is happening can be reached, and an unbearable and unjust situation can be eased. In this way, faith and its practice were reformulated in each new circumstance. The psalms serve this same purpose in faith communities today.

The function of the address is to create the context of the covenantal relationship - dialogue. ‘O LORD’ (v. 1) is the opening address later ‘O LORD, my God!’ (v. 3) Within this context the complaint and the petition are positioned. The believer establishes the right to expect action from God because God has acted powerfully in the past. The complaint of Psalm 13 is primarily against God:

How long, O LORD? Will you forget me forever?
How long will you hide your face from me?

Psalm 13:1

Expressed in this series of questions addressed to God is the weight of suffering arising from the speaker’s sorrow and inner wrestling. God is held responsible for this distress because God appears to be deliberately hiding, forgetting the desperation of the situation. God’s apparent failure to act intensifies the humiliation of the supplicant in the face of the enemy.

Here, the complaint is an expression of God-forsakenness. However, in other laments it may lay a charge against enemies or complain that friends have turned betrayers. In this part of the lament there is often a detailed description of the troubled situation. It may be sickness (Pss 6:2; 13:3; 22: 14-15; 38: 5-6; 39:4-6); loneliness or abandonment (Pss 31:11; 38:11); the threat of enemies (Pss 6:8; 7:1-4, 13; 17:9, 13; 35:4; 64:1-6); shame (Pss 4:2; 22:6-7, 17; 69:19) or the threat of death (Pss 28:1; 59:3; 88:3-9). Vivid imagery, such as attacking lions, bulls, vipers, dogs, armies, nets or traps is employed to communicate various situations of trouble. Complaint may be repressed in ordinary conversation as in prayer. However, in Lament Psalms the anguish can be named and can find a powerful voice.

The complaint is followed directly by petition, pleading with God to relieve the distress:
Consider and answer me ...
Give light to my eyes.  

Psalm 13:3

Firstly, there is a demand for God’s attention, then for action. Elsewhere, in time of sickness the petition begs for healing. If there is abandonment, then the plea is for God to be near; if threatened the plea is for rescue. Frequently, the complaint and the petition are supported by ‘motifs’, recurring themes that God should act. There is appeal to God’s reputation, God’s past action, the guilt, helplessness, trust or innocence of the speaker and the promise of praise. In Psalm 13 these motivational phrases relate to the earlier complaint, “How long?” describing the tragic consequences of God’s inaction: death of the speaker and victory to the enemy. There is great urgency in this approach. The petition uses the same address: “O LORD, my God”, “My God” being a reminder of both an intimate, personal and covenant relationship, which obliges God to rescue.

While the lament is the cry of a desperate person, it is also an act of faithfulness. Turning to God is founded on the belief that God can be trusted and will hear. The speaker has nowhere else to turn and knows that God can transform the situation. Confidence in God, built on past actions, is simply stated. These words anticipate rescue. A simply worded promise follows:

But I trusted in your steadfast love;
my heart will rejoice in your salvation.
I will sing to the LORD,
because he has dealt bountifully with me.  

Psalm 13:5-6

Some scholars interpret this verse as a wish, “May my heart rejoice”. The opening “but” connects and contrasts what follows with what came before. The rejoicing of the psalmist is in contrast to the threat of the enemy rejoicing. Similar in structure to Psalm 13 are many other psalms of lament. Each expresses in a unique way the fear of enemies and various forms of abandonment, loss, grief and shame.

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7 Ibid., 86.
Psalm 22 recalls that when Israel’s ancestors cried to God in their times of trouble they were saved. They trusted in God and, despite their situation, felt no shame. In another place the shame felt when pursued by enemies is central to the call for help:

To you they cried, and were saved;  
in you they trusted, and were not put to shame.  
Psalm 22: 5

In you, O LORD, I seek refuge;  
do not let me ever be put to shame  
Psalm 31: 1a

The first reveals that trust in God with confident prayer is the key to freedom from shame; the second provides a model of how to pray when there is need for a place of safety out of reach of ‘enemies’, who could be the cause of shame.

Pain is never welcomed. More likely complaint will rise up in both the initial period of distress and at intervals when the pain returns, with associated disturbing emotions, bringing further suffering. Complaint is expressed with vehemence in lament. This is possible because alongside the complaint is trust and confidence in God. There is evidence as shown in these examples, that the words of the psalms enable expression of pain and reveal a God who can be trusted for safety. What is of theological significance in the structure of the lament is that it provides evidence of transition from cry of distress to praise of God for rescue, as will be discussed below.

Israel’s faith and prayer are rooted in life as it is, affirming that life has its joys and hopes, sorrows and anxieties. Examination of the use of psalms following recent liturgical renewal suggests an over emphasis on the celebration of life at the expense of life’s pain. Might this drive from Christian communal worship those who are overwhelmed by sorrow, anger, guilt or shame? In contrast, Israel confronts hurt, understanding it to be a faith crisis. Using lament, Israel questions God’s fidelity and gives voice to the expectation that God would help in every need. Hurt is confronted in the presence of God. Israel prays from a position of total honesty. Shame, doubt and anger are voiced without pretence. The darkness is faced with God as companion (Ps 23:4. Cf. Ps 88:18). In a world of HIV/AIDS and its accompanying threats, these prayers retain their importance and are indeed a valuable resource.

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8 See “Introducing Rage into Worship” in S P McCutchan, Experiencing the Psalms: Weaving the Psalms into Your Ministry and Faith (Macon GA: Smyth & Helwys, 2000), Ch. 5.
Lament asserts that God cares and that by voicing pain in this way one enters into the difficult conversation of vulnerability, confrontation and passion. Faith declares that God can be directly addressed, because God’s power is tempered by supplication. Lament is set in the context of the God of justice. The sufferer’s cry will be heard and it will be answered. God will rescue; God will restrain and punish the wicked. The next section explores this biblical concept of justice.

**8.2. **God loves justice

Psalms of Lament are a valuable resource for pastoral theology and ministry because the God of Israel is a God who loves justice and is “Father of the poor”. In an unjust situation, God offers hope for the poor, needy and the falsely accused. Injustice will be overcome.

By covenant, Israel’s God is committed to the practice of justice, *sedeqah*, and right judgment, *mishpat*. God orders all things with justice, ensuring that justice and righteousness triumph over evil. God is just because of just judgements (Ps 7:9, 11; Ps 119:137); tests people’s minds and hearts and so judges justly (Ps 7:10). God is just in all ways (Ps 145:17). Justice demonstrates God’s power to rescue and expresses covenant faithfulness and steadfast love for Israel. Judging consists in God helping people to assert their rights by giving assistance and release; it demonstrates loyalty to victims of injustice, persecution and false accusations.¹

Likewise, Israel’s king must practice justice and righteousness. These qualities refer to social relationships. Justice and righteousness are exercised by the king on behalf of the people, particularly, the afflicted and needy. The Hebrew word, *spt*, is translated ‘defend’. In a prayer for guidance and support for the king, that the king must mirror God’s own eagerness to ‘defend’ the poor is clearly seen:

> May he defend the cause of the poor of the people, give deliverance to the needy, and crush the oppressor
>
> Psalm 72:4

The Israelite king is to exercise power in a distinctive way modelled on Israel’s God. He is to care for the poor and needy; to act on behalf of the powerless. This care is not mercy and compassion; it is justice and righteousness. Society as a whole must be rightly ordered. This responsibility of the ruler, modelled on the God of justice, is no less important or urgent today. National and local leaders in both Church and Government are called to defend the poor, the needy and the oppressed.

Psalm 103

Psalm 103 offers further insight into the meaning of God’s justice (v. 6) and righteousness (vv. 6, 17). Christian theology sometimes gives a negative tone to these words, linking them with condemnation. In contrast, this psalm links justice and righteousness with liberation, freedom from captivity in Egypt and compassion. God’s actions on behalf of the people are remembered. In particular, Moses, to whom God’s ways were revealed, is named. Then the confession of faith follows, as occurs frequently in the psalms:

The LORD is merciful and gracious, slow to anger and abounding in steadfast love.

Psalm 103: 8, cf. 86: 15; 145:8

Psalm 140

In another lament, Psalm 140:12 declares:

I know that the LORD maintains the cause of the needy, and executes justice for the poor.

In this prayer for protection and deliverance from enemies the psalmist appeals for justice for the needy and justice for the violent offender. The central issue here is justice. The attack is a personal one. The wicked “have hidden a trap for me and with cords they have spread a net, and along the road they have set snares for me” (v. 5). Images of war and of vipers vividly describe the impending threat (v. 2-3). Then there is a shift to the needs of the poor of the community, suggesting that this prayer could both be used both in situations of individual distress and also on behalf of the group threatened by “the violent” (v. 11). “Deliver me, O LORD” and “protect me” demonstrate the urgency of the prayer (v. 1). Verse

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10 Ps 103:6 Righteousness: the Hebrew term is in the plural, meaning “acts that put things right.” Broyles, Psalms, 397.
4 repeats the same urgent petition for rescue: “Guard me, O LORD, ... protect me ...” Now the enemies are like hunters. The reason God must rescue is, once again, because “You are my God” (v. 6). This intimate address implies faithful and steadfast love. The psalmist is appealing to a relationship that binds the petitioner to God at all times obliging God to protect.\(^{11}\)

Further petitions, in the form of wishes, speak of the consequences of the actions of the violent. There is less calling on God’s intervention here. Instead, God should turn back on the wicked the violence directed to the speaker. The wicked should suffer irreversible ruin “no more to rise” (v. 10). The prayer ends with confession “I know” that the LORD cares for the needy and ensures justice for them. This refers to the experience of past generations of faithful people who have so often witnessed God’s protection.

Coupled with this confession is a vow of praise spoken by the speaker on behalf of the upright community, whose only desire is to draw closer to its God. The weapon of violence in this prayer is the tongue, “the mischief of their lips”; the wicked are slanderers. Psalm 140 voices deeply felt emotions aroused by vicious verbal attack.

**Psalm 7**

In Psalm 7, another earnest prayer for justice and help against persecutors, God is named ‘refuge’ and ‘judge’ and addressed in the words of a simple personal confession of faith: “O LORD, my God, in you I take refuge” (v. 1). Later, comes the further statement of faith: “you … test the mind and hearts, O righteous God” (v. 9) and declaring: “God is a righteous judge” (v. 11). In urging God to judge ‘the enemy’ the psalmist also stands ready to be judged by the God who loves justice: “… judge me, O LORD, according to my righteousness and according to the integrity that is in me” (v. 8). God does not judge the wicked and the righteous only on external acts. Rather, by testing the mind and the heart God probes beyond actions to the heart of the person. Thus, this readiness to stand openly before God, coupled with the image of God as refuge, suggests that, although ‘refuge’ may originally

\(^{11}\) Ibid., 490.
have been associated with the temple sanctuary, the psalm refers this image directly to God.\textsuperscript{12}

The petition in this lament begs to be saved from a situation of attack from those who are capable of tearing like a lion. The righteous God and judge (v. 9, 11) must maintain right order. The petition begins: ‘Rise up’. This imperative evokes an image of God seated on the throne of judgment (cf. 3:7; 9:7, 19; 10:12). Psalm 7 is not simply a private prayer of one falsely accused, but “the LORD judges the peoples” (v. 8a cf. 96:10 where “the LORD will judge the peoples with equity”). Equality, justice and fairness are emphasised. Importantly, here as elsewhere, the psalms connect the experience of the individual with the wider community and God’s judgment of all peoples. God’s justice is concerned with the aspect of punishment. Justice towards the ‘wicked’ and ‘doers of evil’ is the subject of the following reflection.

\textit{8.3. God’s punishment}

God frees the poor by restraining the wicked. For instance, in Psalm 10, the wicked persecute the poor. It is clear too that wicked actions often have their own dire consequences.

The idea of God punishing can be misunderstood. Firstly, it is important to stress that poverty, illness, trouble and so on are not God’s judgment and punishment for sin. As is evident in the Book of Job, it was commonly believed in Israel that a sick or unfortunate person was suffering because of God’s judgment. This, too, is the belief of the observers of the blind man in the Gospel (Jn 9:2-4). It persists in some communities today and is even preached in some churches. This belief that an unfortunate individual is suffering because of God’s judgment and punishment for sin alienates the innocent, intensifying the sufferer’s pain and isolation.

Psalm 38 seems to arise from that context:

\textsuperscript{12}Ibid., 67.
My wounds grow foul and fester
because of my foolishness;
I am utterly bowed down and prostrate;
all day long I go around mourning.
... I am utterly spent and crushed;
I groan because of the tumult of my heart.

Psalms of Lament give permission to the sufferer to express the strong emotions that accompany pain and suffering and so find some relief.

Uprightness or justice and judgment are two key biblical terms as seen above. The great biblical commandment is to follow “the way of the LORD by doing righteousness and justice” (Gen 18:19). The reason is clear. God is committed to justice and right in the concrete situation, particularly where unjust societal structures adversely affect widows, orphans and strangers. God is known as “Father of the poor” as in Psalm 68: 5 “Father of orphans and protector of widows is God in his holy habitation.” The call to be faithful to God is the call to model oneself on the “Father of the poor”. The image of a ‘father’ suggests the intimacy and affection of the relationship such commitment to the poor requires. It also implies determination to defend the poor by freeing them from oppression and exploitation.

Clearly then, the obligation to care for the poor means that the poor are not persons being punished by God, as the doctrine of retribution claims. Instead, the poor are God’s friends. In the Book of Proverbs is the counsel: “Whoever is kind to the poor lends to the LORD” (19:17a). The full implications of this attitude is revealed when Christ identifies himself with the poor and needy (Mt 25:31-46). The upright person’s life must bear witness to solidarity with the poor and helpless (Cf. Job 29:12, 17; 30:24-25).

God’s covenant with Israel requires solidarity with the poor in order to ease their innocent suffering. This, in turn, requires ‘uprightness and right judgment’, which become the major themes of Israel’s prophetic tradition. The prophet, nabi, is one who speaks in place of God and calls constantly for fidelity to the covenant. The language of the prophets has its roots in a concrete historical situation where the poor cry out for rescue from oppression. The

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13 ‘Orphans, widows and strangers’ is a biblical term for ‘the poor’.

14 Gutierrez, Job, 40.
Psalms of Lament also with their roots in concrete historical situations, provide a way of talking about God out of an experience of injustice and suffering. To reach out to others in solidarity is to find a way to God. The reason for the situation of injustice is not necessarily found, but a new perspective begins to emerge within a commitment to the ‘orphan, widow and stranger’. Solidarity with the marginalized adds urgency to the cry for justice and sets the complaint on a firm foundation. Underlying all else is the knowledge that God desires justice, so acting with justice guarantees closeness to God.

Down through the ages, seeking understanding of God’s justice echoes the feelings and experience of many. As in Psalm 73, justice is about the heart (vv. 1, 7, 13, 21, 26). It is a testimony that only those who draw near to God enjoy security and all that is good. The evildoers who oppress the poor will never know shalom, peace and well-being. Through suffering the psalmist discovers that those who turn to God will find strength for living, and nearness to God will fulfil all their desire.

God’s liberation of the poor from the grip of oppression raises the question of vengeance. Some laments contain elements of violence and vengeance. The transitions in these call for special attention. Vengeance, however, is not executed by the speaker but left with God. God’s punishment of the ‘enemies’ has implications for those who desire vengeance; few people escape that category. If the psalms arise out of life as it is and honestly voice the emotions associated with distress, then the fact that vengeance – the cry for retaliation – has a place in the psalms is not surprising.

Brueggemann underlines the reality of the desire for vengeance in the psalms and notes that it is there without embarrassment or apology. At the same time, he emphasizes that the longing for vengeance is within everyone.15 It is in each human heart and all human communities. For example, as a form of ‘payback’, verbal if not physical assault is common as is waiting and enjoying the feeling of satisfaction when misfortune falls on someone who has caused others hurt. The capacity for hatred and the mystery of the human person belong together as evidenced in Psalm 139. As it draws to a conclusion, this beautiful

15 Walter Brueggemann, Praying the Psalms (Winona: St Mary’s, 1982), 68.
celebration of the mystery of life abruptly shifts, expressing the human capacity for hatred (vv. 21-22).

**Psalm 109**

One striking example of a prayer for vengeance is Psalm 109 which, as noted above, has been excluded from the liturgy. However, careful examination of its structure, especially the juxtaposition of the two major sections, suggests that the main argument can be traced through the fourfold use of the word, *hesed* (vv. 12, 16, 21, 26).\(^{16}\) Adopting the definition ‘covenantal loyalty and solidarity’ and not simply ‘kindness’ Brueggemann notes that *hesed* is translated ‘steadfast love’ in vv. 21 and 26 in reference to God but as ‘kindness’ in vv. 12 and 16 in reference to human interactions (NRSV). The key to the meaning of the prayer is to recognize that it is the same word that refers to both human action and the action of God. The psalm then becomes a reflection on the vital role of *hesed* in the ordering of human life. In this context the cry for retaliation can be understood. In verse 12 the vengeance sought against the wicked who did not show *hesed* is to be denied *hesed* from others:

> May there be no one to do him a kindness,  
> nor anyone to pity his orphaned children.  
> Psalm 109:12

The prayer argues for an exact exchange between guilt and punishment. It is not excessively vengeful. Then the mood of the prayer changes. Verse 21 makes direct appeal to God to intervene; the appeal is that God become involved in the public process of the poor and needy against the strong and powerful. The social situation is intolerable and only God can rescue the poor. The cry of the individual (v. 22) is made on behalf of a whole social group (v. 16). Desiring comfort from God, they also desire solidarity in the processes of society, so that together there can be some movement towards a fairer share of society’s goods. The just claims of the poor and needy have been denied, and so God is called on to intervene, as in the Exodus from Egypt.\(^{17}\)

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Providing a helpful reflection on the classification of this psalm and others as ‘pre-Christian’ and best left to one side, Zenger’s careful interpretation of Ps 109 is linked to his pastoral concern. For him, these psalms are important theological statements and are resources for liturgical and pastoral use. They are prayers that rely totally on God in an unjust world. They are the confident prayers that believe God can overcome the wicked, and they insist that God must put right their wrong-doing.

As poetic prayers the psalms of vengeance are a passionate clinging to God when everything really speaks against God … They are serious about the fundamental biblical conviction that in prayer we may say anything, literally anything, if only we say it to GOD, who is our father and mother.18

Zenger argues that verses 6-19 are the words of the enemy. Although the Hebrew lacks the words, “They say”, to begin this section he believes this introduction is warranted.19 In the pastoral context, he argues that the work of the wicked today calls for the strongest possible opposition and reaffirms that God can and must overpower those who lie and hate and attack without cause. In the face of barbaric actions the just must again stand before God with daring words, which the psalms of vengeance testify are permitted. Indeed they strengthen relationship with God and solidarity with others.

Psalm 109 with its juridical language (vv. 6-20) leaves the impression that the psalmist has in mind a human system of justice, one in which the ruling is made by a just judge. The complainant can go to court and can seek and find real justice. The verdict will condemn the evildoer and exact a penalty. God’s justice should be mediated through society’s institutions following due process. When the complainant seeks a redistribution of property and wealth, God’s justice is administered through human processes. The poor may have lost land through the manipulation of a ‘developer’; the widow and her children may have been disinheritied of their rightful ownership of property. The psalm is concerned with reliable social structures and courts that will hear and respond to the cause of the poor and needy.20

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19 The NRSV translation includes these words. Brueggemann and others disagree with this interpretation placing this section and the following, instead, on the lips of the petitioner.
Much study of lament had been done; still there are questions about the social impact of this prayer form. Brueggemann points to questions that might open up further exploration of this important area: What difference does it make to have faith that permits, even requires, this form of prayer? His answer is that it shifts the balance of power between the two parties; the petitioner is taken seriously and the God who is addressed is called into engagement in the crisis in a way that puts God at risk. The speaker is legitimated, calling into question the supremacy of God. God is made available to the petitioner. Lament psalms provide evidence that the speaker is heard and what is said is valued. Such a prayer form in the community of faith keeps all power relationships under constant review and open to change. He goes on to question what happens when appreciation of the lament as a form of speech and faith is not employed in the community of faith, when speech forms which redress power are silenced, even removed altogether. He believes that docility and submission are encouraged and the outcome is that society will resist change, particularly in the political and economic sphere. The poor and needy will find no relief. Injustice will become more firmly entrenched and there will be no prophetic voice calling for conversion.21

8.4. Finding Hope

Psalms of Lament are a valuable resource for theology and ministry because they testify that distress can be transformed. Lament psalms are characterized by transition. The structure of the psalm emphasizes the transition from plea to praise. They contain not only petition but petition that has been heard enabling lament to become praise. There is evidence of this turning point in most psalms. It may be a simple statement:

[God] has heard the sound of my pleadings

Psalm 28:6

Because God has heard the speaker is changed; the situation of distress is transformed. In another place, in response to the petition of the poor, God actually speaks:

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“Because the poor are despoiled, 
because the needy groan, 
I will now rise up ... 
I will place them in the safety for which they long”  

Psalm 12: 5

The moment of change is often captured by the ‘now’ or ‘but now’ as in Psalm 20:6. However, the change is sometimes more subtle. Where the change occurs almost all the psalms of lament contain the expression ‘but you O God ...’ (Psalms 55:23; 59:8; 64:7) or confession of trust or the assurance of being heard. Westermann demonstrates not only how numerous these examples are but also their ‘vitality’. The transition always occurs within the relationship between God and the petitioner. Both are affected by it. It is most frequently found where there is assurance of being heard and forms a bridge between the petition and the vow of praise, though it is also found between the lament and the petition.

Psalm 69

Hope and expectation are found in psalms such as Psalm 69 which express the psalmist’s eager openness to their God in the verbs ‘wait’ and ‘wait for’. The situation of waiting is vividly described. ‘Waiting’ is not silent. Instead, it involves crying out. It involves constant watching. The one who is praying is “weary” from crying, “throat is parched”, “eyes grow dim” waiting for God (v. 3). Trouble increases, “the waters have come up to my neck” (v. 1) but underlying this distress is the deeper, hidden sorrow of restless, tense waiting and pleading for God to act. ‘To wait’ has special significance in the Psalms. It means not giving up, not growing tired, not surrendering to the burden of grief, but persevering and always open and expectant. Certainty that the LORD’s eyes are on those who “hope in his steadfast love” (Psalm 33:18) is the distinctive feature. This hope is based on the unshakeable belief the God’s love is strong and constant, that God will show his hesed, tender mercies.

23 Ibid.
24 Kraus, Theology, 158.
From the pastoral point of view, knowing that prayer can move a person from distress to relief, from lament to praise, offers the sufferer strength to hold on and to trust, in the assurance of being heard. Prayer sustains hope.

8.5. Contemporary Implications

People living with HIV/AIDS may be at risk of staying isolated and imprisoned in their own misery. As has been argued in the first section, the challenge of HIV pastoral ministry is to assist people to find a language that is adequate to express to others and to God in prayer the suffering that has come into their lives. Psalms of Lament may enable the sick and their caregivers to develop an appropriate language. However, religious language can be ambivalent. As noted in the Introduction, religious responses to AIDS can be both liberatory and repressive. In response to questions like: Why must I suffer? How long? Is God punishing me? The pastoral minister should be wary of defending God and God’s justice in opposition to the complaints of the suffering person. The misery and despair of the sick and their family should be the central concern. No answer is possible to the problem of suffering. The language of suffering in the psalms is spoken directly to God, employing vehement complaint which honestly gives expression to the burden of pain. Complaint includes accusation that God keeps far away. But, as shown above, the psalmist dares to make desperate appeal to the God who has always been faithful.

The language of protest and lament may enable the sufferer to move out of a self-made fortress and to be open to healing and comfort. The insight of Psalm 73 that strength and comfort in the midst of suffering can only come through feeling the nearness of God relies on faith. It is hope when all hope seems gone. The caregiver’s task is to assist the sufferer to transcend feelings of isolation and rejection and experience God’s nearness and healing. The suffering and death of Jesus opens for all access to God’s grace. God’s power is at work and is powerful and more than powerful enough “to accomplish abundantly far more than all we can ask or imagine ...” (Eph 3:20).

To read the psalms with someone who is suffering, is to testify together that God’s presence and power are enough, that God will not leave his faithful one alone or helpless. The faith and experience of the community is that God is not far away and so there is no need to be afraid. Throughout the ages, the words of the psalms have been the human words to God in time of trouble. These words express what might otherwise remain unsaid. They speak the word of God that brings strength and comfort. 26

To pray the Psalms of Lament in public worship, including the Psalms of Vengeance, is to ensure that those who harbour hurt in its many and very personal forms will feel welcome and included. They can identify with the words that are addressed to God and will hear the word of God in a way that can strengthen relationships with God and within the community. For this, the community needs proper preparation.

The findings, as presented in Chapters 4-6, can illustrate what lament is and how it might be understood in the PNG context. Distress when told of HIV infection has been described and can be readily related to the distress of the psalmist, even when participants’ complaints are, for the most part, kept hidden. Complaint is sometimes levelled against family members who do not visit or who discriminate. It is voiced when the cost of food is out of reach or clothing or ‘bedding’ is not sufficient. There is no evidence of complaint against God but it is likely to be considered unfitting and so silenced. Words spoken to God, as reported to me, are usually in the form of petition.

Shame often accompanies illness, as is frequently evident in the data for this study as well as in these psalms. The situation of vulnerability and helplessness gives rise to embarrassment as weakness is exposed for others to see. Shame takes a particular form in a Melanesian society and, as the data illustrate, is too readily associated with HIV. 27 Shame, as well as doubt and anger, are voiced without pretence in lament. The darkness is faced with God as companion (Ps 23:4. Cf. Ps 88:18). In a world of HIV/AIDS and its accompanying threats these ancient prayers continue to sustain hope.

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26 Miller, “Psalms,” 135.
27 Epstein, Shame. For a personal explanation of shame see Winnie’s sister’s account (See 7.3). False accusation brings shame driving a wife to suicide.
The findings reveal the theme of care and the role of caregivers; the theme of justice and prophetic response now add meaning to the discussion and point to further possible action. The widow with her young children is fearful of blame, rejection and disinherita
cnce. Can she approach a human court and plead her cause, confident of a hearing and protection of hers and her children’s rights? Those affected by HIV, suffering stigma and discrimination, may find in Psalm 140 echoes of their own threatening situation and the assurance of protection. Particularly in a situation of denial, as associated with HIV, there is urgency for honest, prophetic utterance in prayer. Public communal prayer must call not only the individual but society as a whole to confront evil and to espouse the good.

“God sees the heart” was given as an explanation several times by guardians in the ward who felt impelled to take action on behalf of other neglected patients. Never an easy thing to do but, despite feeling inwardly torn, the needy one’s spoken or unspoken cry found a response in the person of integrity, the one the psalms describe as ‘righteous’ (Cf. Lk 10:25-37). This kind of witness is strikingly given by caregivers and by volunteers, including pastoral workers whose hearts are drawn to the poor who have no one to defend their rights. Those psalms that link justice with the heart have meaning in this situation.

The occasional gestures or comments heard in the public hospital ward suggest that an individual is often aware of a wider community of sufferers and shares a sense of solidarity with them. For example, when there is a death in the ward and family gather around the bedside, they may not be visible behind the screens wheeled to either side of the bed, but their cries of anguish are heard by all. Female family members may assume their traditional roles bathing the body and wrapping it for burial – their movements drawing the attention of many in the neighbouring beds.

The findings offer many examples of confident prayer (see 6.2). That God hears and comes to help in times of trouble is more often explained with examples from the Gospels than from the Psalms. Mothers readily identify with the widow whose only son was being carried to burial (Lk 7:11-17) or the Syrophoenician woman pleading on behalf of her daughter (Mk 7:24-30). In extreme illness, recalling the raising of Lazarus or Jairus’ daughter might
underlie the confident prayers offered for oneself or on behalf of another. Gospel stories of healing and of being raised to life, when seemingly all hope is gone, are familiar to many and are easily visualised. This is helpful for all who seek healing or comfort. The petitioner is guided to approach God in prayer just as so many people came with their needs and lay them before Jesus. The Gospels record, often dramatically, the compassion and healing of Jesus. The Psalms of Lament may become a complementary prayer form, framing and reframing spontaneous cries for help. Nearness to God in time of trouble brings comfort and strength. Nenge explains: *I thank God for this illness; it has brought me closer to God.*

## 8.6. Global Theology

My process of theological reflection has brought me into dialogue with global reflection on the theology of HIV/AIDS that also seeks to address ethical issues and guide pastoral action. My aim and approach are in harmony with insights shared by theologian, Enda McDonagh, and guidelines he proposes: never ignore the lived experience of those affected by HIV/AIDS in the work of theological reflection, nor the example of Jesus as it is presented in the gospels. In the Christian context, serious consideration is given to the way of seeing, hearing and relating that Jesus reveals. McDonagh explains:

> To appreciate the real challenge to theology in a time of AIDS it is necessary to listen to these stories and their tellers, persons with AIDS themselves, the HIV-infected, their families, partners, lovers, carers. More illuminating still for theologians would be engagement with the struggle in the praxis of caring for and suffering with. On the basis of such stories and praxis, of co-suffering or compassion, fresh analysis may be possible and new understandings emerge.28

Theology results from immersion in the world of HIV/AIDS, listening to the stories of sufferers and sharing the struggle. My findings have much in common with other researchers, such as Mombe from the Central African Republic who has published a detailed account of the care of persons living with HIV.29 A similar project examines AIDS in South

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Africa. Particularly relevant to PNG is research based in Nigeria. It proposes that economic justice and gender power dynamics are key concerns when addressing the AIDS pandemic. Cimperman proposes a vision of the type of people needed in a time of HIV/AIDS. She gives consideration to grief and lament. Central to her vision is the call to be merciful. Lebouche is completing research on HIV, AIDS and religion. Paterson addresses the subject of stigma. She also addresses the ‘gender trap’ challenging aspects of patriarchal societies. Thirty women theologians from across the globe recently published papers on the theme: Calling for Justice throughout the World: Catholic Women Theologians. Significantly, the moral ramifications of the HIV/AIDS pandemic are considered from a feminist perspective.

Kelly’s critique of present approaches to HIV prevention points to the deficiency of the behaviour change model (promoted in PNG) with its unspoken assumption that different patterns of behaviour are real possibilities for an individual, and its failure to address the social factors that shape behaviour. He points to pastoral concerns that arise from the pandemic, including unequal access to resources; power inequities; stigma and marginalization; prevention of sexual transmission of HIV; privacy, confidentiality and responsibility. All of these are matters of justice pointing to the underlying, structural causes of the epidemic.


Kelly, “HIV and AIDS.”
Summary

In this chapter I have argued that the Psalms of Lament are a rich resource for pastoral theology and ministry. The Discussion concluded that with the support of family, community and faith in God many people are finding hope for living. Some, like Maura and Manoka, break new ground and resolve that AIDS will not stop them doing all they can to make a difference. This chapter sought to reflect on the data through the lens of the Psalms of Lament. These ancient prayers were formulated in exile, and I suggest retain their value in a situation of distress when all hope seems gone. They enter into dialogue with a God who loves justice and whose love is steadfast.

I have attempted to show how people can change and grow when able to voice their pain and address it to a just God who is Father/Mother of the poor. Lament is a prayer form that testifies to the power of God to transform suffering and offer hope and so has particular relevance in a time of HIV/AIDS. Lament offers a valuable resource, especially for pastoral ministers, as they attempt to talk about God and to stand with others to dialogue with God.

Psalms of Lament enable the speaker to move from silence to speech, often employing bold questions. The complaint is, in fact, an act of hope by someone who is willing to approach a powerful God and to question. Closely associated with this willingness to question God is to question unjust political and economic systems on behalf of those who are oppressed by them. The issues at stake are authenticity and justice.\(^{37}\) There is a place for outrage.

\(^{37}\) Brueggemann, "Costly Loss," 111.
9. Pastoral Strategies

Just as you did it to one of the least of these ... you did it to me.¹

How can life be changed for the better for people infected and affected by HIV? How can the distress associated with HIV be reduced and the burden of care eased? How can present programmes be sustained and made more effective? Where should Church energies be directed? How can Government-Church partnerships be enhanced? Where are the gaps where no response or inadequate response is being made? In particular, as a pastoral minister, what might I be able to do? The starting point is to identify what is already happening and to ask what can be improved or what supplementary activities are needed. In light of the evidence, what is the next step? Pastoral strategies, developed from the needs identified in the discussion and theological reflections, are outlined.

Strategies for pastoral ministry include:

1. approaching people with an attitude of attentive listening, attempting to give each person a voice, thus enabling change and growth and gathering people together, working to strengthen communities so they may realise their full potential;

Churches are engaged on the ground with people’s daily needs including those related to living with HIV. Prompted by genuine concern for the suffering, they help people with whom, often, they have long-term relationships. Churches provide care, treatment and support, promote prevention and give a voice to vulnerable groups. Healing rituals and

¹ Mt 25:40
memorial services complement the distribution of ART and counselling services. Churches work in partnership with Government and national strategies to prevent AIDS. Pastoral planning that includes careful evaluation can sustain and improve church activities.

Attentive listening is needed in order to begin to understand what it is like living with HIV; it will hold different meaning for each person and their family. Ability to listen and the capacity for simply ‘being there’ is needed, particularly in the pastoral care of the sick or anxious. My own visiting of the sick can become more effective through critical reflection, trying to understand, having a heart for the suffering, responding with compassion.

*Community conversations* - structured meetings with a facilitator - have been introduced. Their aim is to address urgent matters confronting the community. The process includes inviting each member, young or old, male or female, to contribute to the discussion, formulate future directions for the community and contribute to their implementation. This model can be adapted, as appropriate, to local needs. Training in communication skills can better equip individuals and build capacity in community groups.

2 paying special attention to issues of justice for women, both in the Church and in the wider society, working to create greater awareness and to remove the obstacles that prevent women their rightful participation in decision-making and socio-economic-political activities;

*Noken paitim meri* (You must not fight your wife, daughter, sister ...) is a video clip played every evening during television’s peak viewing time. One popular lead artist with support singers, dancers and instrumentalists promotes the *No Violence Against Woman* campaign. Targetting physical and sexual violence, its catchy rhythm conveys the message, slowly overcoming tacit acceptance of injustice against women. Creative artists have an important role to play.

Women are active in Church but are not usually found in leadership positions. In fact, as in the wider PNG society, women are most often absent when important decisions are made. Education – both formal and informal – is an important way to remove the obstacles that deny women their rightful participation. When attitudes in the home and lack of schooling are obstacles, leadership within women’s groups is achieving significant results which can be
further developed. Young women, especially, can surmount difficulties when given words of affirmation and encouragement. Ongoing mentoring of relationships can facilitate women’s participation in church, business, education, health or other field. Facilitating girls’ equal access to education can ensure a better future for them and their families.

3. promoting the dignity of the child and providing greater access for children and youths to educational opportunities for development of the whole person, for life skills and moral training, for participation in decision-making and for capacity to relate with maturity to life’s challenges;

The challenge is to engage young people. Formal and informal education and training, including sport and creative arts, are important in achieving this goal. Evidence points to children’s vulnerability; many are affected and some are infected with HIV. There are unacceptable levels of child abuse in its many forms. The care of vulnerable children is an urgent need. There are opportunities to reach out to children even with a smile, expressing some understanding of their often disadvantaged situation.

The belief that the extended family will care for orphaned children is now challenged and evidence of child neglect, particularly in the city, has been presented by several studies. Government welfare agencies complain of insufficient funds and trained personnel. Increasing numbers of out-of-school children and youths are visible on the streets and involved in law-breaking. This unjust situation cries out for a response.

Small steps are being taken by various organisations. WeCare is one that is mobilising resources in the neighbourhoods of vulnerable children. It is training women in each neighbourhood to oversee the care of children, supporting whatever existing family there is. Funds are raised for school fees and for other emergency needs. The organisation is working to develop structures that will make WeCare a local organisation that will be sustainable. School principals are making space for particularly disadvantaged children and staff, offering the continuing support needed. The challenge is the rapidly growing numbers of needy children.
4 encouraging the voluntary involvement of the wider community, providing materially and spiritually for the sick and their caregivers; drawing on the resources of institutions to enhance life in community and build a culture of hope;

Media often takes opportunities to highlight the voluntary efforts of groups within the community. It is common to see volunteers providing for the sick and their caregivers. Newspaper reports help create a culture of compassion and justice; those who have more can share with those who have less; reports with accompanying photos show what is possible and the efforts of ordinary people prompt others to think they, too, could contribute (See Cover Photo). Such efforts thrive when they are spontaneous. Greater coordination could ensure a steady supply of support but may reduce the generosity so evident is the efforts of the volunteers. Schools, too, develop traditions of helping, often developing awareness in children that not all children are well-off. Donating money or a can of food or drink or soap is a practical demonstration of care. Regular school assemblies draw attention to what the community believes and why this action is taking place.

The business community is concerned for the health and well-being of employees and their families, and ensuring the pool of skilled and experienced workers continues to grow, producing economic benefits. Effective leadership is promoting a vision for the future and showing how that dream can be realised. Involvement with people and their lives is changing attitudes.

5 encouraging families to develop a culture of sexual responsibility that is just and to develop the capacity to care for each other in times of illness, distress, discrimination or other need;

Family Life programmes operate in many church communities making a difference in the lives of a small circle of families but the majority of needy families are not touched. Some schools, colleges, seminaries and universities have developed curriculum for a time of HIV/AIDS but there is much still to do. Training teachers and parents, who can pass on human values associated with responsible sexuality and breaking new ground in fields related to all aspects of sexual health could be the next step. Given the numbers of teachers required and the traditional taboos, education and training is not easy. It is a long-term goal to be worked towards in a systematic way. Religious education programmes are an opportunity to witness to and to pass on gospel values. Gospel dramas provide much
entertainment while creating familiarity with the gospel stories and effectively communicating the message.

6 considering morality in a more holistic way avoiding a narrow focus on condoms and replacing it by discussion of “just and responsible sexuality”; educating and training for HIV ministry;

Support from donor agencies has enabled carefully designed workshops training church leaders for HIV ministry. These have been successfully staged at Catholic diocesan level a number of times, following an initial workshop and follow-up sessions with the Catholic Bishops’ Conference. Though designed for priests, they have made greater impact in those places that broadened the participation in the workshop. Women leaders and pastoral workers bring new and urgent issues to the discussions and an honest and open evaluation of current situations, calling for immediate action. Evaluation of these workshops points to more effective ways of conducting them and implementing their recommendations. Similar workshops, designed for health workers, promote professional development. They also aim to improve treatment, care and counselling, promoting a just and responsible sexuality, leading to health and well-being.

7 confronting and rooting out stigma and discrimination related to persons living with HIV/AIDS;

Faith communities have often sheltered the rejected but they can also be places that reinforce stigma because the root causes are not addressed; effective action is not taken. Attitudes within faith communities can increase the burden. Churches play a vital role and have potential to effect change globally and through local action. Acknowledging the impossibility that there will ever be universal agreement on issues connected with AIDS, the challenge is to work and to move forward together with concrete actions bringing clear, evidence-based HIV prevention messages and quality treatment and care programmes to people in need.

Media is playing an important and effective role in addressing the fear that can fuel stigma and discrimination. Illustrated posters and community messages on radio and television create awareness and challenge many forms of stigma and discrimination. Wide-ranging publications suggest ways of identifying and challenging instances of discrimination.
Paterson’s work on stigma provides practical guidelines. Schools promote values of fairness and acceptance of difference, creating a climate where discrimination cannot take root. Much still needs to be done to protect individuals not only from rejection but also from violence fuelled by stigma. Partnerships between church, government and civil society can highlight examples of stigma and discrimination. Often behaviours are accepted as the norm because they are long established in the community or politically and religiously difficult to challenge. Working together is likely to result in more open attitudes and a united voice, promoting change.

8 Speaking for greater social justice in all aspects of life and adding strength to that voice by a clear witness to justice.

Respected church leaders make statements at Easter and Christmas, which are widely available through the media, inspiring all to love one’s neighbour. Interfaith action against HIV/AIDS is well established in some countries and PNG has rich soil in which to plant similar organisations with their work to improve people’s lives and communities.

But it is the ordinary people who may have even more impact in the family, workplace or small community setting when calling for fair treatment for all, especially those who are least able to speak for themselves. And it is witnesses to justice who often make a greater difference by attitudes and actions that lead by example.

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2 Paterson, AIDS Related Stigma. Thinking Outside the Box: The Theological Challenge.
Summary

Looking to the future there is still much to be done. From the perspective of justice, the Church is called to speak out loudly and clearly on every possible occasion, aiming first to open the hearts and minds of church members and measuring church teaching against the way of the Gospel. Then, it must reject all forms of injustice towards people whose lives have been touched by HIV. Orphans call for special care and practical responses. The Church’s human and material resources must be placed at the service of all working to eliminate poverty and to respect the dignity of women and children. The Church’s own internal structures and practices call for urgent honest review and action. Reducing transmission and providing care and support, promoting an understanding of sexuality that is respectful of self and of others is required. The Church is called to work co-operatively and harmoniously as has been happening in many places, openly and humbly acknowledging that AIDS has infected and affected all our communities, including the families of our leaders. Critical and theological reflection can discern God in the midst of suffering. Then, together, people can help one another experience God and find hope. Christ’s message of hope and victory over suffering and death will become a reality for all.
10. Conclusion

In the face of a phenomenon so intricately linked into the fabric of a society and as personally and professionally threatening as the HIV epidemic, it may be that only programs which penetrate the soul of a community will be effective.¹

The study has reported its findings with detailed illustrations of what it is like living with HIV in Port Moresby. Discussion and theological reflection have highlighted some of the pastoral implications. This chapter contains conclusions and evaluation of the study, suggesting subjects for further inquiry.

10.1. Evaluation

Achievements

1. Participants gave detailed interviews which provided rich data relevant to the research question and the aim of the project.
2. Findings created knowledge of what life is like when infected or affected by HIV.
3. Discussion linked the Findings with existing research.
4. Ethical issues were dealt with, according to professional standards and the research design adapted to the local situation.
5. Ethnography as a method provided unique opportunity to investigate the research question. I became a participant/observer, learning from others.
6. Contextual theology linked with global theology; Psalms of Lament revealed a rich resource for theology and ministry.

¹Ian Campbell
There is evidence that the experience of each person living with HIV is unique and personal. However, common features can point the way to better understanding of how HIV affects people’s lives and to pastoral strategies that are respectful of persons, strengthening and empowering communities.

**Limitations**

1. **Scope**
The small study sample does not allow for generalizations. However, it does illustrate how poverty, gender inequities and power structures, stigma and discrimination can increase the burden of illness. Selecting thirty-five participants, mostly from one ward, limits the sample to those people who cannot or choose not to access private doctors and clinics. In its favour, the sample does have a balance of male and female participants, a balance of ages and a range of cultural backgrounds.

2. **Location**
Though the study is located in Port Moresby, the number of participants originally from this area (17%) is balanced by a representative sample from the Highlands region (26%). Participants from the Southern region included a sample from the neighbouring areas (31%) and others (17%) from places further afield. Though there were no representatives of the New Guinea Island region, Momase had some representation (9%).

3. **Language and culture**
The language of interviews was, most often, not the participants’ mother-tongue which may have limited communication. Lack of privacy in the ward was likely to affect participants’ responses. My limited knowledge of the culture may have encouraged participants to explain in more detail or may have been reason to hold back, for example, belief in sorcery.
Further reflection

Evaluation and critical reflection on the study was guided by the following questions.²

Responses are brief summaries of lesson learned.

*To what degree were the participants influenced by their starting point?* Participants seem to be influenced to a large degree. For example, the person with resources like stable family, education, access to health services, communication, transport ... is more likely to manage HIV infection than the person who lacks these resources, especially family support. Events surrounding HIV testing like recurring illness or pregnancy also affect the degree of distress associated with the diagnosis. Sometimes, an individual’s own resilience, interventions by faith communities and other groups play a role in reversing the fortunes of HIV infected persons.

*How do participants integrate their faith with both their lived experience and the Christian tradition?* Much evidence was gathered of persons living with HIV integrating their lived experience and their understanding and participation in a Christian tradition. When medical science and, perhaps, traditional healing were unable to offer a cure, faith assumed a more central role.

*Does their faith do justice to both the challenges of HIV and to the God revealed in the theology of the Psalms?* There were some instances where ideas about God were not able to connect with lived experience of HIV. Some saw God as inflicting punishment for wrongdoing. A fatalistic attitude to illness appeared to be an obstacle to expressing deeper feelings of regret, rage, hatred and venting these before God in a way that might lead to challenging the structural injustice underlying the spread of HIV.

*To what extent does faith transcend cultural factors?* Faith does seem to transcend cultural factors in many cases. For example, there seem to be at least some people who have put aside traditional notions of sorcery, payback, compensation, the *wantok system* (helping

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only those of the tribe) and other customs because they were not compatible with Christian values and with life as they live it in the city. In some cases, cultural values have been expanded to embrace more universal values.

*How is the view of participants aligned or misaligned with PNG culture?* For the most part, attitudes to illness, its treatment and care are aligned with PNG cultural values. For example, care of the sick is considered a social obligation. Some participants hold a view concerning sorcery, for example, which grows out of traditional beliefs and has incorporated beliefs about HIV. Ideas about sorcery have adapted to the city context. Similarly, witchcraft as a means of healing is still sought. Other participants, when serious illness threatens, turn to God as a helper and a place of refuge. Traditional religion would seek security in ancestral wisdom.

*What is the contribution of the participants’ stories to an understanding of what HIV means in PNG today?* The results of this research create and extend knowledge of the lives of people living with HIV and their families, and assist understanding of the complex factors that are at work. Wise policies and practical responses to the many needs, arising from the personal accounts, can be guided by this evidence and by a faith that seeks justice.

### 10.2. Issues for further enquiry

Some issues for further enquiry have been mentioned earlier, including similar studies on the topic interviewing:

i) young women 15-24 yrs;  
ii) primary caregivers;  
iii) people living with HIV resisting hospitalization, or not requiring it.

Studies on gender inequity and HIV, community responses and society’s changing attitudes in the PNG context are also needed. The data raise other interesting questions related to male roles for further research: Are PNG men willing and able to play a significant role as caregivers, not only in the hospital but also in the home? How might this shift from
traditional male roles be facilitated so that the caring role might be shared? Would the result of the survey be different on another occasion (see 5.3)? Would the response be different if basic needs such as cleaning and washing were required? To what extent would male caregivers provide for the patient’s emotional needs? Would a male presence at night be in accord with the traditional role of protector?

10.3. Conclusion

Writing this thesis has been one of my greatest joys and greatest challenges. The study has revealed the human face of HIV/AIDS in PNG through personal stories. HIV almost always brings distress and suffering to individuals and to their families. Caregivers – in most cases close family members – provide care and support, easing the pain of the sick one. The love and genuine concern of family, the realisation that HIV is a disease that can be managed, and the support of a community can nurture hope and open a way forward.

Pastoral ministry in a time of HIV/AIDS calls for solidarity with all who suffer and is expressed in wide-ranging ways, from simple acts of kindness to advocacy on behalf of the poorest to ensure treatment and care, to act against stigma and discrimination and to exercise leadership at all levels in the fight against AIDS. The pastoral strategies recommended in the previous chapter point to the urgent action required. With greater understanding of what it is like to live with HIV, and the suffering it brings, my own hope is that, with compassion, I may seek to further ease the suffering I encounter and share the burden.

Psalms of Lament offer a theological foundation for HIV pastoral ministry, revealing a personal God who is close to the brokenhearted, who listens and answers. They also offer resources for prayer in time of need, distress, sickness, threat, betrayal or abandonment. The structure of the lament testifies to the fact that God will listen to complaint and will rescue. There is hope in the Psalms of Lament when all hope is gone; there is hope in a time of HIV and AIDS.
Bibliography


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Appendices
Appendix 1

Introduction

Maura Elaripe Mea published a booklet of her poems in 2001.

Maura works as PNG director for GIPA. (Greater Involvement for People living with AIDS) She has travelled widely and spoken at many conferences and workshops nationally and internationally.

“Bundle of Joy” invites the reader to enter into the experience of losing a baby to AIDS.

“Hope of Living” captures the emotions and the challenge to face HIV and the future with confidence and courage.
BUNDLE OF JOY*

I gaze down lovingly at the pinkish little bundle in front of me,
Looking up innocently into my eyes.
I take her hand into mine and wonder
“Will you make it to the end?”

As the days turn to weeks I love my bundle of joy more and more.
I smile and she smiles back ... reminding me that to live is to love.

I felt so guilty seeing you suffer.
It was hard work bringing you into this world,
but much harder for me when you’re infected and struggling to keep this life
that rightly belongs to you.

My bundle of joy
I will remember your courage...
that last look you had in your eyes
before you left me.

It’s your way
of telling me to be brave and
to carry on with my life.
I miss you
and some day I will hold
my bundle of joy
forever.

*Bundle of Joy is dedicated to all babies who have died of AIDS especially
my two babies.

Maura Elaripe Mea
Port Moresby, 2001

Appendix 1
HOPE OF LIVING

Sitting on my platform;
in front of my house
I tend to question myself...
Where am I heading to?
Do I have a hope of living?

All sorts of negative thoughts crowd my mind
giving my eyes a hazy view.
But down within me, there seems to be a little flame burning
encouraging and urging me
to carry on with my life.

I strive and persevere,
struggling to be recognised and accepted
as a productive citizen.
I look at this life as an opportunity,
an opportunity to leave the world
a better place than when I came into it.
AIDS is not going to steal that opportunity away from me.

That gives me the courage to go on.
I am living my life positively,
and I will continue to contribute my bit
in this struggle against AIDS.
That is my hope of living.

Maura Elaripe Mea
Port Moresby, 2001

Appendix 1
Appendix 2

Background to HIV Ministry in PNG

Table 5: Political history of PNG 1964-2007

<table>
<thead>
<tr>
<th>Period (Years)</th>
<th>Features</th>
<th>National Elections</th>
<th>Prime Minister</th>
</tr>
</thead>
</table>
 Appendix 3

Research Design and Methods

The following forms were designed according to the guidelines of the Human Research Ethics Committee (HREC) following critical comments and recommendations on my first research proposal. The modified research proposal with the redrafted forms was then resubmitted and approved by HREC.

Later, when the method of obtaining Informed Consent proved unworkable due to the spacing of my visits and nurses’ rosters I consulted field researchers working in PNG. A further revised, simplified Consent Form was designed and re-submitted to HREC. Replying on behalf of HREC, the Director of Research wrote that my latest amended application was evaluated, and he advised that approval had been given for the research to proceed.
Dear Sister,

Re: Research Project “HIV/AIDS in Port Moresby—cultural and spiritual aspects of care”

My name is Sr. Mary McCarthy. As you may know, I am enrolled in the Doctor of Ministry Degree at the Melbourne College of Divinity (MCD). Part of the degree involves a research project into the experiences and needs of HIV/AIDS patients in this hospital. The hospital has approved what I am doing. There are two stages to my project.

The first stage is just generally looking at Ward 4B: what people do, how they deal with each other. This stage lasts about a month. During this time I shall write notes about what is going on. I shall write about some of these things in the report I write for my study. No names will be mentioned, nor will I talk about anything that could identify you or get you into trouble. The MCD asks me to let the patients know that I am observing them and taking notes on them. Therefore I would like some nurses to hand out the blue forms to all the new patients explaining what I am doing. If the patient does not want me to write down anything he or she does or that happens to him or her, then there is a tear-off slip at the bottom of the form to let me know that.

I encourage all of you to read the blue form. If any of you do not want me to write down things about you in the report, then you can fill in a tear-off slip for yourself and put it in my box. You are quite free to take part or not.

The second stage involves listening to the stories of 15-30 HIV/AIDS patients. Once again, the MCD asks me to ensure that all the patients who volunteer know what they are doing and are not under any pressure to do it. So I need to ask the assistance of some of you for this part too. I would like you to hand out a (yellow) invitation to all new HIV/AIDS patients. If they are interested, you can give them a (white) information sheet and (pink) consent form. Please feel free to read the information sheet yourself, so that you know what the patients will be doing. Could you please also collect the signed consent forms for the patients and put them in my box at the nurses’ station? For those who want to help me, there is a more detailed instruction sheet.

Thank you very much for your help with this project. While there is a possibility that nothing new will come out of it, I hope that it will give a chance for HIV/AIDS patients to have someone listen to what they are going through. And I hope that this increase in understanding can help nurses, doctors and church-workers to care better for people affected by HIV/AIDS.

Yours sincerely

Sr. Mary McCarthy
3.2 Instruction Sheet for Nurses

Dear Sister,

Re: Research Project “HIV/AIDS in Port Moresby—cultural and spiritual aspects of care”

Thank you for offering to help with my research project.

What I would like you to do is this.

Could you please give the (blue) letter to all new patients in Ward 4B? Give them a chance to read it or, if they cannot read, could you please read it to them yourself. (There are also copies in Tok Pisin) When they have read or heard the letter and had a little time to think about it, just gently check that they are happy for me to observe them. If they are not, please write their bed number and the date on the tear-off slip at the bottom of the form and slip it in the box marked “Consent forms for Sr. Mary” at the nurses’ station.

If you have been told by the doctor that

- a patient has HIV/AIDS and
- the patient himself/herself knows this, and if
- the patient understands English reasonably well, and
- the patient is over 18 years old,

could you please give them the letter of invitation (yellow form)? If they cannot read, could you read the letter to them? If they are interested in taking part in the project, could you please give them the information sheet (white form) and the consent form (pink)? If necessary, could you read the information sheet to them?

If they want to take part in the project, please see that they fill in the consent form. (Please read it for them if necessary.) If and when they sign the consent form, please place it in the box marked “Consent forms for Sr. Mary” at the sisters’ station.

If at any stage patients have any questions about the project that you cannot answer, please tell me if I am in at the time, or else leave a note in my box, saying who it is who has the questions.

Thank you very much for helping me in my research project.

Yours sincerely

Sr. Mary McCarthy
3.3 Invitation to Patients

Research Project

“HIV/AIDS in Port Moresby—cultural and spiritual aspects of care”

Living with HIV/AIDS is not easy. Not many people know what it is really like.
Do you want to help other people know what it is like to live with HIV/AIDS?

My name is Sr. Mary McCarthy and I am a church-worker or chaplain in this hospital and I train people as church-workers, particularly those who work in hospitals. I am upgrading my own training through the Melbourne College of Divinity so that I can do my job better. As part of my study I am interested in hearing the stories of people who are living with HIV/AIDS. I hope that hearing these stories will help me to offer better care to people. I also hope that it will help me and other people to train church-workers, volunteers and hospital staff to give better care to people who have HIV/AIDS. You may be a Christian or you may not be a Christian. It does not matter. This invitation is for all people living with HIV/AIDS. If you are willing, I would like to listen to your story.

If you take part in this project, everything you say will be confidential. I may use what you have said to explain living with HIV/AIDS to others, but I will be very careful to make sure that no-one can trace the details of your story back to you.

You are completely free to take part in this project. If you decide not to take part in this project, it will in no way affect the treatment and care you receive at this hospital.

If you want to find out more about this project, or if you think you might want to join, please ask the nurse for more information.
Dear Patient,

Research Project “HIV/AIDS in Port Moresby—cultural and spiritual aspects of care”

My name is Sr. Mary McCarthy. Thank you for showing interest in my research project. I hope that the information here will help you to decide whether to take part or not.

What will taking part involve?
If you decide to take part, I will arrange to meet with you for about an hour. We will meet in a place that you and I choose together. I will invite you to talk about your experience of living with HIV/AIDS. You need only talk about things you are comfortable to talk about. I want to find out what is important for you. At the same time, I am interested in what part, if any, your religion and God play in your life with HIV/AIDS. However, if you are not Christian, if you have no religion at all, or if you simply do not want to talk about that, I am still interested in talking with you. I will not try to influence your views and beliefs. I simply want to know what it is like for you to live with HIV/AIDS. You can stop talking with me at any time you want to.

If, after the talk is over, you decide that there is more you want to say, I will be glad to meet with you again. If I decide that I would like to know more about your story, I will ask you if you would like to meet with me again. If you agree, I may tape the talk so that it is easier for me to remember all that you have said. I would also like your permission to look at your medical record. From there I can find out information such as your age, place of birth, address, whether you have been in hospital before. This information can help my project.

What will happen to the things I say?
I will take notes of the things you and other HIV/AIDS patients say. These notes are for my use only. I will use some important parts of what you and other patients have said to help other people understand what it is like to live with HIV/AIDS. I will write a report. I may also use what I have learnt in journal articles, in conferences for people who give care to HIV/AIDS patients, or in my work teaching people to care for those who have HIV/AIDS. All the time I will be very careful never to mention your name, anyone else’s name you may have mentioned, or any detail that might let people know who you are.
Why is Sr. Mary doing this?
I am studying for a Doctor of Ministry degree at the Melbourne College of Divinity (MCD). I am studying so that I can do my job better: I am a church-worker in this hospital and I train people as church-workers, particularly those who work in hospitals. This research work is part of my degree. Of course, it may be that my research finds out nothing new. But I hope that what I learn will help me and other people—church-workers, caregivers in hospitals, nurses and doctors—to understand how patients’ lives are affected by HIV/AIDS. I also hope that this better understanding may lead to improved care of those with HIV/AIDS now and in the future.

What if I decide not to take part?
You are free to take part in this project or not. If you decide not to take part, there will be no difference in the treatment and care you and your family receive at this hospital. If you agree to take part and then change your mind, you are free to pull out at any time. Just let me or the nurse know. You will be given a write-up of the notes I have taken about you for you to approve. If there is something that you have said that you later decide you don’t want me to use, you can let me know up until the time when the report has been published, and I will leave it out.

How do I enter the project?
If, after thinking about what is said here, you want to join the project, sign the consent form and hand it to the nurse. I will then get in touch with you soon. The MCD asks that all people interviewed in all research projects sign a consent form. This is to make sure that no-one puts pressure on you to take part.

What do I do if I have any further questions if I have any complaints about the project?
If you have any questions, you can speak to the nurse or to me, Sr. Mary. My phone number is 328 1033 (Monday to Friday). If it happens that you want to complain about me, you can speak to one of the nurses.

Thank you once again for your interest in this project,

Yours sincerely

Sr. Mary McCarthy
Title: HIV/AIDS in Port Moresby: spiritual and cultural aspects of care.

3.5 Consent Form

I agree to take part in the above Melbourne College of Divinity research project. I have read, or had someone read it to me, the Information sheet which I keep for my records and the project has been explained to me.

Please Tick ☑ = Yes
Cross ☒ = No

I am willing to:

☑ be interviewed by the researcher
☑ allow the interview to be audio taped
☑ be further interviewed should I or the researcher find that helpful
☑ allow the researcher to have access to my medical records

I understand that there is a break of up to 3 days from the time participants have given their consent; and that I can withdraw at any stage whilst participating and withdraw my data up to one month after the data has been collected with no consequence for my treatment or care.

I understand that any information I provide is confidential, and that the written report of this project will not use the names of the participants in order to protect my identity from being made public.

AND

I understand that I will be given a transcript of data concerning me for my approval before it is included in the write up of the research.

I understand that the results of the project will be included in a Report on the Research Project, published articles and conference papers.

Signature

Name (please print)

Date
3.6 Information Sheet re Ward Observation

Dear Patient,

Welcome to Ward 4B. We hope that the nurses and other staff and helpers here will make your time in the ward as comfortable as possible.

People who work in hospitals are always trying to improve the level of care they offer. My name is Sr. Mary McCarthy and I am a church worker who has been visiting this hospital since 1993. I am studying for a Doctor of Ministry Degree so that I can offer better care and help train other people to offer better care. This involves research into the needs of people in hospital.

In particular I am looking at the needs of patients with HIV/AIDS. Some of the patients in this ward have HIV/AIDS. So one of the things I will be doing is looking at the sorts of things that happen in this ward. I will write down some of the general sorts of things that happen in this ward as part of my research project.

Of course, when I write these things down in the research project, I will take care not to mention anyone’s name or to say anything that could let someone else know which patients or staff I am talking about.

If you are not happy with that, please let the nurse know. The nurse will speak to me and I will be very careful not to write anything in the research project that you or your family and friends say or do, or anything that happens to you, your family or your friends.

If you decide that you do not want anything about you written down, this will in no way affect the treatment and care you and your family get at this hospital.

Thank you for your help.

Yours sincerely

Sr. Mary McCarthy

For the nurse to give to Sr Mary McCarthy

The patient in bed Number............... does not want to take part in the observation of the ward. Today’s date is ............................
Papua New Guinea i laik winim sik AIDS

Stori Buk: Laip wantaim HIV

3.7 Pepa bilong kisim tok orait long wokim stori buk

1. (Em bilong man/meri husat i gat HIV/AIDS)

Mi ________________________ save mi gat sik HIV/AIDS na mi givim tok orait long ol i ken soim mi wantaim dispela sik long Sista Mary i wokim long ol pipel bilong Papua Niugini i laik winim sik AIDS.

Mi givim em tok orait bilong mi long em i yusim wanem kain toktok mi givim na piksa tu taim em i wokim dispela stori buk. Mi save olsem ol i no wokim bisnis long dispela stori buk. Em bilong helpim ol manmeri long komuniti tasol, na mi no inap askim mi long mi stap insait long dispela stori buk.

Sainim Nem ________________________ De ________________________

2. (Em bilong Papa/Mama/Wasman/Wasmama bilong pikinini husat i gat HIV/AIDS)

Mi ________________________ papa, mama, ankol, anti i klia na tok orait long pikinini bilong mi wantaim sik HIV/AIDS em i gat long en i ken i stap insait long stori buk Sista Mary i wokim long ol pipel bilong Papua Niugini i laik winim sik AIDS.

Mi tok orait long wokim dispela stori buk long soim ol arapela manmeri. Mi givim tok orait bilong mi long yusim tok na piksa bilong mi long helpim ol arapela manmeri na mi no inap askim moni long mi stap insait long dispela stori buk.

Sainim Nem ________________________ De ________________________

Appendix 3
Papua New Guinea wants to stop AIDS

Living with HIV: a book of stories

Consent Form

1. (For man/woman who is living with HIV/AIDS)

I _______________________ know I have HIV/AIDS and I give my permission for Sr Mary to tell my story in the study she is doing so that people in Papua New Guinea can stop AIDS.

I give my permission for her to use the story I am giving and my picture too when she writes this book. I know that this book is not a money-making business. It is to help everyone in the community so I will not ask for any money.

Signed _______________________ Date ______________________

2. (For Parents/Guardians of a child living with HIV/AIDS)

I _______________________ parent/ guardian give my permission for my child who is living with HIV/AIDS to be a part of the book Sr Mary is writing for the people of Papua New Guinea to stop AIDS.

I give permission for you to use the story and picture to make this book and show it to other people. I give my permission to use the story and picture of my child to help other people and I will not ask for any money.

Signed _______________________ Date ______________________

Appendix 3
### 3.8 Interview Theme List

The following is an interview theme list for HIV/AIDS in Port Moresby – spiritual and cultural aspects of care study.

[The themes were developed with reference to themes identified in the literature and on the basis of my own pastoral experience. The experience of illness, particularly when it recurs and does not respond to treatment, gives rise to anxiety. I needed to know more about the person’s situation including cultural beliefs to understand the nature of their anxiety and how it might be eased. The contrast between life before and after HIV diagnosis could provide insights. More personal questions about relationships, values and beliefs were designed to invite reflection on the present and nurture future possibilities.]

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Personal history – with attention to cultural and spiritual aspects.</td>
<td></td>
</tr>
<tr>
<td>2. Family history – cultural and spiritual aspects</td>
<td></td>
</tr>
<tr>
<td>3. Life before HIV testing</td>
<td>Way of life, cultural and spiritual activities</td>
</tr>
<tr>
<td></td>
<td>Relationships, responsibilities, level of satisfaction</td>
</tr>
<tr>
<td>4. Life after HIV testing</td>
<td>The test itself. What happened?</td>
</tr>
<tr>
<td></td>
<td>Was the experience shared? Feared? Explain.</td>
</tr>
<tr>
<td></td>
<td>What were the feelings?</td>
</tr>
<tr>
<td></td>
<td>Any effect on relationships? Housing? Employment? Health?</td>
</tr>
<tr>
<td>5. Associated events at that time.</td>
<td>Encounters with medical staff, church members or faith community (as appropriate), clan members</td>
</tr>
<tr>
<td>6. Main activities in life now</td>
<td></td>
</tr>
<tr>
<td>7. Important relationships</td>
<td>Significant family members? Friends? Attitudes to you?</td>
</tr>
<tr>
<td></td>
<td>How have they responded?</td>
</tr>
<tr>
<td>8. How would you describe yourself? Beliefs? Values?</td>
<td></td>
</tr>
<tr>
<td>9. What are the things that are important to you?</td>
<td></td>
</tr>
<tr>
<td>10. Is there anything else that you think is important to understanding your experience of living with HIV that we have not discussed? Any final comments?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3

3.9 CONCEPTUALIZING: an example

The text below is from one interview, labelling some of the concepts identified in the text.

LAMANA

Male/ 34 years

I was born just before Independence. My place ‘home’ is a long, long way from here ‘remote’, in high mountains. I am No. 5 in my family ‘family’ and the last born. My first-born brother is about 40 years old. Then I have three sisters. They are all married and live in their husband’s place. I was baptised ‘church membership’ as a baby. I went to a mission school ‘mission’. When I could read ‘formal schooling’ I had a Bible. The school had Bibles. We had our own two Bibles in the house ‘religious practice’ – Pidgin and English ‘cultures/languages’.

I am married ten years. There was no kastom marriage ceremony ‘informal marriage’; nothing in the church ‘letting go tradition’. Now we have three children – two boys, first-born when we married, last-born, a girl, last year. The children are healthy. Sometimes they have small sickness like head pain, fever, skin pain, diarrhoea. I chose my wife ‘letting go tradition’. We liked each other and got married. Later ‘approval delayed’ parents accepted it. It was not a marriage arranged by parents ‘traditional marriage’ of the boy and girl. I built my own house ‘independence’, started a family ‘adult status’. We live close to my parents ‘retaining tradition’ in the same village. My wife is from another village. We met in another village when we went there for a funeral.
... When I went back to the hospital for my medical review (following accident and broken bones) they told me: you are HIV positive ‘shock’ ‘fear’. I felt like crying... It is very hard to explain ‘confused’ ‘shocked’... I was crying in my heart ‘crying’ ‘distress’. Then the doctor said: ‘Don’t worry ‘reassurance’... there are drugs that will help you stay normal ‘knowing about drugs’. You won’t die ‘reassurance’... So they directed me to STI clinic to the specialist ‘medical care’... HIV – I didn’t know ‘not knowing’ about it. Had heard of it... (That was all)... but didn’t take it seriously ‘attitude’. Thought it was like other diseases. (I would get better). At the clinic I started reading ‘wanting to know’ pamphlets. I was thinking ‘reflection’ if I knew I wouldn’t get infected ‘unwanted outcome’. Before (I was tested) you didn’t go deep into it ‘not knowing’. In the first place I was worried ‘worry’, now no more worries ‘no worries’... Doctor told me not to worry. Worry ‘worry’ leads to trouble, including other diseases. ‘Don’t underestimate your brain power ‘reassurance’ or you might be an AIDS victim. You have to be positive ‘choose life’.’ It is very true. Now I am feeling OK ‘choosing life’.

I shared the result of the test ‘disclosure’ with some friends ‘intimates’... It is best you know ‘knowing’ your status... It’s nothing to hide. You’ll be like me going anywhere you like and you end up sick. I mainly told my relatives... my older brother ‘intimates’. Our relationships still remain the same ‘not rejected’. There is no discrimination. People know how HIV cannot be passed on. This sick comes from unsafe sex ‘unsafe sex’. That’s the way. I don’t believe in sorcery ‘rejecting sorcery’.
Appendix 4

Family

4.1 The Study Group

The Study Group consisted of 35 participants who were interviewed while patients in the ward or as clients of the associated Sexually Transmitted Infections (STI) clinic. Demographic data relating to each participant is presented. Marital status was often missing in the medical record; information from interviews was sometimes unclear. Dates of admission and discharge indicate length of stay in the ward. Participants accessing Antiretroviral Therapy (ART) are shown. Discharge from ward includes patients who died in the ward on the given date.

Table 6: Study Group, demographic data.
See over page.

4.2 Two Case Histories

Appendix 4.2 contains the extended narratives of two participants’ experience living with HIV, from diagnosis till death in one case, and till the time of writing in the other. The narratives enable the reader to begin to understand what it is like to live with HIV. This appendix provides a background against which to compare and contrast the more analytic information about the lives of other participants and their experiences of living with the virus. The two participants have been selected because they illustrate either end of the spectrum of control over one’s own personal life and the availability of care and support. Manoka, an educated woman, is able to face the crisis of her HIV diagnosis and move through it, reflecting on her experience and considering her options. She then decides for herself and her children. Cally, on the other hand, has limited access to personal and material resources. He lives in the city away from his rural home. Though his choices are limited he too claims a voice.
<table>
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<th>Age</th>
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<th>Religion</th>
<th>Province</th>
<th>From</th>
<th>Adm Diag</th>
<th>Final Diag</th>
<th>Remarks</th>
<th>Date Disch</th>
<th>Remarks</th>
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<td></td>
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<td>A&amp;E</td>
<td>RVlCP</td>
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<td>U/C CP</td>
<td>A&amp;E</td>
<td>On ART</td>
<td>17 7 STIClinic</td>
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<td>M</td>
<td>Baptist</td>
<td>NCD</td>
<td>A&amp;E</td>
<td>RVlCP</td>
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<td>6 9 STIClinic</td>
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<tr>
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<td>ALFRED</td>
<td>12 7 M</td>
<td>36</td>
<td>M</td>
<td>Rev SHP</td>
<td>Hed</td>
<td>HIV/AIDS</td>
<td>On ART</td>
<td>18 7 STIClinic</td>
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<td>9 10 F</td>
<td>35</td>
<td>M</td>
<td>Rev CP</td>
<td>A&amp;E</td>
<td>HIV/AIDS</td>
<td>On ART</td>
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<td>AOP</td>
<td>14 ART</td>
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<td></td>
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<td>M</td>
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<td>STIClinic</td>
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</table>

M=Male  
M=Married  
F=Female  
S=Single  
W=Widowed  
A&E=Accident and Emergency Dept.  
N/A=Not applicable  
SE=Separated  

Appendix 4  

See Tables C and D for more abbreviations
Appendix 4.1: The Study Group

Data concerning age of participants related to sex were analysed (see Table 7). The sample is small and so generalisations cannot be made. However, the numbers suggest a higher frequency of females in the 20-29 year range and also in the 35-39 age-groups. Male participants, ranging from 20-54, are more evenly spread, with the highest frequency in the 35-39 age-groups. There were two males but no females in the 45-54 age-groups.

Table 7: Age of participants related to sex

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>20-24</th>
<th>25-29</th>
<th>30-34</th>
<th>35-39</th>
<th>40-44</th>
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<td>6</td>
<td>10</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>35</td>
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</table>

Participants come from a range of church communities. While the larger numbers of United Church and Catholic membership might be expected, given the census data (2.1.e), the high number belonging to the Revival Church may be unexpected (Cf. 6.2.c).

Table 8: Church membership

<table>
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<tr>
<th>Religious denomination</th>
<th>Number of Participants</th>
<th>%</th>
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<tbody>
<tr>
<td>Christian Revival Church</td>
<td>9</td>
<td>26%</td>
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<tr>
<td>United Church</td>
<td>7</td>
<td>20%</td>
</tr>
<tr>
<td>Catholic</td>
<td>6</td>
<td>17%</td>
</tr>
<tr>
<td>Lutheran</td>
<td>3</td>
<td>9%</td>
</tr>
<tr>
<td>Seventh Day Adventist</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Baptist</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Nazarene</td>
<td>1</td>
<td>2.5%</td>
</tr>
<tr>
<td>Mormon</td>
<td>1</td>
<td>2.5%</td>
</tr>
<tr>
<td>Evangelical</td>
<td>1</td>
<td>2.5%</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
<td>9%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>35</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
The table listing province of origin shows a large number of participants naming the National Capital District. This usually indicates that they are Motuans and Koitabus, the original occupants of the Port Moresby area. The large group from Central province come from districts east and west of the city. Six of these give their residential address as a suburb of Port Moresby; three indicate residence in a village, the remainder give no information.

Table 9: Province of Origin as given on admission

<table>
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<th>Province</th>
<th>Number of Participants</th>
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<td>Central (CP)</td>
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<tr>
<td>National Capital District (NCD)</td>
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<td>Gulf (GP)</td>
<td>4</td>
</tr>
<tr>
<td>Western (WP)</td>
<td>2</td>
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<tr>
<td><strong>Highlands Region</strong></td>
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<td>Simbu</td>
<td>5</td>
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<tr>
<td>Southern Highlands (SHP)</td>
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<tr>
<td>Enga</td>
<td>2</td>
</tr>
<tr>
<td><strong>Momase</strong></td>
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<tr>
<td>Madang</td>
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<td>East Sepik (ESP)</td>
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</tr>
<tr>
<td>Morobe</td>
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</tr>
<tr>
<td><strong>Total</strong></td>
<td>35</td>
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</table>

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>100 %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Southern Region</strong></td>
<td>31 %</td>
<td></td>
</tr>
<tr>
<td>Central (CP)</td>
<td>17 %</td>
<td></td>
</tr>
<tr>
<td>National Capital District (NCD)</td>
<td>11 %</td>
<td></td>
</tr>
<tr>
<td>Gulf (GP)</td>
<td>6 %</td>
<td></td>
</tr>
<tr>
<td>Western (WP)</td>
<td>6 %</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100 %</td>
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</tr>
</tbody>
</table>
Appendix 4.2: Two Case Histories

A. Manoka, 30 years old, married woman, office worker

Manoka was born into a generation which has experienced rapid change. She was fortunate to graduate from high school and Business College then found paid employment. She married the man of her choice. She was neither limited nor supported in a marriage arranged by her parents or clan, nor did she benefit from her elder’s wisdom. Roads allow her to move with comparative ease between the village where she was born and the city. She is currently employed in a well-equipped office with access to the most recent technology. Manoka’s story illustrates the possibilities that exist for women in contemporary PNG society and the costs involved.

a. Experiencing the reality of HIV.

Manoka’s life took a dramatic turn some years ago. Her story begins three years after the crisis. I was down last year. I weighed 31kg. Before I was 50kg. I didn’t know the signs and symptoms of the sickness. I lost a child. (Tears) That’s another story. I am from a rural area not far from the city. I married a Highlander. So began Manoka’s story.

Sitting in the clinic waiting for her medical review and her ‘supply’ of medication Manoka shared her story with me. As a young mother her life was largely centred on her three young children. This (indicating the small boy beside her) is my second child, a boy. He’s six years. The first-born is in the house. He is seven years. My third child died two years ago in November, aged one year and six months. That year was a very difficult year. When the baby was born he was OK for three months. I was breastfeeding. I gave birth to the older children in the private clinic but went to the general hospital for my last baby. They tested my blood but I was not told the result. The baby couldn’t sleep. I had no idea of his sickness. There was no counselling at the antenatal clinic. With deep sadness and showing the burden of not knowing she lamented, the staff could have given me information and counselling. They could have said: you may meet some problems with the baby … and given some possible ways of caring for a sick baby. Instead I went ahead … not knowing … It was a very painful time for one year and three months … That year (after the baby’s death) was a very difficult year.

Manoka was a working mother; she and her husband and three little boys were living together in modern housing and paying a mortgage. Her husband was working and Manoka took the baby to the clinic at his workplace. Then, when the baby did not improve, she tried another clinic; they referred her to PMGH where the baby was admitted to the ward. Soon after admission the baby died. Loss and grief remained: I was a working mother. I was living with my husband. My mother was not there. She felt terribly alone but, she added, that was a turning point for me.

As Manoka told her story she moved backwards and forwards to the time of crisis, to the time before and then to the present, reflecting her struggle to make sense of it all. The baby
was admitted to the Paediatric Ward, his blood collected and tested. Two weeks later I was
given the result. The baby was HIV positive. I did not know much about HIV and AIDS so
when the social worker told me that my son was positive I just opened my eyes and asked:
What do you mean? Does that mean my son has AIDS? She said: HIV is the start of AIDS. I
got the shock of my life. I was so devastated. I did not want to listen to anything the social
worker was saying. I told her, you can talk to me later, but not now. I got up from my chair
carrying my baby, tears rolling down my eyes. I walked out of the ward not knowing where
to go, not knowing what to do. It was a very terrible experience. I walked out of the hospital
grounds and started walking down the road still crying. I got a bus and went home. I couldn’t
stop crying. When I got to the house my brother-in-law and his wife came over and took the
baby from me. I was so down-hearted I did not want to talk to anybody. I went straight to
our room and cried my heart out. Afterwards I felt a lot better and I told myself that there
was nothing I could do to change what had happened but to go on living. Yet I really did not
accept it easily and I hated my husband like hell. I would say or do anything to pick a fight
with him.

Following her baby’s death, Manoka’s blood was then tested. She too was positive. It was so
difficult to accept. It came as a shock. I was married. I thought I was protected in the family. I
couldn’t forgive. I couldn’t forgive. I felt shame, regret. I got really sick. I was so worried. I
thought I was going to die. That’s it, I thought. I will die now. Three years later Manoka’s
husband was out of work. They had the mortgage to pay and she had not returned to work
since the baby’s death.

There were times of deep distress. I was put on medication. It wasn’t good for me. I was
vomiting, dizzy. I stopped. At the end of the year I went really down. The medication wasn’t
working for me. I stopped taking drugs for about six months. That’s when I went down. I
decided to just stay in the house. I was wasting away. In fact, I was close to death when my
immediate family came to my rescue. All my uncles and aunties cooked food and came to
our house. We had a big meeting and sorted out our differences. Everyone agreed to take
me to a doctor we knew well.

Manoka explained to the doctor: I am suffering ... I want you to give me medicine for these
infections. He said he could do that but they would not keep me alive very long. Then I asked
what he would suggest. He said I should take ART drugs. I said: Fine, whatever you say. I
took the medication for about three months but I stopped again because every time I felt
dizziness, nausea. I felt very, very sick. I went off the drugs for another six months and I went
to the point of dying. My husband’s relatives, my family from the village, people from the
churches came to visit and shared their last prayers with me. Then my aunty visited me. She
is a nursing sister. I asked her the questions that were troubling me since I stopped taking
the ART drugs. She encouraged me to go to the clinic and get help again. She shared the
word of God with me and she told me to talk to Jesus about my problems and worries just
like I was talking to her. While she was talking to me a cool breeze blew over us and she told
me that this was the presence of Jesus. That’s when I had a change of heart and gave my life
to the Lord. I decided to go to the clinic to get help. Next day my husband took me to the
clinic. I told the doctor the truth that I was not taking the medication and my reasons.

Appendix 4
I’m now on new medicine and I’m doing well. It’s three in one. I started about this time last year and I’m taking it till now. My dose is one in the morning and one in the evening. I regained strength and weight. Now I can work. That was not possible two to three years ago. Now I do the laundry and I’m walking around. This morning I walked to the bus stop.

Manoka experienced the awful reality of HIV with its intense emotions, the anguish of loss and grief. She felt fear, worry and anxiety as she faced an uncertain future. At first there was anger, hatred of her husband, inability to forgive. She felt terribly alone at times almost overwhelmed by regrets. She tells how the disease affected her life and the good and bad effects of her initial treatment with antiretroviral drugs. The initial crisis slowly passed.

b. Responding to the experience of HIV

Manoka’s thoughts periodically weighed her down but she had been brought up in a family where there was an awareness of spiritual things and so she gradually came to realise how she was responding to this crisis. Spiritually, I was stubborn. I just couldn’t move. My heart was hard. I was wasting away till I realised Jesus was there. There was evidence of inner strength as Manoka spoke and described her present life. She was aware of resources in the community but chose to retain her independence and pride. I haven’t joined any (support) groups. I come (to the clinic). I collect my medicine. Then I see the doctor. Then I go back home. If I am not sick there is no need to see the doctor. My last review with the doctor was two months ago. So now two months (again) because I am OK. If I feel sick I come back here. I usually get a month’s supply of medication. Remembering her crisis she reflected: the result of the HIV test and then the death of the baby was a turning point for me. I began to see things from a different perspective. She put it this way: It doesn’t matter anymore. Then lest that statement be misunderstood she continued, It’s not I don’t care … I accept it. My child died. My child died in my place. I went to the point of death … I came back! I still feel strong.

Only slowly does Manoka introduce me to her family yet it appears that she has reflected deeply on who she is in the context of her marriage and of her extended family. She begins cautiously then warms to the topic and enjoys the funny side of the story. She reflects back to the time before she married and her relationship with her future husband, her family’s reservations and her firm intention to decide for herself. I have married into a culture known for polygamy. Woman is treated not as a partner but as a slave. “Yu meri nating. Yu stap long haus.” (You are only a woman. You stay in the house.) They can do whatever they want. In this culture, woman kills woman. Woman kills husband. Husband kills woman. I’ve seen it. A woman has killed her rival!

The culture into which she was born, or at least as she experienced it, was different. She was astonished by exposure to some experiences of marriage during the previous eight years. In those years she had been in paid employment, working in a city office, meeting workers whose way of life reflected a wide diversity of cultures. As a married woman Manoka faced many challenges. A woman was treated not as a partner but as a slave, but she modified that a little. Not exactly ‘slave’ but ‘haus gel’ (female housekeeper), bear children and look after the kitchen. Was this a new awareness or was she aware of this when
she married? (Laughter). I knew it. Not really. I had a fair idea. Despite my parents and sisters stopping me from taking that step, the man forced me. They warned me. They (Highlanders) are known for this, they said. He wanted to marry. Was she saying she had no choice? She was an educated young woman. When you are in a relationship your emotions and feelings... (Laughter). These things did not matter ... Now it is proven. They were right. I was wrong. I regret. I was wrong. Manoka told her story with the wisdom of experience. As she stated earlier, I accept what has happened. And so, in the midst of the conversation, seeds of new hope, of new directions were sprouting.

Like most married women Manoka’s relationship with her husband had its times of stress. Sitting in the clinic after one appointment she explained how she was managing without paid employment. My husband gives me some money but one day he said to me: You should go home and plant food. She was quick with her reply: You know I wasn’t meant to work a garden. I am an educated woman. He did not like that and retorted: You are a parasite! Everyone in the house had been coughing so she challenged him: You should go to the hospital and get a thorough check-up. Actually, she added, that happened just before he called me a parasite. But she spoke strongly: I am your wife. I am dependent on you. That’s why I try not to be a parasite. At that time she had no other source of income and this meant that she could not provide for herself - not even her bus fare to the hospital. She spoke softly: (When we have no money) We trust in the Lord. Later, in contrast to her earlier account of tension arising over her need for money from her husband, this time it was a different story. I would say my husband is a very supportive person. He makes sure the kids and I have money and clothes ... He takes care of his relatives too ... He is a very good person. He is easy-going, open. He doesn’t give me any problems. Does she have money for the things she needs? (She nods and smiles) Today, he said: are you going to the hospital? He gave me bus fare.

Another challenge to Manoka as a married woman was her husband’s extended family. I live with my tambus (in-laws) - my husband’s brothers and sisters. They make life difficult for me. The house is under my name. We have lived in the house for five years. Speaking of the situation in the past when she was working, she explained: I pay the mortgage. My husband helps pay the mortgage. His wantoks (tribesmen) move in and out. They stay years and months. I had my say. I had to fight. Nothing changed. We’ve moved downstairs. My husband’s big brother and his wife live upstairs. They have four children. Two younger ones live with us. The older two live with their aunt who is a teacher in another part of the city. They are in upper secondary school. There are other members of my husband’s extended family. You spoke on the ‘phone to my husband’s sister.

So, in this situation where her husband’s extended family share the house Manoka makes the best of the restricted area where she and the children live with her husband. Me and my husband and two children live downstairs. Also, his little cousin and my husband’s uncle. Women and big children. People laughing day and night. It’s very upsetting. I don’t like these things ... when you know it’s your house! Manoka’s frustration mounts as she recalls the pattern of behaviour she is exposed to each day. They talk at the back (of someone) ... they argue with me ... they question me ... Her voice changes and with emphasis states: It’s my house! The overwhelming feeling is helplessness and it is evident as she goes on. I have no control ... absolutely no control. How does she keep going in this situation? Only the Lord
knows. I tell the Lord. You know what these people are doing. I cannot fight. I cannot take
revenge ... I choose not to fight. I choose not to take revenge. I think of Jesus, who was led to
die. I am treated as he was. I have to accept. That’s how it is ... There is silence.

Time brought changes and so later Manoka could say: At home there’ve been some
improvements like people are acknowledging you are there ... We eat together. They serve
the food. I don’t. My female relatives, they serve the food. We talk. Sometimes they are
ignorant ... They have improved. I think: if that’s their attitude I’d rather live my own life ... to
be yourself ... They don’t dictate to me. They have a ‘don’t care’ attitude. They do what they
want. They have no sense that the house belongs to someone else ... they look down on me
because I don’t have money. I don’t have any income. On a regular basis there were little
things that made life hard for Manoka. They know you are sick. They write you off. They
can’t give you half plate (plate containing uneaten food). Sharing of plates, cups and so on
that was the custom. Now that has all changed. As a married woman, there was no escaping
the relatives of her husband, who seemed content with their dependence on their brother
and his wife for accommodation.

At various points along the way Manoka had some contact with church groups. People give
me books to read. From the SDA (Seventh Day Adventist) Church. They visited me in my
house; gave me books and fruits. I found the books so real. Things I read I once did not
understand. Now I understand why Jesus came down to the world. I can really understand
things I didn’t understand before. He did miracles. He was crucified. The lessons he gave ...
How can I forgive? This question Manoka identified as significant for her own growth. She
had begun to see things from a new perspect

Inspiration came to Manoka through her reading and the teaching and testimony of others.
She came to believe: Jesus rebuked everything with the word of God. He never did anything
harsh to anyone. We react to situations ... Jesus went through hatred ... rejection. My
strength comes from reading, reflection, prayer ... Small kindesses and home visits were
significant moments of healing. There were family members, too, who gave wise counsel. I
also asked my aunt who was a nursing sister about herbs. I had stopped my medicine
because I was so depressed. There are herbs, she said, and you can (also) go to the clinic and
you can trust Jesus to heal you. This holistic approach to care gave support and
encouragement and played an important role in times of discouragement.

The struggle to keep going was not confined to the early period following diagnosis.
Manoka’s experience of discrimination from within her own family circle continued painfully
until she took the decision to sell the house. Discrimination took various forms. (My in-laws)
don’t want to share plates, cups, food. I chew buai. They can’t use my lime. These are people
I live with, next to me. Not my neighbours ... Painful feelings of rejection were all the more
intense because they came from within the family where Manoka expected support.
However, events leading up to this experience of rejection within the family perhaps throw
another light on the situation. Restricting their contact with Manoka with respect to
personal and household items arose because her husband told his family that Manoka was
suffering from tuberculosis (TB). She takes up the story: They don’t know the truth of what

Appendix 4
I’m suffering from. I don’t tell them. They won’t believe it. So having chosen not to disclose the fact that she is living with HIV Manoka must live with the usual precautions to stop the spread of TB. When I ask for cold water they give me a plastic cup. They don’t realise what they are doing. Or a cup of tea. It has to be my own cup or a plastic cup. I know it so I make sure it’s my own things I use. When I want to chew they pour lime into my hand. I don’t dip into their bottle. It’s been going on for a year now. Yes, it hurts me. It’s sad to see so many people who cannot differentiate between what is what ... They don’t understand ... They are unaware. They go ahead and do things like this ...

Having lived with HIV for three years Manoka is beginning to create some distance between her own experience and the issues that affect the community as a whole. Moving out from her own small world into the wider community enabled an objectivity that brought with it a new freedom and sense of purpose. Awareness should begin at home. In every household ... people should know that if you have TB it’s passed this way. HIV is different. 95% of people (living with HIV) stay in the house. Only 5% go to any public gatherings. The (awareness) message doesn’t go down the line. NASFUND (a Superannuation Fund) is doing a very good job. I admire them for that. Awareness programs must talk about the facts. Go from door to door. People are not aware of what HIV is and how it is spread. We must be sure that the message gets through. People must prevent this (HIV infection) happening to them. We don’t have to live careless lives. Money, wealth leads people to act carelessly, recklessly. It’s happened to me. And that has made the difference.

As she continues to struggle to make sense of her own situation and of the challenges facing the wider community Manoka reflects: they were innocent lives. Those already infected or those who have died of AIDS in many cases did not expose themselves to the virus. She is remembering her own shock on finding herself and her small child infected. They (parents/fathers/men) have families, children. Manoka’s own suffering at this point propels her towards action. We have to change our way of thinking, our attitude. They don’t think before doing things. I was married. I felt safe in the family. It wasn’t true! She laments: In PNG people are ignorant. Even though they know, they want to live and spoil other people’s lives. There is a lot of ignorance in this country. In PNG we see different customs, traditions. You cannot change them.

Manoka’s own family stood by her. Their warnings about marriage were not heeded but they still loved her and cared for her in times of need, particularly in sickness. Manoka recalled her mother’s words: ‘We warned you. You didn’t listen’. It was too late. I’d lost it. I lost what I had. Everything I had ... Not everything ... If I’d listened ... Older people know ... They stopped talking to me because I made that choice ... My mother said when I got sick, ‘I told you ... you were wrong’. Not in a harsh way. Mum, she accepts me, takes care of me; she is very concerned about me ... about my serious illness. My brothers and sisters too. It’s a new thing. They’re scared of losing me. They want to save my life.

Manoka’s health occasionally had a downturn. Although ART was eventually working well for her she developed sores on her body. The sores on her lower arms were visible. Some had scabs; some were open sores. She was thinking these might be a side effect of the medicine and asked the doctor for his opinion. The doctor thought they were probably not related to the medicine. It was more likely that they were a reaction to eating tinned fish.

Appendix 4
He advised cutting down; such sores had been associated with local tinned fish before. Later she added, I got some Septrim for my cough. Mostly the clinic provides for us ... If the medicine is not available they refer you to the pharmacy. You have to buy it. That hasn’t happened to me.

Meanwhile Manoka continued to worship in the ‘church’ in the back of their house, on the same property. It had no pastor but a council and delegated leaders. At Easter the people sent a ticket to the Highlands for a pastor to fly down and to lead the service. Like many women Manoka followed the church attendance patterns of her husband who belonged to this small local church.

Manoka’s story, as told here, describes her personal response to the experience of living with HIV within her marriage and in the household which included her extended family. After hearing of her HIV infection and her initial shock and disbelief, slowly changes came. She became aware that her needs could be met by her own family, neighbours, church communities and health workers. She tried to ‘keep busy’ when she reached the stage of being able to work and she expressed with emotion the longing to make a difference to the lives of others. She was now better prepared to face the unknown. Forgiveness brought inner healing. Religious faith gave meaning to her experience of suffering and rejection.

c. Enjoying life again

I had little contact with Manoka for the rest of that year. Then the following year the clerk at the clinic told me that he had seen her. “She is well and building a house”. Where was the house? She had been spending time in the village where she grew up. The clerk continued saying she had a new job working in the office of a foreign government. I gave him my telephone number and told him that if Manoka would like to meet she could phone me. Soon after, I received a call. She suggested a place to meet near her work. It was almost a year since we had last spoken. Manoka sounded well and confident in her new employment. What of her husband? He married again to a woman from the Islands region and they have since had two children. The only detail available about the family’s health was that the mother chose not to breast-feed the babies as is the usual practice. Her health and her HIV status were unknown.

Manoka could communicate from work using either phone or email. However, when I arrived she was nowhere to be seen. I went up to the office and was told she had gone to lunch. I decided to wait. When she arrived back she said, was it today we were going to meet? Sorry, it slipped off my mind. Five of our team are leaving to go overseas for a conference. It’s been very busy. When did you come? You came at 12. What time is it now? 1.15pm? Sorry! We went upstairs and found a quiet place to talk. However, it was not long before people started coming in and out, but Manoka shared some recent experiences. These events and the meanings they had for her provide an interesting contrast to earlier experiences.

Not long after taking up her new appointment Manoka was chosen to attend a conference overseas. She had known for several months and prepared to give a paper. She proceeded
to work on a research project in the field of Antiretroviral Treatments. She was asked to co-ordinate a meeting with the many organizations that were partners in HIV and AIDS policy and implementation. She introduced and chaired the sessions; the agenda included issues partners wanted to raise with the overseas funding agency. The disclosure of Manoka’s condition progressed gradually. Later she attended a conference in Port Moresby. Her participation there revealed the confidence she now has in such settings.

Manoka is maintaining good health and meeting the work requirements and the return to long office hours. She must rise at dawn in order to travel to work and sometimes gets home as late as 7pm, making the working day very demanding. Yet her story of the challenges she meets in her work seem to be accompanied by a high level of work satisfaction and pride in her achievements. I get tired after work. Transport is difficult. Urban PMV (public motor vehicle) to Boroko then sometimes a long wait for the rural PMV to go to the village. My sister helps with the house and the children. My mother lives with me too. She supports me. When I get home I need to rest. They do the cooking. The new house is an ongoing project. I am trying to get a septic tank. I need cement, timber ... And her husband visits her and the children, He comes; he goes. (Laughing) You would think it was his house!

A rather exciting development for Manoka is that she is planning to take a driving test. The organization I work for suggests that girls learn to drive. I thought I would never drive. Now I think it is my business to drive! It’s a stepping stone. I think about driving a car of my own ... with my kids ... taking my kids to school. Working with a foreign agency has had its impact on Manoka’s thinking prompting her to question her cultural assumptions. A woman who drives a car has a degree of independence not within the experience of women living in the village. Owning a car belongs to a very small group of women in PNG.

Living life fully is the last of three stages Manoka has moved through. Her experience has led her to the conviction that her life is important and gives her the feeling of being valued by others. She feels an integral part of a team in her workplace learning new things about herself, about others and about the world. She focuses almost exclusively on the positive side of life. She has retained her role as mother, daughter, sister, even wife though this relationship has shifted. But she has new roles which add richness to her life. She makes the most of each moment, embraces the beautiful environment of a coastal village and the joy of family, the absence of stigma and discrimination. Her spirituality is characterized by faith in God, love of family and love of life. Hope for a future of promise ... with a new home, with children, close to my family, village life, traditional culture: our own symbols, myths, rituals, festivals. I value my access to the city, my work and city life if I choose.

Manoka’s journey with HIV as a married woman in paid employment is summarized in the following table (see fig. 9). The reader can see in the table some aspects of living with HIV and changes over time. Manoka was able to describe what it is like for her to live with HIV. Her story illustrates how appropriate and effective care by health workers, family and others can overcome difficulties that may at first seem insurmountable. The care and support of family, friends, church members and colleagues nurtured Manoka’s hope.
Figure 9: Manoka's journey with HIV, a married woman in paid employment

<table>
<thead>
<tr>
<th>Time (yrs):</th>
<th>4 Before</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0 HIV diagnosis</th>
<th>1</th>
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<td><strong>Emotion</strong></td>
<td>Happily married</td>
<td>Very painful time.</td>
<td>Shock, shame, regret</td>
<td>Helplessness</td>
<td>Hopelessness</td>
<td>Feeling down</td>
<td>Later was doing well</td>
<td>Living positively</td>
<td>Confident</td>
<td>Happy</td>
<td>Work satisfaction</td>
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<td><strong>Work</strong></td>
<td>Paid office employment</td>
<td>Financial independence</td>
<td>Arranges purchase of house. Signs contract.</td>
<td>Impossible to work</td>
<td>Baby is too sick</td>
<td>Financially dependent on husband. Difficult at times.</td>
<td>Thinks about further training for re-employment</td>
<td>Actively looking for work</td>
<td>Paid office employment</td>
<td>Financially independent</td>
<td>Continues paid work</td>
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<td><strong>Spirituality</strong></td>
<td>Brought up in a Christian family according to the traditions of the United Church. Practising Christian.</td>
<td>Stubborn</td>
<td>Couldn’t move</td>
<td>‘My heart was hard’</td>
<td>I accept it. I went to the point of death. I came back.</td>
<td>Support from SDA church: books, fruit Jesus faced hatred, rejection.</td>
<td>Strength comes from reading, reflection, prayer</td>
<td>Easter service with Hlds pastor</td>
<td>Small House Church.</td>
<td>Easter service with Hlds pastor</td>
<td>Small House Church.</td>
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B. Cally, 25 years old, youth, currently unemployed

Cally was a young man who migrated to the city. All went well at first. He had a place to sleep and his paid work provided for his basic needs. Compared with his prospects in the village he felt there was a future for him in the city. However, illness brought changes. Unemployment brought poverty. Lack of education, a father on a very limited income and other handicaps meant that Cally’s prospects were reversed. He used English in a limited way; when he spoke in short phrases, in Tok Pisin, he communicated adequately. His story records in particular the last six months of his life spent largely in the care of staff and volunteers in the hospital ward.

a. Experiencing the reality of HIV

April 24

Though Cally had been admitted on April 24 through the Accident and Emergency department and was described as walking into the ward ‘conscious and alert’ he was also wasted and weak with poor appetite. He was first admitted to an acute care ward where he was given medication intravenously. A week later a nurse noted some confusion and ‘peeing at the back door’. The admission register showed that Cally’s diagnosis on admission was HIV Stage 1.¹

May 9

On May 9 Cally was described as ‘stable’ and transferred to another ward. A month after transfer he was showing some improvement. According to his medical record of May 25 he was being treated with ART. Though he still suffered from sot win (breathlessness), diarrhoea and abdominal pain and could only walk short distances, he could wash and toilet without help. However, he was restless and unhappy, voicing complaints about his situation. Doctors encouraged him and assured him they would keep him in the ward till he was better.

May 26

By this time in his mid-twenties, Cally recalled his birth in the early eighties in PMGH. His first-born sister was also born in the city. However, some time after his birth, while still a small boy, his family returned to their remote Highlands village. Once back in the village his ‘small’ brother was born. He made no mention of any form of schooling. In fact, it seemed he was illiterate; he shook his head when asked to sign his name. You write it for me, he said. His parents were not mentioned as he introduced himself. According to his medical record Cally never married. There was plenty of food in the village, he remembered, naming all the crops that are so plentiful in his place, but there was no money, no market for the crops and no roads. So as a young man Cally came to Port Moresby on a plane chartered by

¹ Stage 1 of a four-stage World Health Organization (WHO) scale indicates an initial stage of infection, stage 4 being an advanced stage.
his local ‘Member’ (of Parliament). This meant a free ride to the city and limited possibility of returning home until he could find money to pay his fare. It seemed he never returned.

Cally was referred to me by the Sister-in-charge. She was prompted by the fact that he had no relative to stay with him to provide support and practical help. She felt sorry for him. Approaching him for the first time, Cally presented himself as a young man with few resources. He was sitting cross-legged on the floor beside the bed. Some empty plastic bottles and a can of soft drink were on the floor. He was holding two white tablets in his left hand. His face had a faraway expression. Crouching down to speak to him he responded by looking in my direction. After a few minutes, seeing his willingness to talk I sat beside him on the vinyl floor. His appearance prompted me to speak to him in Tok Pisin. He was finding it difficult to breathe. Yu pilim wanen? (How are you feeling?) In a few brief words, he replied: Kus (cold), Sot win. I responded: Sot win? He nodded, placing his hand on his chest. Mi pilim pen (I’m feeling pain).

Arriving in the city he found work as a security guard. Larger security companies would normally require a formal Year 10 certificate; an employee is usually expected to be able to both read and write English to an adequate level. Small security firms and informal arrangements with employers might overlook any need for formal education. This work provided a small income in return for long, often boring and sometimes dangerous work. It is unlikely that this pay would have bought much more than food for the day and the merest of basic necessities. Since becoming ill Cally stated frankly now he had no place to live. He slept outside in cardboard boxes near a China store. He gave his address as ‘Gordons’. Homelessness forced his mind back to the village, his as ples (home). There the family was well accommodated in traditional village housing constructed of bush materials and life was good in so far as there was plentiful, nourishing, freshly cooked garden food. In contrast, now Cally was a homeless youth living on the street eating what cooked or packaged food he could find. After he was admitted to hospital, one of his wantoks (tribesmen) from work came on fotnait wik (pay week) to bring him biscuits. As time progressed the visits of his wantok became less frequent till they stopped altogether.

According to Cally he had had five admissions to the wards, four that year and one the previous year. He related a conversation with the doctor in which he told the doctor that he didn’t want to be discharged. He put it simply and clearly, Mi no gat haus (I have no house). In reply the doctor explained to him: This bed is not your bed. It belongs to many people. Many sick people need this bed. So I must discharge you now you are strong. Cally’s readmissions were due to his deteriorating health but it seemed that he was also learning ways to avoid discharge. For example, as discharge loomed, he became insistent that he see a ‘skin doctor’ because of the worsening condition of his skin. The hospital and its doctors and nurses continued to care for him, yet, his lack of interest in washing himself, taking medication or eating hospital food led to further decline in health. Soon he was lying on his bed all day with a sheet pulled up under his chin, even over his head. As the nursing notes recorded: “he sleeps most of the day”.

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2 This possibly referred to an area where there were Asian businesses.
3 ‘Gordons’ probably refers to the vicinity of the large city market.
4 Wantok = one talk or language; a person from the same place.
The youths from the Revival church from an outer suburb of the city offered regular, spiritual support. They would sit with him, pray over him, instruct him and call him to conversion, to turn his back on all sinful ways and follow the teaching of the Bible. They never, however, came to his aid with any material support: food or clothing. Cally’s medical record showed membership of the Revival church so he would decline to pray with church workers of other denominations, as was the strict requirement of the Revival church.\(^5\) It was, however, noticeable that the name of Cally’s religion had been added to his admission form, at a later date, as seen by the different style of writing, suggesting that he had joined the Revival church while in the ward. The style of prayer and healing offered to Cally by these youths met his need for care and support, spiritual nourishment and healing. Cally explained that what he liked about the Revival church was praying in tongues. He talked freely and with enthusiasm about the church. After discharge he was resolved to attend the Sunday Revival Church gatherings. He could get a bus from the market to the place.

Cally was quite talkative about his new found faith. *I got sick because I followed the wrong road. Smoking, drinking, pamuk pasin (‘risky’ sexual behaviour). God was punishing me. But now I have given up all these things and turned back to God. Now I am well again. The Revival Church in the city has many, many people. Lots of youths. People of all ages – young and old.* The belief that turning from sin and to God would bring healing is expressed here echoing the preaching of the Revival church. The person who professes this kind of faith is then subject to severe reprimand and rejection if the illness returns. ‘Backslider’ is the term of accusation in such cases and can leave the sick person confused and hopeless feeling deep shame and guilt. Cally pointed to two other patients near him: *they got sick again because they are ‘backsliders’ and God is punishing them.* The poor, unfortunate patient Cally labels as a ‘backslider’ like himself had no guardian and appeared to have been abandoned by family. *If a person turns back to old ways – smoking, drinking, pamuk pasin then God will punish them.* The sik (sickness) will return, he assured me. Cally, like many who came to the ward, was quick to say: *There is only one God. We all worship the same God. But Revival says, Revivals cannot pray with other churches. ‘No compromise’.* However, many desperately needy patients gravitated to the church that could fill their most urgent need: food, clothing, healing or comfort in any form.

b. **Responding to the experience of HIV**

**June 2**

On June 2, Cally was sitting up on his bed dressed in neat, clean, long trousers with a long-sleeved shirt. A plastic bag hanging from his bed contained a plastic dinner plate, a container of Axion – a strong grease-removing cleaner for washing plates, cutlery and a new sponge. All were neatly arranged suggesting a voluntary group of helpers had made a large donation to the ward in the form of basic items for each patient. The same empty bottles were on the floor by the bed not on the vinyl floor but on a piece of old soiled newspaper. The wall behind the bed had not been washed for a long time and showed signs of spit from

\(^5\) This restriction was not always taken seriously by patients who accepted support in all forms from anyone who would offer it.

**Appendix 4**
betel nut juice. Regular cleaning of the ward was lacking in some aspects but various
volunteers, aware of the situation and needs of patients, were making some difference.
Cally was discharged from the ward on 9 June and referred to the STI clinic for review.

July 21

It was not long before Cally was back in the ward. The admission register indicated that he
came to the Emergency department for treatment. He was in the bed adjacent to the one
he had occupied before. It was as if he had never been discharged. In appearance his
condition had deteriorated. He was sleeping on the bed all the time now. Big sik, he
described his illness. Skin nogut. Hands only. Sot win.\(^6\)

He indicated that he had received medication last week and was due for more this week.
The doctor who distributed and monitored ART in the clinic would bring it to the ward.
Unlike other drugs distributed daily by the nurses in the ward under the instructions of the
doctors, ART drugs were distributed at regular, often monthly, intervals. They were then
self-administered or supervised by the guardian. I feel very weak, was all Cally could say at
first. After a period of silence, he spoke again. Doctor said, go home, so I go. I stay outside.
No house. I stay outside or in the store or in a box. No gut. Sik i kam bek gen.\(^7\) Cold. Dust.
Doctor saw me, said, you can sleep in the ward. Food. 20 toea.\(^8\) Kaukau. Kumu. Not a good
way to live. Maket kaikai nogut.\(^9\) My only hope is this one. For Cally, sleeping in the ward
and enjoying the benefits offered, seemed his only hope.

As this reality took hold, after another period of silence, he spoke again. My father is
working. He gives me two kina (K). Go buy kaukau, cordial, cold water, he says, Eat and drink
and sleep. Bifo sik i kamap mi gat wok long sekuriti. Taim mi sik, papa i tok: Go long wod.
Dring marasin. Dokta i givim mi marasin: 2 yellow, 2 white capsule, 2 tablets: white and
green. I stay in the haus sik... no one comes... Family are at home. Yu get balus and go. Ticket
is K425. Big money. Father works for security. He gets K50 or K60 fotnait. Govment is
corrupt. Don’t pay well. In your country (he addresses me) govment pays well... very hard. So
you stay in Mosbi?

August 4

Surprisingly, on 4\(^{th}\) August, there was an older man with Cally. The man introduced himself
as Cally’s father and mentioned his home village and province. As the conversation
progressed, he described living in the city for twenty years. Cally was now in his mid-
twenties and his older sister had been born in the city, so it may well have been longer.
Perhaps he returned to the village after Cally’s birth and a little later returned to the city and
stayed. His father explained that he was not working now. He looked after slot machines...
20 toea, 20 toea.\(^{10}\) He added that the rest of the family “stap long ples”.\(^{11}\) Indicating that I

\(^{6}\) His hands were the only part of his body that were not showing signs of disease. The rest of his body
appeared to be infected with scabies or a similar skin disease.

\(^{7}\) Sickness came back again.

\(^{8}\) Probably insufficient for even a small bread roll.

\(^{9}\) Cooked sweet potato, green vegetables might occasionally be available. The market food is no good.

\(^{10}\) 100 toea = K1.00

Appendix 4
would return later, because his father was visiting and they had been talking, Cally spoke eagerly, wanting to tell me more stories “for my book”.12

Some investigation among nurses in the first ward where Cally had been admitted in April revealed that he had had a visitor which she understood to be his father. Later, too, it seemed that his father came again to make a brief visit when he transferred to the present ward. His appearance like his son’s suggested that he was barely surviving in the city. Cally replied with an inaudible mutter when asked about his father, seemingly a complaint that he doesn’t visit and some reference to his father’s work with pinball machines.

Later that day Cally told his story. It had the quality of a last testimony or life review. He demonstrated a capacity for reflection which appeared to lead to an attitude of acceptance and peace. I was born in Moresby. Went back to the village. Papa too. I was four years old. Now I am 26 or 27 at Christmas. Nogat skul. Mi gaden wantaim Papa. Planti suga, banana, kaukua, taro, yam... Mi laik go bek tasol tiket i bikpela moni. Sapos mi gat wok, mi inap long go.. Mi nogat wok... i hat... Papa i bringim bred na tinpis. Just 2, Papa na mi in Mosbi. Nogat haus. Mi slip long hapsait long China stua. Mi gat sik, mi kam bek gen. No house to sleep. Very hard life. Papa i slip long wokples. It’s outside.13

Taim bifo, mi raun, laip long stel. Mi mekim trouble. Nau mi go long lotu. Mi go long Bomana (jail). Six months in Bomana... Pinis... Kam aut... Lusim olgeta. Tingim Bikpela. Taim mi sik sista na dokta i lukautim mi. Taim yu gat dispela sik i hat tru. Mi laik go long ples. Mi laik painim wok. Taim mi gat wok long security mi gat gutpela haus. Haus bilong bikman. Taim mi stap long haus bilong unkel i orait tasol em i salim haus na go bek long ples. Em i gat planti famili.14

Cally’s pastors, the elders and the youths from the Revival Church, continued to visit him regularly and to pray with him. He liked to pray in tongues because then he felt that he was talking straight to God and he felt at once that God was healing him. His pastor laid his hands on his head and Cally felt the power of God raise him up. He felt, he knew he was healed. They don’t come every day. They come Monday, Wednesday and Friday. I know this helps me. God has given me gifts. God i marimari long mi.15 One small boy is my best friend. He goes and buys mango for me. However, the discomfort of the skin disease that covered

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11 They live in the village.
12 When the research project was explained to him he wanted to be a part of it. He understood that it would include a written report containing information gathered from patients in the ward. For him, this meant he could add his stories to the ‘book’ I was writing.
13 I didn’t go to school. I worked in the garden with my father. There was plenty of sugar, banana, sweet potatoe, taro, yam. I would like to go back (home) but the plane ticket is expensive. If I had paid work I would save my money and go. But I have no work. It is hard. My father brought bread and tinned fish. Just the two of us in Moresby. No house. I sleep near a Chinese store. When I get sick I come back again (to the ward). Papa sleeps at his work-place.
14 Before I got sick I would roam around and I would steal. I would make trouble. Now I go to church. I went to Bomana jail for six months. When I came out I had lost everything. I began to think of God. When I am sick the sisters and doctors look after me. When you are sick it is very hard. I would like to go home. I would like to find work. When I worked as a security man I had a good house belonging to an important man. When I lived in my uncle’s house it was good but he sold the house and went back home to the province. He has a large family.
15 God has mercy (pity) on me.
Cally’s body was still a major concern. *I need a skin doctor. First time in my life to have this. Mi ting i marasin tumas.* 16 I am confused. *Punishment from God?* According to Cally, the doctor had said he would make a referral to a skin specialist who would try to help. So Cally was waiting and hoping.

**August 18**

Cally was lying on his bed under a bed sheet. He was sufficiently alert to notice activities around him. He was watching the guardian of the patient in a neighbouring bed, an older man, packing all his wife’s belongings, preparing for discharge. Cally showed little interest in my approach. When greeted and asked how he was, he responded: Very big *Kus. Sot win. Can’t talk.* I sat with him for a while. He continued to watch the action on the next bed. What was he thinking? I imagined Cally was glad he was not being discharged. More than anything he wanted to stay in the ward.

c. **Death in the ward**

**September 11**

Cally died in the ward in September. On his death certificate was written: Cause of death: acute respiratory distress syndrome due to chronic gastro-TB. His death certificate was collected by his ‘cousin-brother.’

This sketch of Cally’s story provides only broad brush strokes. The rest of his story is unknown. Where was he laid to rest this being an event of considerable significance in PNG? By whom? What meaning did life have for Cally? How did his father and family at home receive the news of his death? Who was the ‘cousin-brother’ who collected his death certificate? To what purpose? So many details of the story are not known. Cally’s story is uniquely his own. Yet, it has much in common with other stories of young men from the Highlands region, and elsewhere, who migrate to the city often attracted by “city lights” and perceived enhanced opportunities. Finally, Cally’s story illustrates the significance of acts of kindness which clearly made a difference. Cally’s story, living with HIV and dying possibly alone in a public ward, spans less than a year. Stigma and discrimination were not a strong feature of the story though they may well have existed and had some bearing on the care Cally received. Overall, it seems, the positive aspects of care, as described here, offered some possibility of transcending the suffering brought by poverty, illness, and a degree of abandonment. This care was sensitive to both Cally’s cultural background, the contemporary culture of poverty in the city and his belief that faith in God and conversion of life would bring salvation and peace.

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16 I think it is too much medicine.
### Figure 10: Cally’s journey with HIV, a single man unemployed

<table>
<thead>
<tr>
<th>Time (mth):</th>
<th>Before HIV Diagnosis</th>
<th>HIV diagnosis April</th>
<th>May</th>
<th>June</th>
<th>July</th>
<th>August</th>
<th>September</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences related to:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family:</strong> of origin</td>
<td>Second-born child. Born in city like elder sister. Returned to remote rural village as a small boy. Birth of ‘small’ brother.</td>
<td>Traditional way of life, housing, gardening, cooking.</td>
<td>Homeless youth living in the city. Father is also in the city. Limited contact with father. Wantok provides a little food and some support.</td>
<td>Supported by volunteers, church workers. Supplied with basic items: clothing, plates, soap.</td>
<td>Father visited. Papa bringim bred na tinpis. (Papa brought bread and tinned fish) Spent time talking. Sisters, doctors lukautim mi. (They look after me.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Disclosure</strong></td>
<td>Talkative but no reference to HIV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Emotion</strong></td>
<td>Happy as a child. Restless as a youth?</td>
<td>Taim yu gat dispela sik i hat tru. (When you have this kind of disease it is very hard.)</td>
<td>Happy to be in ward. Basic needs met: shelter, food, water, harmony, good order.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Work/Food</strong></td>
<td>Subsistence farming. Food plentiful. No cash.</td>
<td>Hospital food</td>
<td>Wanting noodles to eat. Aloe vera for skin provided by volunteers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Spirituality</strong></td>
<td>Papa i Lutheran. (Papa is a Lutheran)</td>
<td>Conversion to Revival church Guarded about contact with church workers other than Revival church. ‘No compromise’. Likes to pray in tongues: feels the healing power of God</td>
<td>My (Revival) leader comes, puts his hands on my head. I feel good. Holy Spirit comes down. I pray with tongues. I get strong.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SUMMARY

Maroka believed that HIV was no threat to her hence her distress when she became infected. She was married. She had believed and followed the prevention message: be faithful to one partner. Despite her contact with various Christian churches none offered her another prevention method. In other words the denial of the vulnerability of many married women is not acknowledged by church or government leaders. Her resolve to begin again and to quietly challenge this denial is evidence of hope. Maroko eventually obtained access to her HIV test results and a degree of counseling though the delay inflicted much suffering - the death of her child and a sense of hopelessness that almost cost her life. With support she gained access to medication and care both from health workers, her own family and others such as church members and her work colleagues.

Cally appeared to be typical of many young men living in rural areas. Perhaps frustrated by lack of opportunity he took his chance to migrate to the city in the hope of a better life. Unprepared for what lay ahead he lacked education, family support, social responsibility and the skills and attitudes needed to face social change. While his church gave some comfort and hope of salvation its teaching that HIV is a punishment from God and that faith will bring healing had adverse consequences for him. Health workers and volunteers appreciated his need and offered what help they could. He died with some measure of human dignity in the ward - not abandoned on the street.
Appendix 5

Discussion

Table 10: Categories – similar concepts across all the collected data.

Table 11: Participants contrasting experiences

Figure 19: Major Categories
Table 10: Categories, similar concepts across all collected data

<table>
<thead>
<tr>
<th>Place</th>
<th>Family</th>
<th>Culture</th>
<th>Church</th>
</tr>
</thead>
<tbody>
<tr>
<td>– home</td>
<td>– parents</td>
<td>– language</td>
<td>– membership</td>
</tr>
<tr>
<td>– remote</td>
<td>– siblings</td>
<td>– community</td>
<td>– beliefs</td>
</tr>
<tr>
<td>– poor</td>
<td>– in-laws</td>
<td>- tradition kept</td>
<td>– practice</td>
</tr>
<tr>
<td>- happy</td>
<td>– children</td>
<td>– tradition lost</td>
<td>– healing</td>
</tr>
<tr>
<td>- burial</td>
<td>– extended</td>
<td>– adultstatus</td>
<td>– pastoral work</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>Employment</th>
<th>Religious Experience</th>
<th>Personal Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>- ‘knowing’</td>
<td>- informal</td>
<td>- faith/God</td>
<td>- shock, distress</td>
</tr>
<tr>
<td>- ‘not knowing’</td>
<td>- formal</td>
<td>- prayer, reflection</td>
<td>- fear, confusion</td>
</tr>
<tr>
<td>- cultural</td>
<td>- well paid</td>
<td>- spiritual reading</td>
<td>- sadness, loss, grief</td>
</tr>
<tr>
<td>- informal</td>
<td>- average pay</td>
<td>- action/service</td>
<td>- worry, no-worry</td>
</tr>
<tr>
<td>- primary</td>
<td>- poorly paid</td>
<td>- hope</td>
<td>- relationships</td>
</tr>
<tr>
<td>- secondary</td>
<td></td>
<td></td>
<td>- mystery/meaning</td>
</tr>
<tr>
<td>- tertiary</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sexuality</th>
<th>Marriage</th>
<th>Health Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>- taboos</td>
<td>- arranged by parents</td>
<td>- knowing HIV status</td>
</tr>
<tr>
<td>- heterosexual</td>
<td>- approved by parents</td>
<td>- knowing med. Sci.</td>
</tr>
<tr>
<td>- homosexual</td>
<td>- informal, civil, church</td>
<td>- knowing drugs</td>
</tr>
<tr>
<td>- safe</td>
<td>- stable/unstable</td>
<td>- not knowing</td>
</tr>
<tr>
<td>- unsafe</td>
<td>- recent/adult children</td>
<td>- medication</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregivers</th>
<th>Dying</th>
<th>Personal Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>- family</td>
<td>- alone</td>
<td>- disclosure</td>
</tr>
<tr>
<td>- health workers</td>
<td>- family present</td>
<td>- family</td>
</tr>
<tr>
<td>- church workers</td>
<td>- other carer</td>
<td>- intimate relationships</td>
</tr>
<tr>
<td>- volunteers</td>
<td>- home/hospital</td>
<td>- rejection/acceptance</td>
</tr>
<tr>
<td>- other guardians</td>
<td>- painful/peaceful</td>
<td></td>
</tr>
</tbody>
</table>

Cultural World view: Beliefs, Values, Rituals
Cultural Response: Care/Rejection, Talk/Silence, Burden of Care
Personal Response: Listening, transcendence, finding meaning
Health Services: Medical language, death as failure, control/negotiation

Appendix 5
Table 11: Participants' contrasting experiences

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HIV test</strong></td>
<td>No illness, no warning.</td>
<td>Recurring illness</td>
<td>Serious illness</td>
</tr>
<tr>
<td>Manoka, Lamana, Vincent</td>
<td>Stanley, John, Michael, Cally, Bonnie, Sally, Luke, Alice</td>
<td>Meggie, Regina, Peter</td>
<td></td>
</tr>
<tr>
<td><strong>Context</strong></td>
<td>Healthy family life</td>
<td>Frequent conflicts</td>
<td>Major conflicts</td>
</tr>
<tr>
<td>Gordon, Sam, Meggie</td>
<td>Noreen</td>
<td>Financial stress</td>
<td>Poverty</td>
</tr>
<tr>
<td>Financially secure</td>
<td>Lamana, Stanley</td>
<td></td>
<td>Mary</td>
</tr>
<tr>
<td>Gordon, Vincent, Sally</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educated</td>
<td>Early school leaver</td>
<td>Early school leaver</td>
<td>Never been to school</td>
</tr>
<tr>
<td>Leo, Gordon, Manoka</td>
<td>Christine</td>
<td>Gender discrimination</td>
<td>Cally, Meggie</td>
</tr>
<tr>
<td>Gender equity</td>
<td>Some HIV knowledge</td>
<td>Some HIV knowledge</td>
<td>Violence against women</td>
</tr>
<tr>
<td>Manoka, Ellen, Meggie</td>
<td>Manoka, Lamana</td>
<td></td>
<td>Nenge</td>
</tr>
<tr>
<td>Knowledge of HIV</td>
<td>Protection sometimes</td>
<td></td>
<td>No awareness/knowledge</td>
</tr>
<tr>
<td>Stanley</td>
<td></td>
<td></td>
<td>No protective measures</td>
</tr>
<tr>
<td>Protection against HIV</td>
<td></td>
<td></td>
<td>Winnie, Manoka, Ellen</td>
</tr>
<tr>
<td><strong>Religious experience</strong></td>
<td>Strong relationship of trust and confidence in God</td>
<td>Routine religious rituals</td>
<td>Little awareness of God</td>
</tr>
<tr>
<td><strong>God</strong></td>
<td><strong>Church</strong></td>
<td>Occasional involvement</td>
<td>Nominal or no link with faith community</td>
</tr>
<tr>
<td>Church membership,</td>
<td></td>
<td></td>
<td>[Stanley, Gordon]</td>
</tr>
<tr>
<td>active involvement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regina, Winnie, Nenge, Meggie</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Healing</strong></td>
<td>Sacramental church rituals</td>
<td>Medical treatments</td>
<td>Herbal medicine</td>
</tr>
<tr>
<td>Baptism in the Spirit</td>
<td></td>
<td></td>
<td>Sorcery, Witchcraft</td>
</tr>
<tr>
<td>Cally, Meggie</td>
<td>[All]</td>
<td></td>
<td>Stanley, Noreen, Regina, Joy, Leo, Sally</td>
</tr>
<tr>
<td><strong>Finding Hope</strong></td>
<td>Choose life for self and family</td>
<td>Uncertainty</td>
<td>Lose hope, despair of any future possibility</td>
</tr>
<tr>
<td>Questions</td>
<td>[Manoka, Stanley, Nenge, Sam, Meggie]</td>
<td>[Vincent, Leo, Luke, Peggy, Gordon]</td>
<td>[Cally, Philip, Mary]</td>
</tr>
<tr>
<td>What changes will I make?</td>
<td></td>
<td>How will I manage?</td>
<td>Is there any future for me?</td>
</tr>
<tr>
<td>[Manoka, Stanley, Luke, Nenge, Sam]</td>
<td></td>
<td>Who will support me and my family?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>[Lily, Joy, Lamana, Leo, Peggy, Gordon]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>[Cally, Philip, Mary]</td>
</tr>
</tbody>
</table>

*Appendix 5*
## Cultural World view

- **Beliefs**
  - Spirit World
  - Illness
  - Sorcery
  - Christian

- **Values**
  - Land/place
  - Family
  - Community
  - Health

- **Rituals**
  - Marriage
  - Healing
  - Death/Burial

## Cultural Response

- **Care / Rejection**
  - Mutual Obligation
  - Women
  - Conflict

- **Talk / Silence**
  - Shame
  - Anger
  - Loss/ Grief

- **Burden of Care**
  - Accepted
  - Poverty
  - Children

## Health Services

- **Language**
  - Knowing HIV
  - CD4, Viral load
  - “Don’t worry”

- **Death as Failure**
  - Diagnosis
  - Treatment
  - Fear
  - Threat

- **Control / Negotiation**
  - Partnership
  - Discussion

## Personal Response

- **Reflection**
  - Remembering
  - Life review
  - Reconciliation

- **Transcendence**
  - Relationships
  - Nature
  - Mystery

- **Integration**
  - Meaning
  - Hope

---

**Figure 11: Major categories**

*Appendix 5*
Appendix 6

Photographs
Figure 12: Sign board at the Jackson's International Airport, Port Moresby.

Figure 13: Sign board in rural town warns against AIDS.

Figure 14: Sign board outside a home in Port Moresby advertising coffins for sale.
Figure 15: 9-Mile Cemetery serving the city of Port Moresby

Figure 16: Maura Elaripe Mea and husband Max at the grave of their two babies
Figure 17: Port Moresby General Hospital Main Entrance

Figure 18: PMGH celebrating 50 years.
Figure 19: Heduru (Sexually Transmitted Infections) Clinic, PMGH.

Figure 20: Family Support Centre, PMGH

Appendix 6
Figure 21: Accident and Emergency Department, PMGH.
Figure 22: Adult Outpatients, PMGH

Figure 23: Caregivers: Family visiting their relatives.
Figure 24: Tessie Soi, Director of Social Work, PMGH.
The AIDS Memorial Quilt bears the names of people who have died. The words of Psalm 23 form the centrepiece. Tessie is founder of Friends Foundation supporting PLWHA.

Figure 25: Sr Elizabeth Waken, Sister-in-Charge, Medical Ward, PMGH
The 60-bed medical ward is in the background.

Figure 26: 'Leo' as he appeared on television documentary, Four Corners.

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