

“There’s no stigma here”: The Complexity of Stigma among Healthcare
Providers in Wamena, Papua

by

Kathleen Gregson
B.A., University of Victoria, 2009

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

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Abstract

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This thesis is an ethnographic study of AIDS-related stigma in the work and discourse of healthcare providers in Wamena. Wamena is located in the highlands of Papua, the eastern-most province of Indonesia. HIV/AIDS rates in Papua are dramatically rising and stigma continues to hinder HIV/AIDS programs and initiatives. This thesis looks at assumptions about stigma and shows intersections of stigma with Christianity and racism to be integral aspects of AIDS-related stigma in Wamena. The connection between stigma and HIV/AIDS as a disease is not as strong as intervention programs appear to assume. In 2010, I conducted ethnographic research among health care providers in Wamena. I employed semi-structured interviews, participant observation, and casual interviews to collect materials and assess current practices that contribute to stigma in the healthcare setting. The results of this research challenges current HIV/AIDS-focused approaches to stigma by showing stigma is expressed in subtle ways even among well-trained healthcare providers, that stigma is expressed through Christian values and through assessments of racism, and that some aspects of stigma can also work to protect patients from other forms of discrimination.

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Dedication

For all those in Papua who have been touched by the hardships of HIV and AIDS through work and in life.

Chapter 1: The Tip of the Iceberg: AIDS, Stigma, and Healthcare Providers

This thesis looks at the particular role of healthcare providers in stigma related practices in a highlands town in the centre of Papua, Indonesia. Wamena is a town of approximately 30,000 people, and is located in the easternmost province of Indonesia. Wamena has experienced rapid growth in the past 3-4 years and is the central hub for healthcare in the Baliem Valley. The healthcare community in Wamena presented an interesting picture of stigma to me upon my arrival. “There’s no stigma here,” healthcare providers kept on saying. This view runs contrary to current reports, and the statement led to an exploration of the complexities of stigma in this location, and into the wider social relationships and influences that intersect HIV/AIDS-related stigma among health care providers. Discussions of HIV/AIDS-related stigma repeatedly led to the topics of race and religion. This connection to race and religion is a significant departure from current approaches to HIV/AIDS-related stigma that typically focus on education about HIV, and about stigma that is focused on physical aspects of HIV and AIDS, or on contagion more predominantly. The links between HIV/AIDS and stigma that my research describes move significantly beyond the focus on the physiological aspects of HIV/AIDS.

The dominant definition of HIV/AIDS-related stigma strongly links stigma to the presence of HIV or AIDS. HIV/AIDS-related stigma is defined by UNAIDS as “a process of devaluation of people with or associated with HIV and AIDS” (WHO, 2007). The UNAIDS Global Report (2010) shows that 92% of all countries have programs in place to address HIV/AIDS-related stigma and discrimination. HIV/AIDS-related stigma is a serious issue; it is credited with poor uptake of HIV/AIDS services as well as low standards of care in the healthcare setting (UNAIDS, 2007; Varas-Diaz et al., 2010;

Castro, Arachu and Farmer, 2005; Li et. al., 2007). Despite the efforts of global institutions like UNAIDS and WHO, as well as other stakeholders to reduce stigma and increase treatment opportunities, there remain pockets of people and communities where global efforts are insufficient. Papua, Indonesia and their healthcare community is one of those pockets. Scholars have identified stigma as a significant problem for AIDS awareness and management in Papua (Hewat, 2008; Butt, 2005; Butt & Eves, 2008) and therefore exploring the prevalence of HIV/AIDS-related stigma is both warranted and integral to addressing the AIDS epidemic.

HIV rates in Papua are estimated to be around 7% of the indigenous population (Butt and Morin, 2010). As a province, HIV and AIDS rates in Papua are 20 times the rates in the rest of Indonesia (WHO, 2007). Traditional HIV/AIDS programs do not seem to be having the same effects that they have had in other locations where HIV incidence rates and stigma have been successfully reduced (see WHO, 2002; World AIDS day 2002 Advocacy kit, www.WHO.org; Mahendra, V. S., & Gilborn, L., 2004). Traditional stigma reduction programs generally focus on education about HIV/AIDS, transmission methods, and debunking false beliefs about HIV/AIDS (Nyblade et al., 2009). The high HIV/AIDS rates and the low uptake of services in Papua suggest that current approaches to AIDS-related stigma are not addressing the issues relevant to highlands Papua, Indonesia.

This project draws from qualitative research I conducted in 2010, where I used semi-structured interviews and participant observation to approach the problem of persistent stigma that is not reduced through current AIDS Industry HIV/AIDS-related stigma reduction programs. This thesis will answer why current approaches to stigma do

not address all aspects of HIV/AIDS-related stigma in Wamena. HIV/AIDS-related stigma in Wamena is unique, subtle, and complex.

Discussions of AIDS-related stigma focus on healthcare providers in this thesis because this group has been identified by HIV-positive Papuan patients as a major barrier to receiving HIV and AIDS care in Papua (Butt and Morin, 2010). This thesis will use the Indonesian term *orang dengan HIV/AIDS* (ODHA) to describe a person living with HIV/AIDS. A healthcare provider, in this research, is defined as any person employed by either an Indonesian government clinic or a clinic recognized by the government as a legitimate source of healthcare. Healthcare providers work at hospitals, clinics, and smaller medical posts in rural areas around Wamena.

Healthcare providers are important to the study of stigma because they have access to patient information and provide patients with information about HIV/AIDS. They play a unique role in the international involvement in local AIDS epidemics because of their position as a mediator between the goals of international interventions and local populations. They act as gatekeepers, and are influenced not only by interventions, but also by their own thoughts about interventions, the validity of those interventions within the group being targeted, the value of the intervention, and the motives of the intervening person or group (Reeves, 2010). Healthcare providers are taught about HIV/AIDS, about treatment, and about prevention so they can pass on the information and treatment needed to deal with the AIDS epidemic in their communities. But, like the game of telephone I played as a child, the intended message is not necessarily the one people hear in the end.

This thesis explores to what extent stigmatizing values and practices are present among healthcare providers who deal with HIV-positive patients. Generally, in internationally funded HIV/AIDS training sessions, there is an expectation that there will be a smooth transition of knowledge and practice about HIV/AIDS, treatment, and prevention. What actual impact does stigma have on how messages are conveyed? This thesis demonstrates that the assumption that information would translate smoothly from one place to another is highly problematic, and ignores local expertise, values, culture, politics, religion and the ability to reinterpret biomedical interventions. This thesis focuses on the values and practices of healthcare providers in order to argue two key points. First, I argue that the local practices of healthcare providers may be stigmatizing even though they do not acknowledge this. I show that the local Christian worldview coupled with the local culture and international HIV/AIDS interventions creates multiple opportunities for healthcare providers to stigmatize HIV-positive persons. Second, I argue that stigma is not necessarily a negative phenomenon; that there are positive responses as well. This thesis shows that some aspects of HIV/AIDS-related stigma in Wamena are put in motion to protect patients from larger structural mechanisms of discrimination within the healthcare system.

The results described in this thesis draw from ethnographic fieldwork I conducted on stigma with healthcare providers in the city of Wamena for six weeks in June and July of 2010. Before arriving in Wamena, I often heard “*you haven’t seen Papua unless you have been to Wamena.*” This is because culture and practices among the Dani and Lani in Wamena are much less affected by Indonesian influences than elsewhere in Papua. The

area surrounding Wamena is referred to as the Baliem Valley and is located in the Jayawijaya District (see figure 1).

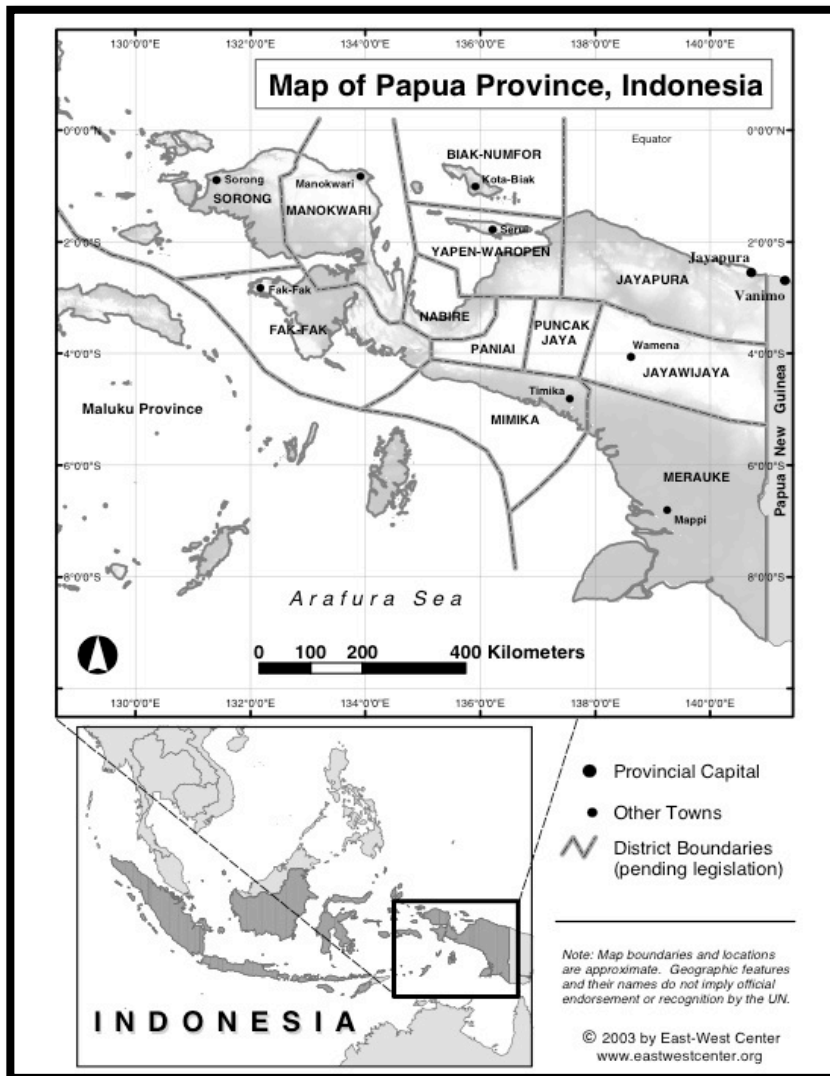


Figure 1: Map of Papua

During my fieldwork, I conducted interviews with a total of nine healthcare providers from four healthcare facilities with access to HIV/AIDS resources. I observed healthcare providers and participated in community activities revolving around HIV/AIDS. Before describing research protocols and results in more detail, it is necessary to understand how stigma is understood in academic discourse, in global initiatives, and what the local conditions are that shape healthcare provider responses and

values in Wamena. The following sections in this chapter will outline global approaches to HIV/AIDS-related stigma, discuss HIV/AIDS-related stigma in detail, outline the healthcare system in Indonesia, address the political background, and highlight important religious attributes needed to understand the complex nature of HIV/AIDS-related stigma in Papua.

AIDS-Related Stigma and Interventions

In this thesis, the term HIV/AIDS-related stigma is used extensively. In general, the term ‘AIDS-related stigma’ is applied by UNAIDS, and other major donors, to a number of concepts, making it difficult to say what actually constitutes HIV/AIDS-related stigma. Some definitions of HIV/AIDS-related stigma include,

- The negative experiences of HIV-positive people because of other people’s actions,
- Negative personal judgments about one’s own HIV/AIDS status,
- General community beliefs about HIV/AIDS and who can acquire AIDS,
- An inability to accept HIV/AIDS as a real threat,
- Any discrimination that is in response to HIV/AIDS
- Any discrimination based on a perceived notion of a HIV/AIDS status (Li et al., 2007; Mason et al., 2001; Scambler, 2009; UNAIDS, 2010; Whiteside, 2008).

The consensus in the literature is that local HIV/AIDS-related stigma is one key reason for failed HIV/AIDS programs and initiatives worldwide (Li, Wu, Wu, Zhao, Jia & Yan 2007; Castro & Farmer 2005; Nyblade, 2009). The term can be problematic because in the actual application of interventions the term HIV/AIDS-related stigma can provide an

excuse for failed programs, without needing to be specific about why people are not responding to the specific programs.

Education, politically correct label changes, and programs aimed at behaviour change are current methods being used by international bodies to eliminate stigma (Narain & Gilks, 2004; Li, Wu, Wu, Zhao, Jia & Yan, 2007). These programs are attempts to change the behaviour of populations to fit internationally accepted norms. However, these methods have had mixed results and HIV/AIDS-related stigma is still a major problem (Li et al., 2007). India, Vietnam, and Tanzania have all had success in reducing HIV/AIDS-related stigma by focusing training on transmission methods, involving individuals who are HIV-positive, and focusing on individual fears about contagion in order to change the behaviour of healthcare providers (Nyblade et al., 2009). Behaviour change programs are often culturally loaded and biased initiatives. Scambler points out that behaviour change programs “tend to be top-down and aspire to empower individuals to behave in ways prejudged to be in their interests (an odd but recurring perversion of the concept of empowerment)” (2009, p. 452). This type of program that focuses on behaviour change is the main tool used internationally to combat stigma (Scambler, 2009). The ideals taught in these programs are rooted in a biomedical view of HIV/AIDS which inherently simplifies and ignores social relations that are a part of the HIV/AIDS experience. The solution to stigma is often simplified in this manner because local situations are not taken into account when designing solutions (Scambler, 2009).

One reason for the prominence of behaviour change models in programs to eradicate stigma is because of the strength of the ‘AIDS industry.’ Dennis Altman’s (1998) term the ‘AIDS industry’ encompasses both the global community and the

rhetoric of the various institutions driving HIV/AIDS interventions. This term AIDS Industry acknowledges the convergence of “individual states; international agencies; transnational pharmaceutical companies; particular academic disciplines (above all various fields of biomedicine; virology, epidemiology, immunology, etc.); and NGOs, both local and international” (Altman, 1998, p. 235) in creating a biomedical approach to AIDS care and treatment (Treichler, 1992).

The AIDS industry draws from a set of values grounded in biomedical renderings of HIV/AIDS. The general idea is that treatment should be given to everyone, regardless of age, gender, race, or lifestyle. This is reflected in the Millennium Development goals where the aim is “universal access to treatment for HIV/AIDS to all those who need it” (UNAIDS, 2010). There are instances recorded where creating the perfect AIDS patient supersedes universal access to treatment (see Biehl, 2008) as the AIDS industry tries to implement a kind of universal one-size-fits-all style intervention that focuses more on the biomedical renderings of HIV/AIDS than on the specific circumstances and resources in a location.

Biomedicine supports the one-size-fits-all intervention style, but as a system of healing, is only one of many ways to understand health. In this research, I define biomedicine according to Atwood and Davis-Floyd’s definition, “as a socio-cultural system, a complex cultural historical construction with a consistent set of internal beliefs, rules, and practices” (Atwood and Davis-Floyd, 2003, p. 2). Biomedicine is embedded in culturally specific value judgments and once something is deemed scientifically valid, it is applied to both the individual body and the larger social unit as a universal truth. The biomedical view emerged from a specific historical and cultural perspective grounded in

sterile laboratories, as well as a specific perspective which views the body in mechanistic terms, and as something that can be fixed (Atwood and Davis-Floyd, 2003).

Elaborating on the use of biomedicine, Kleinman (1995) defines biomedicine as “a medium through which the pluralities of social life are expressed and recreated. It is a practice that is “more theoretical than actual” in its application (Gordon, 1988). This perspective on biomedicine more accurately reflects the acceptance of international interventions because it highlights the approach to health in Wamena and in other parts of the world where there are multiple, and often competing, forms of healing. Biomedicine is only one form among many approaches to health. It has been argued that manipulating biomedical solutions to work outside of laboratory scenarios where they were created results in lowered rates of efficacy and culturally incompatible solutions (Zhou, 2007; Latour, 1983). I argue this is especially relevant for Wamena because biomedical resources are scarce, not often trusted, and many people rely on alternative forms of healing like indigenous healing systems, special kinds of foods, or more recently, *jamu*, an Indonesian form of herbal medicine. These traditions compete with and interweave with biomedicine in daily practice.

The rigidity of the biomedical model often conflicts with indigenous models of health. It can become a new tool of social subjugation, as the morals embedded in each medical system can challenge one another. In some cases, the prestige of biomedicine becomes a tool to create difference where a person’s association with biomedicine can be used to create prestige in the community over those who are not educated, while still not furthering medical goals at all (Robbins, 2010, p. 97). Traditional ideas of health are defined as wrong or as something that is no longer believed in and new medical standards

and new categories of social inclusion and exclusion are created. These conditions have an impact on healthcare providers and how they respond to HIV-positive patients. Thus, biomedical interventions can create inequalities and judgments, and can lead to stigmatizing practices.

Unpacking Stigma

Understanding stigma is a central aspect of this thesis. This section moves away from the global standard of stigma and looks at various analyses of stigma that have been discussed in scholarly literature. Studies of stigma found a different response to stigma at the community level from the international level. Stigma was seen as a socially agreed upon identification of a discrediting attribute within a person or group of people that runs contrary to normal. Stigmatized characteristics vary depending upon place and time. Castro and Farmer define stigma as “the identification that a social group creates of a person based on some physical behaviour, or social trait perceived as being divergent from group norms” (2005, p. 54). This definition is useful to understand the construction of stigma with the community, but it does not account for the ways stigma is experienced, applied to a subject, or that stigma can be fluid.

Social interaction is essential to stigma, for stigma is “a language of relationships, not attributes” (Goffman, 1963. p.3). People exercise sanctions against the stigmatized person or group to protect themselves from the stigmatized. The protection is from the deviant person as well as the perceived contagiousness of that person’s deviance. Goffman writes; “society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories” (1963, p. 5). For example, expectations of proper behaviour, community involvement, and family

obligations are all communicated through institutions like school, jobs, family life, church, etc, and are reproduced to feel normal. Stigma is manifest through interactions with people who, for the sake of their own reputation and identity, must differentiate themselves from the abnormal person.

Global interventions take a similar view to Goffman's perspective of stigma. Behaviour perceived as deviant is understood to be at the root of stigma. In the context of an international view of HIV/AIDS, AIDS stakeholders are expected to change the "group norms" of the local community in order to reduce stigma (Scambler, 2009). They must convince or train the community to alter their practices around HIV-positive people to match global standards. Stigma as a concept can therefore be used to justify interventions based on an outside rendering of the problem, and not local reasons for certain practices.

This approach to HIV/AIDS interventions implies that there is one type of stigma and one response to AIDS. An important counterargument is that stigma relates specifically to personal and social attitudes of a specific location (Varas-Diaz, Neilands, Rivera, & Betancourt, 2010). Stigma becomes embedded within social structures that cannot be manipulated easily by an education program or new drug protocols. Parker and Aggleton (2003), who have written extensively about stigma and discrimination, move away from Goffman's restricted definition of stigma because his work has been used to infer that stigma is as if a visible blemish is permanently attached to a person. HIV/AIDS-related stigma is much more complicated than this, Parker and Aggleton (2003) suggest that stigma is "a constantly changing (and often resisted) social process." Political and economic conditions, as well as religious and cultural contexts, affect the

manifestation of stigma at the local level. The constant change is evidenced in everyday experiences, moral judgments, the altering of social connections, and categories of health, sexualities, and power. They all influence the manifestation of stigma. Healthcare institutions and healthcare providers are a part of the community that influences stigma: “patient labels, social hierarchies, and rules to accessing care promote categories of stigma in the hospital as well as in the community” (Mason, Carlisle, Watkins, & Whitehead, 2001). I adopt this framework, and argue that the experiences of healthcare providers are therefore an important part of understanding HIV/AIDS-related stigma in Wamena because they are the point of contact where the more narrow global view of stigma meets, and potentially conflicts with local perceptions of HIV/AIDS and stigma.

In this thesis, I view AIDS-related stigma as not confined to the medical aspects of a person’s illness. Stigma surrounds the care, opportunities, and social relations of a person, including healthcare providers, patients, family, etc. AIDS-related stigma at the local level in Wamena is not only influenced by international classifications of AIDS risk populations, but also by local beliefs and experiences of disease and health that have nothing to do with HIV/AIDS. It is in everyday, subtle experiences of discrimination that people feel the sting of stigma.

Racial Tensions: The Annexation of Papua

To understand the unique and complex nature of HIV/AIDS-related stigma in Wamena, it is important to understand the religious and political landscape of Papua. Religion and politics have a profound impact on daily practices and the annexation of Papua is a sensitive topic from both a religious and a political standpoint. Papua, as the largest province of Indonesia, has an abundance of natural resources. Previously, from

1828 until 1962, West Papua was a colony of the Netherlands, but in 1969, through a voting process cloaked in controversy, the area formerly known as Dutch New Guinea, officially became Irian Jaya (what is now Papua), a province of Indonesia (Van Den Broek and Szalay, 2001).

Tensions between Papuans and Indonesians rose at this time. Between the years 1966 and 1967, in the Baliem Valley alone, Indonesian soldiers “shot dead 103 Dani males and hanged a 10-year-old boy” (Van Den Broek and Szalay, 2001, p. 78). The killings were rarely acknowledged, but when justifications were given, they included the refusal of Dani men to abandon clan names and become Indonesian (Van Den Broek and Szalay, 2001). Today, Papua is governed under a special autonomy rule, but the results of this arrangement have not been favourable for indigenous Papuans, and Indonesia continues to exert a greater influence over the Papuans than the people living in Papua do (Suter, 2001).

Indigenous Papuans have a noticeably different appearance from Indonesians, which reflects their different ethnic origins. Wallman’s definition of ethnicity is useful in this context: “ethnicity is best thought of “as a sense of difference that can occur when members of a particular cultural, tribal or national group interact with non-members”” (Wallman cited in Elam and Fenton, 2003). Papuans are of Melanesian descent and have darker skin. In private conversations, Indonesians are referred to as “*rambut lurus*,” “straight hairs or long hairs” by Papuans who predominantly have tightly curled black hair. This definition of ethnicity which includes physical differences and social tensions grounded in a specific historical context reflects the relationship between Papuans and Indonesians.

The rocky relationship between Papuans and Indonesians has raised fears of genocide. Papuans view AIDS as a form of genocide by the Indonesian government. The claims of genocide and HIV/AIDS consistently expressed by people in Wamena need to be understood from this historical context of colonialism. Racial tensions have existed since Papua was incorporated into Indonesia and the Papuan people have had to struggle for control and rights in their land (King, 2002; Suter, 2001; Broek and Szalay, 2001). The recent history of Indonesia's annexation of Papua heightens fears that the current HIV/AIDS epidemic is being sustained as a means of genocide and is consequently a contributing factor in HIV/AIDS-related stigma in Wamena. Indonesia has been accused of Human Rights violations against the Papuan people, and these claims are well documented and recent. In October of 2010, a video showing the torture of Papuan villagers was posted on the BBC news site (Vaswani, 2010). The torture happened in Wamena and was reported by the BBC to be too disturbing to show in its entirety. While torture and genocide is a discussion that is not usually thought about in conjunction with HIV/AIDS-related stigma, genocide conspiracy theories have been associated with lower HIV testing rates in South Africa and the topic is relevant to how HIV/AIDS is constructed and understood in Wamena (Bogart et al., 2008).

The historical context of Papua's annexation and continued violence against Papuans, as well as the AIDS crisis, extends into current discussions of Papuan survival regarding HIV/AIDS and contributes to an issue of mistrust between Papuans and Indonesians (Butt, 2005). This history affects experiences within the community as well as how healthcare providers provide care, and how the community responds to HIV/AIDS.

Culture and Religion in Papua

At the community level, animosity between Papuans and Indonesians is directly related to the process and results of the annexation of Papua. Religious tensions rise from the political context. Almost ninety percent of Indonesians are Muslim (Warta, 2010). While the majority of Indonesia is Muslim, the majority of the Papuan population identifies as Christian (Tebay, 2007; Warta, 2010). Papua is considered a Christian territory in a majority Muslim country (Tebay, 2007). At the time of annexation, the main religious traditions were traditional Papuan animist beliefs and Christianity.

The monolithic term “Christianity” is misleading. Catholic and Protestant missionaries have been in Papua since 1855 and numerous denominations exist within these categories (Warta, 2010). Christian missionaries were unable to completely erase animistic beliefs and as a result the form of Christianity in Papua is syncretic. Missionaries venturing to the highlands of Papua did not arrive until later but were still a successful and influential group.

Religious loyalties predominantly follow racial lines in Papua. The numbers of Indonesians, who are mostly Muslims, moving to Papua through government transmigration programs has greatly increased, and violence towards the indigenous Papuan population has risen in conjunction (Tebay, 2007; Van Den Broek and Szalay, 2001). As a result, Christianity has been incorporated into Papuan nationalism in response to assimilation and continued violence against Papuans.

Religion is one of the main influences on community practice and moral values (Hewat, 2008; Butt and Eves, 2008; Hammar, 2007), so it is unsurprising that local Christian beliefs play an important role in affecting healthcare provider practices. Christianity significantly contributes to the way people in Wamena understand

HIV/AIDS. Christianity is an important factor that affects healthcare providers and stigma in Wamena. Christianity serves as a rallying point against both HIV/AIDS and the Indonesians, further complicating discussions of stigma in Wamena. This is a key theme in chapter 4.

Alongside religious differences, tribal differences also complicate community-level interactions. Understanding that there are important differences between people living in Wamena and that these differences are significant to how people relate to others is a key aspect of HIV/AIDS-related stigma in Wamena. Indigenous Papuans identify strongly with their family's places of origin. Papua has over 300 different groups of people and 300 different medical traditions. Highlanders are different from Valley people, and migrants from other parts of Indonesia are especially different. The traditional belief systems that missionaries tried to replace through Christianity also affect how indigenous communities respond to biomedical interventions (Warta, 2010; Rutherford, 2002). Traditional beliefs are still a major influence in Papua. The Dani tribe is just one example of people with a complex belief system pertaining to health and healing that compete with biomedical interventions.

The Dani tribe is one of three main tribes in the Baliem Valley. The other two tribes are the Lani and the Yali. The Dani are one of the largest ethnic groups in Papua. They are skilled gardeners and use terraced gardens in this mountainous region. Pigs are important animals in Dani culture and are used in brideprice payments and penalties. The Dani people of the Baliem Valley have a number of different explanations for physical maladies and believe it is very important to find the right kind of healer for the right problem (Butt, 2004).

The Dani's healing system is just one example of why biomedical interventions do not smoothly transfer to Papua. Treichler points out that HIV/AIDS in a developing nation such as Indonesia should be understood as a "discoverable entity in nature but is assigned different names and meanings within the signifying systems of different cultures" (1992, p. 68). She argues that not all renderings of HIV are correct but they should be treated as valid because that construction of the virus is relevant to the community. In the Papuan case, constructions of HIV are shaped by features of the healthcare system. The variations on ways to heal maladies and community priorities means that health care workers must adapt to those practices in order to keep their services in demand. Kielmann (2005) points out that some medical practices accepted in one country may not be relevant in another country. She argues that biomedical concepts of disclosure and confidentiality are not always beneficial to a patient. Some medical protocols within biomedical interventions are not relevant to certain indigenous medical systems. The irrelevance of certain practices within biomedical interventions cause healthcare providers to act in ways contrary to AIDS Industry standards because they must adapt practices to work in local scenarios. This phenomenon was noted in Latvia where healthcare providers found international HIV/AIDS communication guidelines about patient-provider relationships to be inappropriate in the context of their healthcare practices (Vinita Datya et al., 2006; Kielmann, 2005). Targeting behaviour of healthcare providers from the biomedical and international view of what is pertinent to the HIV virus does not sufficiently address the needs and practices in all societies experiencing an AIDS epidemic. Papua is especially complicated because there are so many belief

structures converging on the understanding and treatment of HIV/AIDS and to complicate the issue further, resources are limited.

Healthcare Providers: Making Do with Few Options

Healthcare facilities in Wamena are limited and this affects the standard of care available to patients. Healthcare providers develop their understanding of HIV/AIDS through a combination of the standards of care expected in the AIDS Industry and practices learned from personal experiences working in their field. The medical environment in Wamena is not as technical as in developed nations. By this I mean resources and information about HIV/AIDS take longer to get there, training is rarely adequate, funding is minimal, and therefore, people explain experiences and treatment of illness or disease using the information they do have (Gunawan et al., 2006).

The Indonesian health system is made up of three tiers of care. There is the Community Health Clinic (*puskesmas*), health sub-centers, and mobile clinics. There are also three distinctions in community participation; there are service posts (*posyandu*), maternity posts (*polindes*), and drug posts (*pos obat des*). Indonesia spends roughly \$5 per person a year on public health; this is minimal in comparison to neighboring countries and is only 4% of the government expenses (WHO, 2007). WHO (2007) recommends a 5% minimum spending on healthcare, which suggests resources and services are going to be already stretched even if there were no HIV/AIDS epidemic.

People use private healthcare in Wamena but this is limited to the upper-middle class and elite. Many elite individuals in Indonesia are prone to visiting neighbouring countries for medical services and in Papua elites visit a neighbouring province at the very least. There is a visible line between those who can access healthcare and those who

cannot. HIV/AIDS programs and others are heavily subsidized by foreign organizations, but this is still not enough to make a dent on the current HIV projection (Gunawan, et al., 2006).

Without a sufficient health care structure, front-line health care providers must adapt to what is possible rather than what is expected by the AIDS Industry. For AIDS prevention and treatment, much of the initiatives are dependant upon a healthcare structure. Without such a structure, not even condoms are useful (Haley, 2008) because distribution is too difficult. Being able to understand HIV/AIDS and respond in a way that is dependant upon the ideal structure rather than the real structure is highly problematic. Often the solutions just do not work. In addition, specific knowledge and rights that are assumed in biomedical interventions do not evenly apply to the whole population which can make education not very relevant (Hammar, 2008).

To adjust the biomedical AIDS industry HIV/AIDS framework to meet the needs of the rural populations, the AIDS Industry has focused training on healthcare providers, as opposed to changing the structure of the healthcare system in impoverished areas (Robins, 2009). The healthcare provider is treated as a messenger by the AIDS Industry in this sense, and is generally perceived as the easiest point in the healthcare system for creating change. Accomplishing change through healthcare providers relies on them to fully adopt the belief structure embedded in biomedical interventions, and then transmit this change with little structural modification.

By looking specifically at HIV/AIDS-related stigma in the context of indigenous health workers within Papua's generalized AIDS epidemic, I am exploring the nature of the relationships healthcare providers have with the healthcare system and their patients.

The scholars Mason, Carlisle, Watkins, & Whitehead (2001) and MacDonald (2007) believe that healthcare workers are an important factor in issues relating to stigma because they hold a position of power over a patient and within the community. Varas-Diaz et al. (2010) assert that stigma originating from healthcare workers affects the standard of care and in some circumstances deters patients from seeking care at all.

This thesis will argue that official AIDS programs to combat stigma are failing Papuans because they are not tailored to local belief systems and practices, do not acknowledge racial discrimination, and do not address the complexity of stigma as a potentially protective as well as discriminatory mechanism. I will show that HIV/AIDS-related stigma is not only about HIV, but about wider social inequalities. Ethnographic results from my fieldwork in Wamena, Papua on stigma, religion, and racial discrimination show the need to broaden what is understood by HIV/AIDS-related stigma.

Summary of Thesis

This thesis will be organized as follows. Chapter 2 will discuss research methods and introduce the fieldwork site and methodological approaches. I will describe my contacts, who enabled access to interview participants, as well as my experience as a researcher in the field. This chapter will situate the discussion of HIV/AIDS-related stigma within the context of Wamena, Papua, paying special attention to the city and the background information that is necessary to understand the complex nature of stigma in Wamena.

Chapter 3 will examine health care providers' ideas of stigma and the factors that contribute to HIV/AIDS-related stigma as introduced by the interviewees. Results draw

from the interviews and a stigma scale that was administered in the field. . The results show subtle ways stigma emerges in the values of healthcare providers. This chapter will establish the mindset of healthcare providers towards stigma and show that HIV/AIDS-related stigma is subtle but influential and present.

Chapter 4 looks at the religious landscape and the blurring of boundaries between religious morals and medical goals. Religion and medicine mutually reinforce each other and create an environment where stigma is embedded within the expectations of being a good Christian. Discussing religious beliefs and adherence to those beliefs will show that the expectation of being a good Christian is intertwined with the expectations of being a good patient, and these values have a greater influence on stigma than HIV/AIDS does.

Chapter 5 looks at the responses of healthcare providers to racial tensions and how the issue of race is intertwined with HIV/AIDS interventions in the minds of respondents. Papuan healthcare providers respond by acting as protectors of Papuan patients within the Indonesian healthcare system. They protect their patients from stigma of Indonesian healthcare providers, and they justify their actions based on an ethos of Papuan survival in the face of genocide.

Chapter 6 summarizes findings and suggests further research in the area of HIV/AIDS-related stigma influenced by racial inequalities and religious expectations, recognizing the ongoing importance of keeping stigma central to understanding HIV/AIDS prevention and treatment strategies in remote locations. Future research can focus on identifying medical interventions that are appropriate for the conditions, and the kinds of interventions that will be supportive and conducive to the needs of Papuan patients.

Chapter 2: Contextualizing Results and Collecting Data

There are five topics important to understand the results and the context of my research. I have titled these topics: Field Work Preparation; Field Site Introduction; Kathleen, the researcher; Field Site Experience; Data Collection, Field Site Tools, and Methods; and Data Analysis. These six sections will introduce the pertinent background information about the research site and the ways information was collected during fieldwork. This chapter will also introduce the circumstances and locations healthcare providers were working in during the time of this research. I begin with the language program I attended in Bali prior to conducting research in Wamena, Papua because it was an important aspect in the preparation of my fieldwork.

Field Work Preparation

Fieldwork began April 2010 in Bali, Indonesia, at a language training facility to prepare for research in Papua. These 4 weeks revolved around intensive language classes at the Indonesia Australia Language Foundation (IALF) in Denpasar, Bali. Prior to these classes, I had studied Indonesian for two years at the University of Victoria. In Bali, I lived with a Balinese family to facilitate language practice opportunities and language immersion. While I was in Bali, I met with Papuan students and established networks with them. My language skills improved considerably at this school.

The Indonesian language has local variations throughout the country. To prepare for the Indonesian spoken in Papua, I spent time with the Papuan students who were learning English at IALF. Together, we attended social events, church services, study sessions in the library, and shared meals. This was a mutually beneficial experience

where the students and I were able to help build each other's vocabularies while also improving pronunciation and grammar.



Figure 2: Networking with students in the cafeteria at IALF

Interactions with students at IALF made significant contributions to the success of my research. At IALF I learned common use of the language; many students found great enjoyment in teaching me slang and Papuan-style grammar that would be integral to fitting in and understanding conversational language in Wamena. These conversations were also introductions to Papuan culture, and we shared opinions about AIDS, stigma, and Papua. Equally important to the success of my fieldwork were the students who gave me names of family members living in Wamena. Two contacts in particular, Nona and Hana, became friends and I remained in touch with them throughout my fieldwork. (All of the people mentioned in this thesis have been given pseudonyms).

Nona is Papuan, from the coast. Nona holds a degree in law and aspires to continue her studies in an international context. Before coming to Denpasar, she worked with a Christian AIDS awareness organization in Wamena. She is a leader among her friends. Her friendship meant that I was accepted among the Papuan students at the school. She functioned as the gatekeeper for the close-knit group of Papuan students at IALF. Atkinson and Hammersley (2007, p. 27) define gatekeepers as people who have “control over key sources and avenues of opportunity.” This relationship facilitated greater access to important information about the research site (Hammersley & Atkinson, 2007). Nona made numerous phone calls before I arrived in Wamena to ready her family for my arrival. I practiced interview questions and discussed interview topics at length with Nona before leaving for Wamena. I used her experiences and opinions to help tailor my interviews and word choice to my audience. Common topics that I enlisted her help with were clarifying cultural practices, explanations of political issues, and religious practices, both animist and Christian.

Another key contact, Hana, is non Papuan and is originally from Sulawesi although she grew up in Papua. I met Hana in Denpasar and she returned to Wamena before I moved there. Her husband is an Indonesian journalist and they have two children, a girl and a boy. She works as a teacher at a local Christian school. Interactions with Hana provided useful insights into Indonesian and Papuan relations in Wamena, in particular the depth of racial tensions between Papuans and Indonesians.

Interactions with these two women and others at IALF were key to the success of my fieldwork because they taught me about local communication styles, current feelings and beliefs about issues of race and religion, as well as answering questions that only an

outsider would need to know. When I began 50 days of fieldwork in Wamena in May 2010, I found that my experiences and contacts in Denpasar, Bali, helped me to become quickly immersed in the community to make connections with the right people, and to fulfill the research goals in a considerably shorter time than if I had not had their help. It was important that I hit the ground running, and while Hana and Nona were not the only sources of information, their help continued throughout the whole of my research experience, and continued to impact my understanding and analysis of life in Wamena.

Field Site Introduction

Wamena is a unique city. My introduction to it began while waiting for the plane in Jayapura, the provincial capital. Wamena is only accessible by air. The people waiting for flights to Wamena were an eclectic group. The waiting room at the airport was packed with well-dressed, poorly dressed, luggage laden, and luggage-less people, Papuans and Indonesians alike. There were a few grubby European trekkers with guides, a pilot heading back into the mission field, and me, a researcher from a far away university, all waiting for a flight to Wamena.

Wamena is a frontier town 1,555 meters above sea level and has a reputation of being exotic and savage (see Kirsch, 2010). At first, I experienced a friendly, small town feel, but this soon disappeared as I became better acquainted with the city. I learned that many men hide large knives in their trousers for added protection,¹ and that it is not safe to be outside city limits after dark. The streets are dusty and potholes are plenty, making a ride on the local transportation of a *becak* (a bicycle with a carriage in place of handle

¹ One evening on my way home there was a man four meters away to the left of the road unbuttoning his pants. I quickly scanned my flight options when I realized he was just readjusting the giant knife he had down his pants. This experience confirmed the stories I had heard from nurses about similar observations regarding the discovery of knives during check-ups at the clinics.

bars) not for the fainthearted. Getting from point A to point B is a matter of dodging pedestrians, dogs, pigs, other *becaks*, vehicles, and potholes alike. I preferred to walk most places because it provided great opportunities to observe people living in and around Wamena.

The population of Wamena is composed of people from varying socioeconomic backgrounds. There are Indonesians who have come from other parts of Indonesia on business ventures or to occupy government posts, and increasingly, Indonesians who are born in Wamena. There are Papuans in the city who were born and raised in Wamena, and there are Papuans coming in from outlying villages for work, money, and education. There is also a significant population of foreign missionaries and pilots living in gated and guarded compounds and other places around Wamena. Their varied lifestyles meet in remarkable ways here: it was common to see Papuan men standing naked, except for the traditional penis gourd, otherwise known as a *koteka*, in an Internet café, and it is not uncommon to see a foreign missionary in a *koteka* participating in a pig roast.

The infrastructure of Wamena resembles the social relations of the community. I was surprised at the number of churches in the small town, and there were still more churches under construction. In addition to the churches were mosques, their presence made known with regular calls to prayer from faded speakers up high. The building tops along the main streets of the city had recently been changed to make the roofs look like the domes on mosques, a distinctly Indonesian symbol that does not resonate with the majority of Papuans. This caused resentment among some groups in the Christian community, as the majority of the stores are Indonesian owned and staffed, providing very little economic benefit to the Papuan population. It is quickly apparent to the

newcomer that the Indonesian population is significantly better off than the indigenous population, and that the indigenous Papuans resent this inequity. Figures 3 and 4 show the extreme differences in the workplace and types of goods being sold. Navigating the structural and inter racial relationships of Wamena was a constant part of my fieldwork experience as I negotiated the local clinics and healthcare providers working there.



Figure 3: Papuan women and children selling vegetables in the market



Figure 4: Indonesians working in the local grocery store

Key Sites

There are four clinics that I focused on for this project. These four sites were chosen because, according to the Jayawijaya AIDS Commission, *Komisi Penanggulangan AIDS Kabupaten Jayawijaya*, they are the only clinics in the area equipped with HIV testing and treatment facilities. All but one of the clinics is located within the city limits of Wamena. The other clinic is located in an area just outside of Wamena. The pseudonyms I am using for these four clinics are the Secondary Clinic, the Papuan Clinic, the Boundary Clinic², and the Main Clinic. All of the healthcare providers interviewed in this study worked at one of these four facilities.

Moving past clinic reputations and surface impressions of place and people took a considerable amount of preparation and diligence. I visited these clinics regularly to build

² The Boundary Clinic had recently lost its eligibility for government AIDS-funding due to their failure to meet service standards but I included this clinic because the nurses and doctor maintained that they were still treating and screening HIV/AIDS patients.

familiarity amongst the healthcare providers. The language training in Bali prior to fieldwork in Wamena created a number of opportunities that were integral to gaining access to the community but Dessi, a connection that was in place before leaving Canada, was a very important person in facilitating introductions and interactions with healthcare providers at these four health centres.

Dessi as Gatekeeper

I met Dessi in Jayapura before coming to Wamena. Dessi is Dr. Leslie Butt's former research assistant. Prior to my departure from Canada, Dr. Butt arranged for Dessi to facilitate the logistically complicated task of getting travel permits to go to Wamena. There are important documents needed to go to Wamena and Dessi arranged this, as well as my flight. Dessi's official work responsibilities were over once I arrived in Wamena but our friendship continued. I did not pay Dessi to work with me in an official capacity but we travelled together and ate together often. I predominantly paid for these events because I could but there were many occasions where she would not allow our friendship to be unequal in this area. While she was not a research assistant, her contributions through networking and friendship had a significant impact on this research.

Dessi is a highly capable Papuan nurse. She had worked in the local Papuan Clinic, and before that, she ran one of the medical wards at the local hospital. She is a devoted Christian and regularly challenges what being a Christian means for her actions and attitudes in context of her job, the foreign missionaries, and her roots as a Papuan from the Highlands. She is a widow but she does not speak of her husband's death and continues to grapple with the social expectations of her widowed status.

Dessi's possession of an Apple iPod (a personal music player and social organizer), given to her by one of her foreign friends, provides an example of the unique social position she holds (see figure 5). She was never amused when I teased her about being a "*city kid*," with her white headphones on show. She identifies personally with village-life and would often talk about her village as being a place she would like to return to, a "*more simple place*." Yet, her affinity for foreign music, the social networking site Facebook, technology, as well as her previous experiences living in Bali, distinguishes her from others in her job.



Figure 5: Dessi and I outside the city. Dessi is wearing her classic white iPod ear-buds.

Dessi was invaluable in Wamena, helping to introduce me to healthcare providers that I needed to interview. She was especially helpful with informants who were not easily approached, for example, older men and very busy professionals. She provided useful feedback with practice interviews, and her experiences and nursing expertise provided points of confirmation and caution in research findings.

As I discussed in the introduction, people living in Papua have many different traditions, beliefs, and expectations regarding social protocols. As a result, place of origin or tribe, also known as *suku*, is a significant aspect of social relations in Wamena. Under Dessi's influence, I lived and socialized mostly among a tight-knit group of Papuans who identified themselves as Christians from the highlands as opposed to Catholics from the valley. To compensate for this, I sought out some interviews specifically with Catholics from the valley and went out of my way to utilize other connections through other contacts who were not from the highlands.

Dessi was a double gatekeeper because she not only introduced me to healthcare providers, but she also made the decision of where I lived and at times, controlled other people's access to me. She was protective of me and liked to know how, when, and where I would be travelling in Wamena. There are two important aspects to the relationship between Dessi and I. The first is that I chose to involve her in my work because she was helpful and willing. The second is our close friendship allowed us to challenge each other's ideas, learn about each other's life experiences more than colleagues might, and have fun. These attributes were assets in the fieldwork. Our friendship also meant that I purposefully did not tell her everything I was doing because often, I did not believe my research activities concerned her. Gatekeeper relationships of this nature have the potential to drastically affect research goals because of the gatekeeper's power to limit and filter access (Reeves, 2010; Hammersley and Atkinson, 2007). While close connections with Dessi directed my interactions somewhat, the opportunities and insights made through her networks outweighed the limitations.

Dessi found me a place to live in Wamena. Before arriving in Wamena, I had planned to stay with some contacts I made through a friend. As the date of arrival drew near, I was told that I would be staying with a different family and that everything was taken care of in regards to my accommodations. This change again highlights the influence gatekeepers have on the researcher's experience. Dessi informed me that the change had been made because the people I initially planned to live with were people from the valley and valley people are "drunk people" (*orang mabuk*) who chew "betel nut" (*pinang*). In her opinion, the people from the valley did not have as strong a character as the Highlanders did. This small exchange highlights both her influence over my experiences, and how an association with a gatekeeper affects research and is filtered through the gatekeepers' personal feelings, networks, and motives as well (Reeves, 2010).

I lived with Mama N and Pak E. Mama N is a relative of Dessi's. Mama N and Pak E had been married for four years and did not have any children. The lack of children was an obvious strain on their relationship. Regardless, they were happy with the income that came with renting out their extra room. My room was just large enough for a bed and a small table. It was a noisy little spot between the living room and the kitchen. I ate breakfast, lunch, and dinner with whoever was living at the house at the time.

When I first arrived, communication was tough for reasons that highlight the potential problems facing nation-wide HIV education programs. Mama N and Pak E were away on business, so they had asked Mama N's father, Te Te, and a female friend to stay with me. It did not take long to realize Te Te and his friend did not speak any Indonesian. They only spoke the tribal language Walak. We struggled for a week with hand gestures

and feeble attempts to converse until Pak N arrived. Unfortunately he also did not speak Walak, he spoke Lani and Indonesian. Pak N could understand Walak, but he could not speak Walak, leaving their conversations to be rather one sided. This experience of multiple language barriers suggested that communication about HIV/AIDS education would be very difficult.

Mama N had many family members who were experiencing health issues and because Dessi was a part of the family and a nurse, there were numerous occasions where I was invited to accompany them as they checked on various ill family members. These experiences provided a look at healthcare outside of the government healthcare system, thus the connection facilitated a more thorough picture of health care and experiences of health outside the governmental and professional health structure in which I was conducting interviews. These experiences outside the specific research goals facilitated opportunities of triangulation and a context for the events and experiences I was seeing and hearing about in the specific research sites. Triangulation ensures that, whenever possible, information from one source is confirmed by two other sources (Hammersly and Atkinson, 2007). Embedded in the approach to ensuring that research results are credible is the researcher's role and contributions that cannot be separated from the methodological process of gathering data.

Kathleen, the Researcher

This project was my first time living in Indonesia but not my first time travelling and living with people from other cultures. In particular, I have spent time in Uganda, India, and Mongolia in communities grappling with the intersection of international and local ideals. In Wamena, my willingness to do and act as those around me helped me to

gain an acceptance that I had not anticipated. When the rains were too heavy for travel, I would sleep on the floor with the rest of the women in my age range. When we travelled, I would squish into the back of the truck with the sweet potatoes, travelers, and chickens. Most importantly, I ate the same food everyone else did. This act was important to one of my case study informants in particular, and she noted it as something that set me apart from other foreigners and allowed my hosts to relax more easily.

My experience as a practicing Christian, and my informants' awareness of this (I wore a small crucifix) were assets in the field. I have participated in Christian meetings and ceremonies in various western denominations and in non-western cultures in Africa, China and India so my understanding of the range of Christian traditions and faith-based world-views were beneficial in helping me see the various ways Papuan Christians approached religion and spirituality. I do not classify myself as either an insider or outsider on the topic of Christianity because experiences of religion are very different in different cultures. On this point, I am in agreement with Ganiel and Mitchell (2006) who write that, "religious identities of researchers and participants are better conceptualized as points on a continuum (on which they move or are moved by others throughout the research process)."

Many of the people I encountered felt more comfortable with me when they discovered I am a Christian. With these people, trust increased when I was able to actively participate in their faith-based activities, such as praying or attending church services. In general, people appeared to open up more readily when they felt a common ground about faith. I expect they also acted more naturally when I was present at Christian events or when Christian practices occurred at social events, because they

assumed that I had similar practices and traditions, and therefore would not be offended or judgmental. Many people I spoke with were surprised at my open-mindedness towards Protestant Christianity and Catholicism, believing that researchers, on principle, could not also have a faith.

For others, age, gender, and even mutual friendships were the relatable aspects (Ganiel and Mitchell, 2006; Hammersley and Atkinson, 2007). One male informant, around my age, found it easy to relate over stories of peer pressure, drinking alcohol, and friends doing stupid things. After discussing these topics at length, he seemed to realize that I was not trying to find out who was misbehaving, but just trying to understand what people do and under what circumstances. This put the young man at ease because he no longer felt he might be telling someone else's secrets. At other times, I also found my newly married status to be an asset because I could relate to both being married and dating. Those around me considered marriage to be an appropriate event for my age and stage of life. Many older women, and even some men, felt comfortable giving me advice about marriage and children.

Many of my connections were also influenced by my connection to Dr. Leslie Butt. This thesis is part of a larger project on stigma in Papua being funded through Dr. Butt's Social Sciences and Humanities Research Council grant. There was a stipulation within the funding to focus on an aspect of HIV/AIDS-related stigma in Papua and Dr. Butt was available for consulting on goals and results of this project in the latter half of the fieldwork section in Wamena. Initial contacts were facilitated through this relationship, but the specific thesis goals, relationships with participants, research activities, and findings in this thesis are my own.

Field Site Experience

Relying on my contacts, friendships, and communication skills, I was able to put people at ease. HIV/AIDS and stigma are sensitive issues because of the lifestyles associated with the disease (Herdt, 2001; Li Li et al., 2007; Dayte et al., 2006). Trust and genuine interactions with informants are integral to the researching of stigma because stigma is often hidden to the outsider (Herdt, 2001). The willingness of healthcare providers and community members to talk about stigma was integral to the data collection process and in this section I will show how I gained the trust of healthcare providers.

Impression management helps to build trust with contacts, which is a key aspect of fieldwork (Bernard, 2007; Charmaz, 2004; Elam and Fenton, 2003). However, balancing trust and safety can be a challenge in the locations where I was working. I was a small, 27-year-old woman travelling alone in a place I had never before visited. In every airport and dusty street there seemed to be groups of Indonesian men taking a greater interest in my presence than I was comfortable with. I often spotted cell phones placed strategically to snap a picture of me. With the help of a Papuan friend from Wamena, I chose conservative clothing in Bali that would be considered acceptable in a number of occasions. “Safety and not standing out” was a high priority in her opinion as well.

In interviews, the researcher must take every opportunity to build trust with the interviewee, who at times is a total stranger. If “trust or an emotional bond is established, a researcher—whatever their status—may be invited to come inside the respondent's world, and may be helped to cross pre-existing, imagined social boundaries” (Ganiel and Mitchell, 2006). To facilitate trust with people I wanted to interview, I would meet

people in groups or in casual situations before requesting an interview. Sometimes I would try to cross paths with them at church or through family members. Other times I would hang around the workplace so people would begin to recognize my face and hear about my intentions without any pressure. Building the necessary trust in this environment required a constant assessment of people, the surroundings, and myself.

Informants ranged in gender, age, ethnicity, and social status. Therefore, with different people I emphasized different aspects of my self to facilitate trust and environments conducive to sharing. Ganiel and Mitchell (2006, p. 8) refer to this idea as multiple identities, “gender, age, class /level of education, communal and national identities.” I relied on various identities throughout the fieldwork but the most common identities were, as a woman, a researcher, a wife, and a Christian.

Data collection, field site tools, and methods

Data collection took multiple forms. I used interviews, a stigma scale, photographs of AIDS information collateral, the physical accumulation of flyers and books, as well as personal notes of observations, experiences, and feelings in the field. Collateral is anything ranging from flyers and posters to educational videos. I used a number of methods in my collection of data in order to minimize the effect of my intermediate language skills on my research. Recording interviews and follow-up questions helped to minimize this issue. I also put considerable effort into being available to whomever wanted to speak with me. Openness created many networking and fascinating observation opportunities that I would have missed relying solely on pre-determined meetings and questionnaires. The following sections describe the specific methods I used to collect data.

Participant Observations

Participant observation was a useful tool for understanding values and cultural categories. It also helped to gain acceptance among participants (Bernard, 2006; Hammersley and Atkinson, 2007). To reflect decisions made in the ethics application I adhered to an ethical standard of not observing or interviewing ODHA. I observed nurses in their workplaces, but not while they were working with patients. Keeping the boundary between the patients and myself ensured their anonymity and avoided any scenarios where an association with the research project could compromise patient reputations with regards to HIV status. Maintaining ethical standards is important to produce useful and strong results (Elam & Fenton, 2003) and therefore respecting those seeking treatment and taking care to ensure the safety and good reputations of the people willing to work with me is important. I observed healthcare providers in public places, like churches as well as private places like the home. The goal of observing was to learn and to prepare myself to “intellectualize what [I’ve] seen and heard, put it into perspective, and write about it convincingly” (Bernard, 2006). I spent considerable time hanging around the common areas of clinics taking notes and checking out resources used in counselling sessions.

Participant observation allowed my presence to become familiar among healthcare providers. Using this method enabled me to learn about practices instead of only asking questions. I was able to show people I was eager to learn without being in the way. This method provided insight into the worker’s surroundings and the general feelings towards AIDS information in the clinic in the form of posters, flyers, and body language.

I chose to write during most interactions. Taking notes greatly increases recall of a conversation or how a person acts in certain circumstances. Fabian cautions the ethnographer to be aware of “the memory in contexts of recognition” so that the process of exploration is sharp and less affected by personal assumptions (1999, p. 51). If note taking was distracting for those involved, I would use the next available time to jot down my observations.

The Stigma Scale

The Stigma Scale is a questionnaire designed to detect stigma within healthcare providers. This questionnaire was adapted from Kalichman and Simbayi’s AIDS-related study in South Africa (2004). This questionnaire was translated into Indonesian and adapted for the healthcare providers in the study (see Appendix B for the original version in English or Appendix C for the Indonesian translation).

The purpose of administering the stigma scale is two fold. The stigma scale shows if stigma is present among health workers, and it shows which stigmatizing beliefs are more prominent than other beliefs. The Stigma Scale is made up of 15 questions intended to detect discriminatory beliefs about HIV positive people through true or false answers to statements about HIV-positive people.

The Stigma Scale was administered to twenty-eight people working in the healthcare system. The sample consists of nurses, counsellors, doctors, secretaries, front desk staff, including both Indonesian and Papuan healthcare providers. I made contact with the head doctor at each location and explained the Stigma Scale before I handed out the questionnaires. The scale was administered in all four clinics where I conducted research. In two of the four clinics, the doctor collected all of the questionnaires. In the

other two cases, I collected the questionnaires from each healthcare provider. I ensured that the majority of healthcare providers involved in front line work were included by regularly visiting the clinics and working with the doctors running the clinics.

The limitations of this tool are that some healthcare providers interpreted the questions differently and not everyone was able to clarify their questions with me because some healthcare providers took the Stigma Scales home to complete. Some of the questions caused healthcare providers to waffle on their answers as they felt some of the statements were true within the experiences of ODHA, but did not necessarily reflect their own thoughts. The results are interpreted as a general result of the healthcare provider sample and is not uniformly analyzed in association with each healthcare provider interviewed. The Stigma Scale shows general stigma trends and is used to support the findings in interviews and observations.³

Interviews

I conducted nine semi-structured interviews with healthcare providers. The criteria for selecting subjects were healthcare providers who:

- Had regular contact with people seeking medical HIV/AIDS care,
- Indonesian or Papuan descent,
- Had worked for at least a month in any of the four clinics in Wamena involved in AIDS care, and
- Had experienced contact with HIV/AIDS Industry rhetoric and/or HIV/AIDS patients in their work.

³ The use of the Stigma Scale was requested by Dr. Butt as an aspect of my research assistant responsibilities. I use it as supporting evidence for the interviews and observations, and for triangulation purposes. I have chosen not to use this Stigma Scale as a major aspect of this project because it did not integrate sufficiently into my presentation of research results.

The method of finding informants based on a specific set of criteria is called the purposive method and is efficient for finding people who are likely to be appropriate for the research topic (Lindlof & Taylor, 2002). I relied on this method using my own observations as well as suggestions and contacts from previous interviews in order to find healthcare providers that met this criteria. The interview sample is made up of six women and two men. Seven of the participants are Papuan and two are non-Papuan. The gender and racial makeup of the group is a result of the criteria that focused specifically on people working with HIV/AIDS. I asked a total of nine healthcare providers for interviews and all nine participants agreed to be interviewed and all nine participants were interviewed.

Interview results are an integral component of the data in this project. I used interviews to elicit feelings and perceptions about the role of the health worker in the HIV/AIDS epidemic and the existence of stigma. See Appendix A for the interview themes. Due to the socially sensitive nature of AIDS, it was important that confidentiality and consent be explained and stressed by the researcher (Legard, Keegan, & Ward, 2003). Before each interview began, I read and explained the project as well as the letter of consent to the interviewee. Ensuring consent is discussed before the interview and helps to create space for the interviewee to prepare for discussion about sensitive matters and affirms the expectation that the interviewer will ask sensitive questions (Elam & Fenton, 2003). The healthcare providers gave their signatures to confirm their participation and consent. Each healthcare provider was paid 100,000 rupiah (about \$10USD) for their time. I also provided snacks or a meal depending on the circumstances.

The semi-structured interviews took place wherever the participant felt comfortable. These locations ranged from cafés to offices to the airport tarmac. Semi-structured interviews were used in this project to increase the potential of gathering personal perspectives and values from the interviewee while allowing specific topics to be covered as well (Bernard, 2006).

The interview questions were generated based on themes of HIV/AIDS-related stigma that I had identified from scholars working in the area of stigma. I also created questions to explore their work experiences and how the healthcare providers saw themselves in their jobs. My goal was to encourage healthcare providers to speak about their experiences, their reasons for working in the area of HIV/AIDS, and their thoughts about HIV/AIDS-related stigma.

Recordings of the interviews were important because my Indonesian vocabulary is limited in some aspects. All interviews were recorded with permission, and all informants agreed that I could contact them if there was anything that needing clarification after listening to the recordings. Minor clarifications were required with four of the informants but I also spent a great deal of time outside of interviews with respondents to get to know their lives outside of the medical environment, and to spend time with them in that context.

Data Analysis

The interviews and field notes were coded and catalogued by using the computer program, MAXQDA. MAXQDA is a program specifically for qualitative textual analysis. Eight of the nine interviews recorded were transcribed and imported into MAXQDA. One of the interviews had too much background noise and was not used.

This program allows the researcher to compile responses by theme, enabling me to look at multiple reactions together rather than rely on a single subject's experiences.

The initial research goals revolved around themes of physical and verbal discrimination within the clinics and with patients. I found that most healthcare providers were aware of this discrimination but did not perceive these issues to be overly serious. The themes that did emerge out of my field research was the importance of religion and racial tensions. I have chosen to focus on these two issues because they were regularly referred to by healthcare providers as major influencing factors in their practices. While my pre-defined topics were probed in interviews, I found it important to follow issues that were presented by the interviewees (Charmaz, 2004). I did this to ensure I was covering aspects that the healthcare providers felt were important instead of imposing the topics I perceived to be important through literature research before I had entered the field. The following chapters first summarize patterns of stigma of healthcare providers and then I go on to discuss the roles Christianity and racial discrimination play in HIV/AIDS-related stigma in Wamena.

Chapter 3: “There’s no stigma here.” Stigma among Healthcare Providers in Wamena

The HIV Ward in Wamena, Papua

I walk into the hospital’s HIV ward, apprehensive; four Papuan men lay on cots. I’m unsure whether a nurse will question our reasons for coming or maybe even ask us to leave. This is my first visit to the ward. We have reluctantly acquired a chaperone, a nurse, who is unsure about our presence in the ward because we are clearly outsiders. There is an odd tension in the small dingy room, barely large enough for the four creaking beds. There are drops of blood on the floor and trays of untouched food sitting at the ends of the beds. The initial moments are particularly awkward, as the attending nurse is visibly conflicted on whether or not we can be trusted alone in the room. A shrivelled up man lay in the bed next to the window, his hands tied to the bed to keep him from removing a catheter, the bag of urine attached to him half full of murky urine and blood. Dried food and other stains decorated his faded black t-shirt. I became keenly aware of my queasy stomach. I speak with a different man in the middle of the room for some time. He appears healthier than the others do. If I had only visited this one room, I might think that low standards of cleanliness and care were standard in hospitals such as this. Unfortunately, I had just seen the maternity ward, immaculate and bright, with vases of fake flowers outside each room. Only about ten meters away yet the differences between the two were obvious: life and death. Only the men in the HIV ward were not yet dead.



Figure 6: A patient and Dessi in the HIV ward displaying open sores on the patient's body. Photo courtesy of Leslie Butt

Walking into the HIV Ward was one of those experiences that stuck with me well beyond the actual event. All the stories about stigma, AIDS, and working with patients I had heard previously were somehow disconnected from the experience of stigma I witnessed in that small room. The HIV Ward is where death happens for many HIV-positive people and it is a sad and disturbing site. The patients were poorly cared for: it is the culmination of stigma in Wamena. This experience led me to question even more the claim “there's is no stigma here” that I had heard over and over in interviews with healthcare providers, because in the hospital it was clear to me that some people received adequate care and others did not.

The denial of stigma that I heard in discussions with nurses, medical secretaries, caseworkers, counsellors, doctors, and pastors did not fit the scene I witnessed in the

hospital. The contradiction between what I heard and what I saw led me to look beyond the claims of healthcare providers. This chapter argues that healthcare providers in Wamena enact and perceive stigma in complex and subtle ways. In this chapter I describe the results of interviews and observations of healthcare providers and explore stigma to show there are several subtle and not so subtle ways healthcare workers actively stigmatize ODHA. Because it is subtle, stigma is often concealed and ignored in everyday discussions. I organize this chapter along the lines of what healthcare providers say versus what they actually do because this shows that stigma exists despite the sentiments expressed by many people.

In emphasizing say versus do, I am able to support Li et al.'s (2007) findings that show the ease with which people slip from what they think into actions. The connection of socially deviant behaviour with HIV/AIDS creates an environment where people easily, and lazily, attribute blame for HIV/AIDS to anyone with or suspected of having HIV/AIDS. Li et al. (2007) found that this association is especially relevant to healthcare providers in China because many patients felt they were being judged for inflicting HIV/AIDS upon themselves. They suggest that "HIV training and knowledge might not have a direct impact on provider's discriminatory behaviour at work but they can inversely influence providers' general prejudicial attitudes toward PLWHA [people living with HIV/AIDS]" (Li et al. p. 759). This finding is provocative because it suggests there may be other salient factors beyond the understanding of the virus and transmission that should be considered when addressing how healthcare providers understand stigma and stigmatize patients. In particular, my results show that healthcare providers appear to

respond affirmatively to the view that HIV/AIDS, as an illness or form of suffering, should be traceable to a source.

What Do Healthcare Workers Say about Stigma?

Healthcare providers refer to stigma as something that used to be in Wamena, but no longer existed. Returning to the quote in the title of this chapter, “We don’t have stigma here,” the idea that stigma does not exist is common. This statement was first relayed to me by a doctor in the office of the Main Clinic. A group of nurses, the secretary, the doctor, and myself were sitting around drinking tea and chatting about this project. The doctor clearly stated her opinion, “we don’t have stigma here,” and nobody contradicted her. On another occasion, I was preparing interview questions with Nona, the Papuan woman I met in Bali, and she criticized the inclusion of some interview questions based on her belief that nurses have already received stigma training. She said that people are no longer afraid to touch HIV-positive people and therefore stigma was no longer a serious issue. On yet another occasion, Dessi explained on a walk through town that stigma had not existed in Wamena since 2006. This date was repeated multiple times by other people but no one could tell me the reason why 2006 was a significant year for the end of stigma. The list of community members who believe stigma is no longer a problem is long. I now turn to how healthcare providers talk about stigma, showing how they distance themselves from any wrongdoing and participation in stigma.

Mantri Rian, an Indonesian nurse, clearly states that stigma is not the problem as much as ODHA themselves are the problem. He explained:

ODHA are scared because they are the problem, for me at least. I do not have a problem with stigma. Discrimination is not like that for me. The patient has a

problem of stigma because he doesn't know enough, even though there is enough information out there. Because of this, stigma is not the problem of nurses.

Mantri Rian is keenly aware of the problem of stigma, but he does not connect his actions as having any bearing on the patient's experience.

The role of patient fear in furthering stigma was emphasized by a local Papuan HIV educator who explained the threat HIV/AIDS poses to a member of this community: "When people get sick, they don't go to the hospital to be examined because they are ashamed. The community doesn't know about HIV/AIDS and they usually don't accept people who have HIV." Being accepted among family and the community is very important and this statement stresses the importance of healthcare providers respecting the confidentiality of patients in Wamena. The repercussions of confidentiality being broken are particularly pointed in small communities where anonymity is limited. In their own self-assessments, healthcare providers are not the instigators of stigma.

Another example where the stigma of the patient is identified but the actions of the healthcare provider are not considered was expressed by Suster Paskalina, a Papuan nurse working at the Main Clinic. I was waiting in the staff room of the clinic for an interview with Suster Paskalina and heard the following story upon her return. Suster Paskalina had a patient who believed he was sick and had HIV. The patient felt he had made some bad choices that led to his current sickness. Because he would not admit to being sexually active, Suster Paskalina refused to test the man for HIV. Instead, she mocked his knowledge of HIV/AIDS, his fears, and shared them with other healthcare providers around her. This example shows the patient internalizes fear about HIV and associates his own bad behaviour with it. More importantly, it shows the healthcare

provider broke confidence with the patient. This example shows the healthcare provider made light of the patient's fears without thinking much about her own actions, or the possible wider consequences of her actions. Suster Paskalina has a well-defined idea of the kind of person that will get HIV/AIDS and the kind of person who will not, and it has nothing to do with her actions.

There are two aspects worth highlighting in this example. The first is that Suster Paskalina refuses to test the man for HIV based on her pre-existing expectations of what an HIV positive person acts like. This is a stigmatizing act which links HIV to behaviour. The second is that she breaks patient confidence, a blatant stigmatizing and discriminatory action that can have serious repercussions for the patient. Herdt points out that the regulation of stigma has the potential to “degrade, dis-empower, and dislocate people” (Herdt, 2001). Both actions and assumptions made by Suster Paskalina support Herdt's observations. The pattern of a healthcare provider blaming patients, and not recognizing her own stigmatizing practices, is widespread. I explored aspects of this pattern of blaming patients, and other stigmatizing practices of health workers when I administered the modified stigma scale to twenty-eight healthcare providers (See table 1).

The results of the Stigma Scale show that healthcare providers do articulate stigma. However, some healthcare providers do not display stigmatizing values. The following table summarizes responses to statements about stigma. It shows that some health workers do not display stigmatizing values:

Table 1 Stigma scale statements that generated a low-stigma response among healthcare providers (n=28)

Statements about stigma	Agree	%	Disagree	%	N/A	Total %
People with HIV/AIDS cannot be allowed to work.	1	4	27	96	0	100
I don't want to become friends with people who have HIV/AIDS.	1	4	27	96	0	100
People who have HIV/AIDS must be accepted like regular people.	25	90	2	10	1	100
People with HIV/AIDS must be isolated.	3	11	24	86	1	100
People with HIV/AIDS can participate in social activities.	24	86	3	11	1	100
People with HIV/AIDS experience rejection from their friends.	3	11	24	86	1	100
People who have HIV/AIDS are dirty.	4	14	24	86	0	100
People who have HIV/AIDS are cursed.	4	14	24	86	0	100

My results show that many healthcare providers answered in a way that Kalichman and Simbayi understand not to be stigmatizing. For example, 90% of respondents agree that people with HIV/AIDS must be accepted like regular people and only 4% of respondents felt that HIV-positive people should not be allowed to work. These are positive results and show that, to a certain extent, healthcare providers as a group articulate non-stigmatizing beliefs about patients that run contrary to the assumption that there are high levels of stigma among healthcare workers.

However, the stigma scale also shows that a significant portion of healthcare providers harboured stigmatizing beliefs that may negatively affect ODHA. Table 2 shows statements which generated a high stigma response from healthcare providers. For

example, 86% of healthcare providers believe people who have HIV/AIDS should feel ashamed of themselves, and 61% of healthcare providers believed that HIV-positive people must accept boundaries on their behaviour. These statements resonated strongly amongst the group as a whole. A key finding of this study is that by using a scale that asks healthcare providers for their personal opinions about discriminatory behaviour, results show that a significant number of healthcare providers hold values that can stigmatize ODHA. If stigma eradication programs by NGOs were as successful as healthcare providers claim, there would be very few stigma-positive responses.

Table 2 Stigma scale statements that generated a high stigma response among healthcare providers (n=28)

Statements about stigma	Agree	%	Disagree	%	N/A	Total %
People who have HIV/AIDS should feel ashamed of themselves.	24	86	4	14	0	100
People who have HIV/AIDS must accept boundaries on their behaviour.	17	61	9	32	2	100
People who have HIV/AIDS experience discrimination with the family.	8	29	19	67	1	100
People with HIV/AIDS must have done something wrong and deserve to be punished.	6	21	22	79	0	100
People with HIV/AIDS are no longer respected by the community.	6	21	22	79	0	100
People who have HIV/AIDS experience violence.	5	19	22	79	1	100

According to survey responses, all healthcare providers articulated at least one stigmatizing statement at all four of the locations offering HIV screening in Wamena. At least one or more people out of twenty-eight participants harboured stigmatizing beliefs about all of the statements. Quite simply, stigma is evident, yet all respondents received

some level of training about stigma aspects of their job and therefore, it is surprising that not a single statement recorded a score of zero.

The percentages also show that only two of the high-stigma questions scored over 50%, and I show in the remaining sections that stigma is also enacted in subtle ways that are not necessarily detected in a scale like this. Significant numbers of healthcare providers did not have high rates of stigma according to the Stigma Scale. Out of twenty-eight people, only two people believed that ODHA should not be accepted like regular people. While this Stigma Scale does show that stigma exists, it also shows there were only a few questions that resonated strongly with specific beliefs held about ODHA in Wamena. This is possibly because the scale was created for broad international testing purposes and not tailored to the unique local practices of Papua. By looking at the specific questions that scored high for stigma, we see that stigma in those areas are high, but from the perspective of the whole scale, stigma is not as high as one might expect when contrasted with my observations. In the next section, I present examples of six actions that display subtle stigma. Some of the subtle forms of stigma revolve around issues of trust and confidentiality which can lead to gossip and slander, problems that are exacerbated by racial tensions in the healthcare system. Other examples are embedded in accepted Christian ways of living that are very similar to the expectations of being a good HIV/AIDS patient. Underlying all of them is a belief that acquiring HIV is the infected person's fault.

Six Stigmatizing Practices

In this section, I describe six stigmatizing behaviours that I either observed or heard about. According to a group of authors, stigma is “influenced by power dynamics

that serve to oppress the stigmatized and maintain social control over them through the use of restrictive, stereotyped or punitive beliefs” (Varas-Diaz et al., 2010, p. 297).

The first stigmatizing behaviour I observed was the violation of confidential interactions between the patient and healthcare provider. The role and expectation of the nurse masks the practice from being considered stigma. For example, I saw one nurse, after counselling a patient in the adjacent room, enter the general area of the clinic and discuss the habits of her patient in front of the secretary, another nurse, and myself sitting in the hallway. The two nurses then discussed the patient’s actions, their opinion of his actions, and how the whole session progressed. Another male nurse who witnessed the event assured me that in the medical profession, consults are very important and common, and the female nurses’ actions were not problematic because consulting was an expected practice. The term consult was key in justifying the conversations that took place. However, the healthcare providers did not see their actions as stigmatizing even though the content of the consult was comprised of mostly non-medical judgments, like his trepidation about being in the clinic and that he had already been to the clinic on multiple occasions.

Breaking the confidentiality of patients shows stigma because it shows a lack of respect for patients based on their HIV status. The use of the term ‘consult’ allowed the actions of the healthcare provider to be considered a legitimate practice within the healthcare environment, but what it did was excuse the exchange of personal information.

The second behaviour I observed was strong criticisms of patients based on medically unrelated topics. Nurses enforced medical punctuality on HIV-positive patients in order for the patient to gain access to treatment, but were not regular in their own work

attendance. Many healthcare providers only showed up to work when they felt like it because being paid is not contingent upon showing up for work. HIV/AIDS patients were dismissed by healthcare providers as bad patients based on assumptions about their inability to follow any medical regimen and for being associated with ‘bad walking’ (*jalan salah*). The phrase has connotations about acting in an incorrect manner or making bad choices.

The third behaviour was a disregard for patients in public areas outside of the medical community. I observed healthcare providers educating patients about medications in the doorways of clinics. While this behaviour was explained to me as acceptable behaviour I interpret it as stigmatizing because of the negative social repercussions to a patient deemed HIV-positive by the community.

In general, there was very little privacy awarded to patients. The windows between the waiting area and the counselling rooms were open, such that conversations inside the room could be heard outside the room. The head doctor at the Main Clinic and a member of the AIDS commission also confirmed that medical records of patients were very loosely kept. While these actions were considered fairly normal and benign practices within this environment, in terms of protecting patient privacy and rights, they are all very problematic. One doctor working at the Secondary Clinic described her interactions with the family of an HIV-positive man. She described how she rarely interacted with the HIV-positive man, only with his family. The potential for these practices to deter new patients is high and the danger of a patient’s personal medical history becoming public is high.

The fourth behaviour that exemplified stigmatizing practices was blaming patients for their predicament. For example, I had a discussion about the differences between treating Indonesians and Papuans with Mantri John. John is a Papuan healthcare provider working at the Main Clinic and he stated:

If the person is Papuan, it is much easier, he can receive good advice and respond to treatment, but Indonesians, they are very scared of stigma. If a Papuan person, no, no, no, no, they're not afraid of stigma, he is not afraid of discrimination. But if the person is Indonesian, he is very scared.

The conversation continues and Mantri John explains that the Indonesian person is difficult because he does not want to be open and the root of the Indonesian's secrecy was because "over there he often practiced gay sex, he has sex with men. He likes men."

This is an interesting example because the nurse explained the Indonesian man's unwillingness to be open because he feared stigma, yet within five minutes of the man leaving, the healthcare provider shared the whole story with me, stigmatizing the patient in the process and effectively confirming the patient's fears. Confidentiality between the nurse and patient was broken, but the nurse maintained that the fear held by most Indonesian patients was unfounded.

The previous example highlights another way healthcare providers stigmatize and talk about the transmission methods of HIV/AIDS. The transmission method of HIV is central to the construction of HIV/AIDS amongst healthcare providers in Wamena. Healthcare providers were able to rattle off the list of possible forms of transmission in very little time but this was also in conjunction with risky behaviour: "You get HIV from sex, that is first. You also get HIV from eating and drinking alcohol. Consuming like that,

later you will have HIV.” These are behaviours that are considered risky and are summed up with the term *jalan salah*, literally “wrong way,” which is commonly used to refer to negative life choices made by patients and people in general.

The fifth and sixth examples of stigmatizing behaviour are described through two case studies. These examples show health care providers make judgments about religious conduct, and they marginalize specific groups of people. The case studies will show in more detail the ways healthcare providers justify and explain their action in a way that stigmatizes their patients. The examples are subtle and show that there are boundaries set by the healthcare providers and the patient must fit into these boundaries in order to, in one example, not be looked down on, and in the other example, to gain access to condoms.

Case Study: “Together we must have faith in God, that is first”

Mantri Hendrik is a 49-year-old Papuan man who became a nurse in 1981. He is taller than most men, although significantly more gaunt. Dark circles under his eyes and salt and pepper hair round off his grandfather-like demeanour. He is married with four children, two boys and two girls. He is a Christian and attends church regularly. He decided to become a nurse when he was still in high school and prides himself on following through on his goal, neither changing job responsibilities nor location. He works in the Boundary Clinic. Mantri Hendrik’s house is in the city and he uses the clinic motorbike for personal transportation. A bad back has apparently slowed him down recently, although one would only know this by talking to him because I saw him all over town running various errands, just never at work.

Mantri Hendrik is the only nurse who deals with HIV patients at this clinic. Aside

from the doctor, he is the only person who has received training specific to diagnosing HIV-positive people and administering ARTs. His training has been predominantly in Wamena at special seminars that he could not remember sponsors or dates of. He travelled once to Jayapura for training.

Mantri Hendrik is a kind man who stands by his convictions. Every morning he follows the same routine. First, he wakes and washes, dresses, and then prays. Every morning before work, he believes it is very important to pray. He arrives at work for 8:15 because it is the busiest time for the clinic. This is what he said but I was never able to find him at the clinic at the time he said he went to work. Mantri Hendrik was hard to find after our initial meeting, and it took another week or two before I could track him down for some follow-up questions.

Mantri Hendrik's convictions and adherence to social expectations are noteworthy. It became clear over the course of our interview that I was living with some of his relatives. He came over for a social call, and within 20 minutes, was probing my hosts on the topic of children and why my hosts did not yet have any. The meeting took on a new level of seriousness when he instructed my hosts that there needed to be a family meeting to decide what would be done about their lack of children. The roles and expectations within the family and his right to act in a forthcoming matter appeared very important to Mantri Hendrik and he attempted to exert his medical status as a reason to influence the practices of the family.

Mantri Hendrik showed the highest score on the stigma scale of all the respondents. Out of fourteen questions, he gave thirteen stigmatizing answers. He was the only respondent to say he did not want to be friends with an HIV-positive person and that

HIV-positive people should not be allowed to work. He is also the oldest nurse to be interviewed for this project.

Taking his expertise and knowledge of local customs into consideration, Mantri Hendrik takes advantage of his dealings at work to support his identity as a devout Christian in the community. The knowledge he has acquired from training and working in the health sector has enabled him to stand by his Christian convictions even more strongly, as from his perspective, HIV/AIDS is a direct correlate of un-Christian behaviour. This case study has shown that Mantri Hendrick focuses more closely on Christian ideals than HIV/AIDS knowledge and expertise, and he stigmatizes people who do not adhere to these values. These correlations between Christianity and health will be explored in detail in the following chapter.

In contrast to Hendrik, who frames his actions and expectations of patients using Christianity, the final case study, Mantri John, reinforces subtle stigmatizing patterns through his understanding of risk populations. Mantri John's case is important because it highlights how stigma is subtle and not necessarily connected to persons with HIV.

Case Study: Mantri John and Marginal Populations

The sixth example revolves around Mantri John who is a plump 45-year-old Papuan man. His regular attire for work is a white nursing uniform with sweat stains around the neck. His teeth are stained from years of chewing betel nut and his hair is greying. He comes across as a slippery fellow, as he would often suggest times to meet but would rarely show up. Mantri John was an unsettling man and he gave off the feeling he was always jockeying for something. He is not a shy man and speaks harshly of Indonesian homosexual men, berating them for not being more open in counselling

sessions. He identifies himself as Catholic and attends church on a regular basis.

He grew up in Wamena, becoming a nurse in 1989. At a young age, he did not want to work as a nurse but his parents did not give him a choice. Their opinion was: “you enter nursing school so that you can serve people.” Mantri John appreciates the prestige that his job affords him. He points out that many people come to the clinic looking for him and calling his name. He is referring to people he has met as patients but also people from previous training courses.

Mantri John helps distribute condoms in the community by taking them to the places women sell sex. He took pride in his proactive behaviour and condoning of condoms. It was surprising to hear that while the condoms he distributes are free, he charges gas money to the women. He believes this is a fair deal because he is helping them:

I usually supply condoms to street kids and the commercial sex workers that work in the shops. If they are out of condoms, they call me and I drop them off. I drop them off sometimes just because I have the motorcycle. They can always service people so they have money, surely they have money, I must ask for gas money. It's not like that, but I must ask for money maybe one or two litres of gas. They have to pay for the service.

As he told this story, he began to back peddle in his prices, how much gas it took, and how often he charged. Mantri John spoke of many instances where he would provide services outside the clinic for various fees. Sometimes, he meets people at the bus station with their medications or in a hotel if they are sick.

Mantri John focused on opportunities that emerged from his job and the social

connections that were important to him. His behaviour was both helping and at other times, like the example of the condoms, a little questionable, especially with his assumption that sex workers always have money. The role of prevention in his job allowed him to benefit financially. In his mind, his beliefs about commercial sex workers justified his behaviour. The relevance to stigma is that he has access to resources that would help the women to guard against HIV. He is the gatekeeper to condoms and possibly other medical resources. He could provide condoms free of charge, as he is supposed to, but he charges money. In making condoms expensive, he further marginalizes an already marginalized population, commercial sex workers, and takes advantage of them under the auspice of HIV/AIDS prevention. He can do this because sex workers are already marginalized in the community. Even though he claims to be an advocate, his actions subtly reinforce the stigma of sex workers.

Assessment

This chapter has shown that contrary to healthcare providers claims about the absence of stigma, stigma is present in areas that are not directly and overtly associated with HIV/AIDS and the healthcare system. Stigma is expressed in specific actions and values, but often in a subtle manner. I have shown that stigmatizing practices emerge in the assumptions of healthcare providers and in the relaxed approach to medical protocols like confidentiality in general. Judgments about patients were primarily about expectations of moral behaviour. The practices that were highlighted and led to stigma by healthcare providers were focused more around ideas about being good Christians, the blaming of patients, and shortcomings attributed to race. In Wamena, community ideals

and medical practices are converging to create a very complex system of stigma that is predicated upon multiple belief structures.

In sum, while healthcare providers do appear to be conscientious and caring overall, their claims to be stigma-free are not justified. One of the dominant issues that they raised was the impact of Christianity on HIV/AIDS and morality. In the next chapter, I focus on Christianity and its intersections with medical care in order to show that dominant stigmatizing beliefs are concealed within a mutually reinforcing relationship that shifts stigma from being focused on HIV/AIDS to being focused on the patient's ability to fit within the confines of Christian morals and HIV/AIDS treatment goals.

Chapter 4: The Bond of Medical and Religious Values

Religion and HIV/AIDS

Things are always changing in Wamena. One minute we are heading out for a nice leisurely walk in the sunshine, and the next minute I am tucked away from prying eyes and the sudden downpour, watching chicken organs being dissected and scrutinized. A family had gathered in the small, dingy kitchen. It was an unfortunate time; a very close family member was sick. Old age had something to do with his distress, but the sudden worsening of his condition left uncertainty as to the family's options. The first step had been for a family member, who in this case happened to be a respected nurse, to go to his village and retrieve the sick man who was now poring over chicken pieces with his son. They had brought the chicken along to perform a ritual with the hope of discovering the true nature of the sick man's ailments. Before the beheaded chicken died, the man spoke aloud to God saying, "if you kill the chicken now, I will take this as a sign that I will not seek medical treatment and cost my family any more money." With the head already chopped off, the chicken eventually died and the feathers were removed. They cut the chicken open and discovered that both the man's heart and the chicken's heart were slightly too far to the left. The heart of the sick man was discovered to be to the left by the nurse listening intently with her ear to his chest. The blood appeared to be thickening in the chicken and therefore was interpreted to mean the blood was not circulating as it should have been to the old man's heart. The old man's unorthodox heartbeat was taken as proof of this. After witnessing the event, I was asked not to tell anyone by my friend, the nurse, about the incident. As a nurse, she didn't want to be seen believing in using chickens as a diagnostic tool for human sickness. Also, the family as

Christians, were not supposed to practice or believe in such rituals.

Religion in Papua is complex. Adogame argues that religion is important to the experience of HIV/AIDS, and that there is not enough focus on the “complexity of religious world views” in the discussion of HIV/AIDS (2007. p. 476). While Islam and Christianity dominate official religious debates in Papua, religious syncretism is a part of everyday life, including healing (Warta, 2010). Warta explains that as Christianity was introduced in Papua, and rather than replace the existing belief structures, Christianity merged with the existing structures. As the above example shows, the sick grandfather seeks answers about his illness using a traditional ritual, but also incorporates Christianity and God to influence the process of interpreting what happened in the ritual. Also, the nurse, a devout Christian, is present because of her expertise in biological matters, but she is also using her medical expertise grounded in biomedical training about the human body to interpret a traditional ritual involving a chicken.

Religion is often utilized as a way to understand the world and to make sense of things such as illness or suffering (Eves, 2003). For Papua in particular, Christianity is a significant factor in making sense of the AIDS epidemic and defining boundaries of social mores and activities (Butt and Eves, 2008) and therefore is integral to the discussion of the complexity of stigma (King, 2002). The role of religion in making sense of events positions religion very close to the topic of health as people try to cope with what can often be scary circumstances.

Some scholars have argued that introducing Christianity, in Papua, was perceived by the colonizer as a strategy to cleanse bad behaviours in the local community (Rutherford, 2002. p. 197). This emphasis is on the political uses of Christianity and is

not well liked by indigenous Christian Papuans or accepted by everyone who hears this opinion. Sitting in the common area of IALF in Bali, four young Papuan men spoke very passionately against this simplification of their beliefs. The consensus among the men was that because God can speak their local dialects and knows their language, they know God is from Papua and is not a foreigner's God.

Many of my contacts in Wamena expressed that the only way to convey important information to large numbers of people was through the church and with the help of pastors. This suggestion by indigenous Papuans and local Indonesians supports the claim that the church is both relevant and respected among many Papuans. Furthermore, the Christian church is one of few resources already set up to help combat the AIDS epidemic in Wamena. Alternately, Herdt (2001) stresses that the way stigma is regulated "leads us to examine secrecy and shame, contradictory beliefs, disagreement between communities, and the denial of rights to the stigmatized by other actors." This chapter will explore these areas and the extent to which Christianity affects practices of healthcare providers around stigma of ODHA. What is seen is a blurring of medical and religious morals in Wamena.

Religion is also important to Papuan identity (Warta, 2010). Christianity serves as a rallying point about inequality experienced by Papuans (King, 2002, pg. 100). Rutherford observed that in Papua "Christianity became equated with modernity" (2002, p. 197). All of these aspects contribute to the unique Papuan identity that Christianity supports and symbolizes in Wamena.

Religion as an identity is not unique to Papuans and can be seen all over Indonesia. Every person registered with the government must have a religious

designation on his or her identity card. The religious designation helps to create smaller communities and support networks. Religion, in this sense, reaches beyond the canons of the various religions and into social and political realms as well. The reason religion helps to create that bond is because community loyalties grow from religious networks as well as religious networks grow out of community loyalties. The shared belief of the religion creates a basis for relationships. Kirsch (2010) argues that Christianity among West Papuans is used as a tool to differentiate themselves from Indonesians who are generally perceived as Muslim. Christianity is an important marker that separates the Papuans from the Indonesians. Christianity is not solely the religion of Papuans, but I only saw one Papuan Muslim woman and this was not well received among my Papuan friends. There were a significant number of Indonesians who practiced Christianity in Wamena and therefore within the Christian population in Wamena there are varying degrees of Christianity as a Papuan identity but, nevertheless, is still a Papuan identity marker and every indigenous Papuan healthcare provider identified as Christian.

There is considerable evidence in academic literature suggesting that religion affects how healthcare providers see their relationships with ODHA. Varas-Diaz et al. (2010) found that the social dynamic of religion in Brazil is important to understand social factors embedded in stigma which, at times, can encourage stigma among healthcare workers. Christianity was a motivating factor for healthcare providers to treat people in need. Christian beliefs encouraged healthcare providers to treat people that others would not touch or treat. Christianity can affect stigma from both a judgmental stance and a compassionate stance, two ideas that will be discussed further in this chapter.

This chapter argues that the impact of Christianity on stigma among healthcare providers takes two dominant forms. First, healthcare providers regulate HIV treatment based on adherence to Christian morals. Second, healthcare providers associate the behaviour of ODHA with the patient's merits as a Christian. In describing and discussing these two points, I argue that some stigma practices and beliefs are hidden because Christianity, as the dominant belief structure, acts as a filter to explain and cope with poor resources and patients.

This chapter is laid out as follows. In the first section, I describe expectations of behaviour connected to Christianity, and I show that the goals connected to health mandates are blurred. Within the blurred relationship, stigma is concealed because it is embedded in the structures used to explain the circumstances of being sick and suffering. Evidence for this section will come from ethnographic observations, interviews and two case studies. In the next section, I show how healthcare providers use Christian models to judge ODHA, in particular, how they describe ODHA as people who have turned away from God. This second section will revolve around the case study of Suster Nari. Suster Nari associates ODHA and sin, which allows for strong and stigmatizing judgments.

Blurring the Boundaries: Christian Morals and Medical Goals Intertwined

In Wamena, Christian beliefs are used to explain and make sense of HIV/AIDS. This quote is from a local Christian organization's information booklet titled *Do You Know About AIDS?*: "The only 'medicine' to prevent HIV and AIDS is to stay pure before marriage and stay faithful after marriage." This statement is generally representative of healthcare provider sentiments and shows the strong connection between Christian morals and health. The message of abstinence and monogamy are

common to the Christian church and HIV/AIDS protection campaigns but they are utilized by each for different purposes. The message supports the Christian moral expectation and also supports the health care goal of fewer opportunities for HIV transmission. The Christian message and the health care goal mutually reinforce ideals about acceptable and healthy behaviour in the face of HIV/AIDS. While some of these messages are supportive and educational, others alienate people.

Christianity and medicine are intertwined throughout Wamena. The two churches I attended always had a sermon or allotted time for prayer to address HIV/AIDS in their community. Sometimes this would be done by a pastor and other times by a church member sharing a personal warning or experience about HIV. Other examples where medicine and Christianity intersect are HIV educational sessions for youth paired with after church activities. One church put on a large open-air rally to educate locals living around the church about HIV. The churches that were willing to address HIV appeared to be the most vocal organizations in town.

Many HIV/AIDS organizations in Wamena were connected to a church in some way. Many healthcare providers and community members insisted that the only way to convey important information about HIV/AIDS was through churches because the churches are the main venues where large groups of people gather. HIV/AIDS educational and treatment organizations were often funded and supported by some of the churches. The clearest example of church funding in initiatives is the Papuan Clinic. This clinic is run by a local Christian denomination and financially supported by a foreign Christian church organization. The pairing of Christian organizations and medical goals brings foreign missionaries specifically working in the area of HIV/AIDS.

Access to treatment in Wamena is another area of HIV/AIDS care that shows the pairing of Christian morals and medical goals. The decision of whether or not a patient can have access to anti-retroviral drugs is predominantly up to the healthcare providers. Regulation of medication is important because patients are subjected to a trial run with Tuberculosis (TB) medications and sexually transmitted infections (STI) medications before they are put on anti-retroviral therapies (ARTs). The reason for closely regulating access to ARTs was said to be the high cost of anti-retroviral drugs. The government does not want to pay for people who will not be good patients because they see the investment as a waste of money and resources. The cost-saving mentality is clear and understandable, but the actual choice of who will reliably take the medication is predominantly left in the hands of healthcare providers. Consequently, the decision for who can receive treatment is a place where personal bias is very involved with the treatment process.

The boundary of Christian morals is blurred with medical justifications of treatment protocols when the healthcare provider maintains a personal bias that does not always conform to the biomedical bias that is inherent in the treatment. Within social circles, conversations with doctors, and among nurses, I was told that only certain people are given access to ARTs. Before access is granted, there are set stages a patient must pass through. The following case study will illustrate how personality, religious beliefs, and prioritizing of personal behaviour in assessments is involved in this process.

Case Study: Lia and Anger Towards Patients

Figure 7: Lia, HIV/AIDS counselor.

Her clothing and crucifix are symbols reflecting her Christian beliefs.

Lia is a lot of fun. She is 24 years old, loves to drive fast, and always seemed to be on a different motorbike, borrowing them from various family members and friends. She is short and slightly overweight with a tough demeanour. She does not like to back down either. One night a couple of men on a motorbike drove past us and tried to slap my buttocks and within seconds she was yelling and ready to throw rocks at them. She is not a stranger to taking risks or challenging ideas and expectations in the community. She attends church regularly and lives with her brother who is an important pastor in the community. Family is very important to Lia. She looks after her niece and nephews as if they were her own and appears to have a great sense of joy when she is hanging out with them.

Lia often framed the stories of her past to imply that she was becoming a better Christian. There are rumours among family and friends about her past drinking days but she referenced the loss of a dear friend as giving her cause to think about her future and the need to alter her social activities in light of her friend's death. While she had made significant changes to her social activities, she liked to reserve certain holidays for secret parties with friends in nearby cities. To ensure no one found out about her escapades or that she accidentally come into contact with a family member or friend while intoxicated, she would create an elaborate story of visiting family and then stay with friends from there. Lia kept many secrets and even though she knew young people all over were acting in similar ways, she did not want any of her relatives to know she was just like everyone else.

Lia works at the Papuan Clinic as a counsellor. Looking at Lia as a whole person, we can see multiple influences affecting the way she interacts with patients as well as the expectations she places on patients. Lia feels that she was initially tricked into her job. She explains how she became involved in the clinic like this:

Dessi always encouraged me saying that I must work at the clinic, "you must work there with me!" she would say, but Dessi tricked me. She said, "you will work in the laboratory today" so I came to work and I was very quiet. I was shocked because when I arrived Dessi said "this is your boss, Nadia." So, I followed Nadia who did not work in the laboratory. The patients entered the clinic and then the examination room where Nadia asked them questions. She spoke about HIV and the people outside the clinic. I was not expecting to work with HIV patients so I spoke to Nadia saying, "Nadia I am working with HIV/AIDS

patients but I don't want to." I became very angry with Dessi and Nadia. I said to them "why did you trick me? I do not like to work with people with diseases, this is not what I want!" After some time, they said a lot of encouraging things to me and I began to learn and follow the expectations of the job. Eventually I came to the realization that I must work here. That is how it happened.

Lia later explained that she felt, in retrospect, that being tricked into her job was a good thing and if not for their "trickery," she would not be in this job that she enjoys. Lia appeared to rationalize this job through her beliefs and believing God had a hand in the process that enables her to be happy in her job:

It is not other people that make me who I am and challenge me, but according to my beliefs, I must help and assist people with what they need. Before I did not like this job but now, I am happy working with ODHA, assisting ODHA, and helping ODHA. I am very happy with these circumstances because I think if I don't help now, when will I have another opportunity to help. I can do all of this with one God, Jesus, helping me and guarding me.

Lia was often exasperated with the circumstances of HIV in her community. She could easily become exasperated with people and circumstances. When I asked Lia if she ever gets frustrated with her patients, this is what she replied:

Yes I get frustrated, especially when we have already explained to the HIV positive husband that when he goes home he will eventually pass the virus to his wife. It might be when they sleep or when they are eating. We want to be able to give the knowledge about HIV to the wife, or maybe she could come into the

clinic and have an examination with the husband to learn about the disease. Sometimes, the men are not honest with their wives. They want to come alone for their medicine. In some cases, maybe the wife is already sick but because she never comes in with her husband who is HIV positive, she thinks she is sick with a regular sickness. This kind of behaviour I am very angry about, and I say “Aduh!” this is not good. It is even more harmful to the families of these men. If the husband loves his wife, he should not do this to his wife. This is a difficult problem in Wamena. I am so angry about it and on top of all this, the man usually forgets to take his medicine so I become angrier with him. Nevertheless, what can we do? People don’t have watches, taking medicine on time is very difficult here, and you need a watch for ARTs and maybe for prophylaxis as well. Whatever! If ARTs are what must be used for HIV, almost all the people in Wamena don’t have watches and so the whole situation is very difficult.

Lia’s comments are passionate and emerge from considerable experience working with patients and trying to convince patients to follow protocols and best practice routines. The expectations she places on the patient regarding protocols and best practices revolve around the man’s personal life more than the medical goals. She views the medical protocols to be insufficient, leaving the patient’s behaviour as the only topic she can really address. Lia has already stated that her expectations of behaviour identify strongly with Christian morals. She expects that the men should take care of their wives and to display love towards his wife in the maintenance of her health. This example again shows the blurring of medical goals and Christian morals in interpersonal relations with patients in an attempt to try and help the wife. Lia judges the man based on her

expectations that this man lead a life that conforms with her Christian expectations. Not only is she frustrated with the man but also she is frustrated with the current system and the futile nature of enforcing such expectations.

This case study shows the varying beliefs and attitudes that sway the opinions of Lia. In some circumstances, she utilizes her Christian beliefs to understand her situations and actions, but in other instances, she acts in ways contrary to her Christian beliefs. The same seems to happen with how she treats her patients. There does not seem to be one particular influence, like her faith or her biomedical knowledge, that guides her decisions any more than the other. There is clearly a mixture of motives and concerns, which influence Lia's actions.

Another place where I noticed an association between religion and medical values was a regular focus on alcohol consumption in patients. This area of a patient's life seemed to be more accessible to the healthcare providers than treatment regimes, and they were quick to judge on this basis.

Healthcare Providers Fixate on Alcohol Consumption

The importance of specific influences varies depending upon the people involved. For some alcohol is a much larger issue than it is for others. Alcohol is a substance that is spoken about regularly in conjunction with HIV/AIDS. On one of my visits to the Secondary Clinic, I sat down with Suster Debi for clarifications regarding our first interview. The sun was shining brightly and she chose the front steps of the building next to the clinic to have our discussion. She was not trying to hide from the clinic in any way but seemed to desire some distance from the many patients sitting outside waiting for various medications. On this specific day, I was curious about the treatment process for

patients. Suster Debi kindly explained that healthcare providers conduct trial runs with patients using TB medication or other STI treatments. If the patient could stop drinking alcohol and successfully deal with either their TB or STIs, they would be moved to the next stage of treatment.

Alcohol use was a topic that some healthcare providers specifically looked out for in patients and alcohol use was an important church topic in association with HIV/AIDS warnings. Regulation of HIV/AIDS supports moral claims that both affect the perception of HIV/AIDS and the moral standing of the person with HIV/AIDS. One worker said: “Here, they can get HIV because of sex and they can do random sex because of alcohol.” This quote from a healthcare provider shows that alcohol is understood as an enabling factor. In another quote, a healthcare provider shows alcohol as a source of HIV/AIDS: “firstly, HIV comes from sex, then, you get HIV from eating and from drinking alcohol.” The strong association of HIV/AIDS to alcohol shows that Christian morals affect healthcare provider notions of HIV/AIDS risks and for some healthcare providers, the line becomes so blurred, alcohol becomes a cause of HIV/AIDS. Suster Uut, another healthcare provider working in the same clinic, later elaborated on this idea, explaining that in Wamena they did not have access to tertiary level ARTs. Therefore, judging the dependability of the patient was very important and was justified by the medical risks of treatment failure.

Seeing alcohol consumption as a mark of poor patient dependability pertains more to Christian morals, than it does serious risk factor for HIV/AIDS. Their comments were part of a larger discourse. Alcohol was a common point of discussion for healthcare providers and not drinking alcohol was included in some of the job expectations. For

example, to work at the Papuan Clinic, staff were not allowed to smoke, chew betel nut, or drink alcohol. In other clinics, healthcare providers were allowed to chew betel nut and smoke. Drinking alcohol however, is still not considered acceptable behaviour.

For health care providers, alcohol and AIDS are often paired together in conjunction with avoiding HIV/AIDS within the wider community. The expectation of sobriety found in opinions of healthcare providers is echoed in church sermons. On one occasion at a Sunday church service I attended, a government official was speaking about recent HIV/AIDS findings in Wamena. The sermon revolved around some Indonesian men making illegal alcohol. This story was told as a warning both against the ills introduced by Indonesians but also the association of alcohol with HIV/AIDS. This example shows HIV/AIDS is being mixed with Christian moral warnings that are not directly connected to the HIV virus.

The pairing of HIV/AIDS with behaviour and Indonesian bootleggers not condoned by the church shows how HIV/AIDS-related stigma is consistently strengthened in subtle ways by being linked to behaviours such as alcohol consumption. The threat of the virus is used to influence community and individual adherence to Christian morals. The following case study builds on this pattern of mixing Christian and medical morals, showing how hard it is in the local context to separate religion from beliefs around HIV.

Sometimes the Medicine is Lost Altogether

The final example I will use to support the claim that Christian morals and medical morals are blurred comes from an HIV/AIDS educational session I attended. The session was conducted in a village just outside of Wamena and was organized by Pastor

Oli, who is part of the leadership staff of this Christian education organization. Attendees for this session were mostly women and children but some teenagers and a few male young adults also attended. The session consisted of skits, stories, and a movie.

The skits and stories revolved around the transmission of HIV. The main skit of the night explained HIV/AIDS at the level of the virus. The actors apologized through a translator before the skit began because the young people doing the skit could not speak the local dialect. The skit was specifically about how the HIV virus attaches to white blood cells and the resulting symptoms that eventually result in AIDS. The HIV virus was symbolized by a man in a crocodile hat while the other actors had different illnesses written on their hats. At the end of the skit, all the symptoms (symbolized by the actors) overpower the man and he dies. The message conveyed in this skit about the immediacy of death has the potential to obscure information about the actual timeline of HIV/AIDS and perpetuate stigma through the fear of sudden death caused by HIV-positive people.

Prior to this session, I had been told the Christian organization uses a movie about a young Papuan couple who die of AIDS to teach people about the risks of HIV/AIDS. I had watched the movie, *Tanius and Demina* (Tangan Peduli & Netaken, unknown), and noted that the content covers HIV risk, relationships, openness with family, focusing on God as a source of strength, and the progression of HIV/AIDS. The movie they played this night was not this movie about HIV/AIDS. Instead, it was a movie in English called *The Ten Commandments*, produced in 1956 and starring Charlton Heston. This was an interesting movie choice given that this was an information session about HIV/AIDS, no one spoke English, and most people were not able to read the Indonesian subtitles. Choosing to use the movie *The Ten Commandments* over the movie *Tanius and Demina*,

kept the Christian content of the event but cut out the content about HIV/AIDS.

HIV/AIDS content was secondary to the religious content. There is a quote on the movie case of *Tanius and Demina*, which sums up this approach “Total repentance to prevent total death.” The HIV/AIDS education approach is focused on Christian adherence, and skirts the issue of HIV/AIDS and transmission. Pairing the two concepts of HIV/AIDS education and Christianity was expected and praised as an important tool by the organization and the village elders, but in the end, Christianity was the dominant message communicated to the audience.

Maintaining Christian Beliefs in Medical Advice

The previous section showed the blurring between Christian moral expectations and medical goals. This section is a continuation of the themes noted above but looks more closely at daily practices and beliefs in action. I will show that in some cases the maintenance of morals, both medical and Christian, are being understood in terms of good Christians and bad Christians. Eves (2003) observed among a group of Apocalyptic Christians in Papua New Guinea that AIDS was understood as a way to distinguish good Christians from bad Christians, and encouraged the idea that only bad Christians can get AIDS. The following examples show similar patterns and how medical goals and Christian morals work together to strengthen ideas about good and bad patients.

To illustrate the connection of HIV/AIDS to bad Christians I will first draw from an interview with Mantri Hendrik. Of all my respondents, he displayed the most unwavering opinion of how people should be acting in their personal lives. This particular interview took place in a small, sparsely furnished room inside the Boundary Clinic. Mantri Hendrik was probably the most excited person to be interviewed and

frequently took my hands in his, shaking them vigorously to convey his gratitude towards my interest in this subject matter. At the point in the interview I am using, I was probing for stories about how he dealt with possible HIV positive patients when they would come to see him. In the following quote, Mantri Hendrik explains how ODHA must act after receiving a positive result in a HIV test:

Ah, one thing is that it is not okay to have sex. It is not okay for ODHA to do whatever they want, they must believe in themselves and return to God with their wife.

If we think only about medicine, there isn't enough HIV medicine. We check everywhere and there isn't enough medicine. There just isn't enough medicine so the one thing we can do for that person we can't do. Only with faith in God, that is first.

The husband and wife did not stop sinning. They did not stop their sexual relation. As a result, their baby began to cough eventually becoming infected with HIV. This is not ok. Ah! Today, in the name of Jesus, a new curse has come.

Mantri Hendrik associates the HIV positive status of the ODHA as a consequence of turning from God, as is implied by the expectation that the person needs to "return to God." He has an expectation of what the patient is permitted to participate in, or in this case not participate in, and he stresses that the patient's only option is to return to God, never to have sex again. This statement implies fault, which under some circumstances could lead to greater judgments or discrimination by healthcare providers.

For some healthcare providers, the association of HIV/AIDS and bad behaviour is a reason to preach and reach out to patients through Christianity. Suster Nari takes this approach, and I discuss Suster Nari's Christian motives and goals in the following case study.

Case Study: Suster Nari Preaches Compassion



Figure 8: Suster Nari wearing her Papuan Clinic uniform

Suster Nari is very focused and efficient but in a relaxed way. During the week, she runs the Papuan Clinic. She wears her hair pulled back tightly in a bun and has a warm smile. She is a sweet, short woman who easily makes others comfortable in her presence. Her laugh is contagious and nothing beats her hugs. She has three children, two boys and a girl, and a husband who is heavily involved in the church. Her job never

seems to end. On average, she cooks dinner for eight or more people every day and is usually the last to eat. One evening at her house, she made chicken and yams for everyone only to have her youngest son burst into a tantrum because he was not eating instant noodles for dinner. It never took long for Suster Nari to crumble at the requests of her son. The instant noodles were prepared for the boy and calm returned to the household. She doted on her children with an endless store of patience. By evening her hair was rarely still in place but that did not appear to be anything she would care about anyways.

Suster Nari situates herself within familial and religious boundaries. One day in the clinic, I asked about a teaching tool called an Evangecube that was sitting on her desk (see figure 10). The Evangecube is a teaching puzzle that helps people to explain the story of Jesus Christ through pictures that change depending on how you fold and rotate the blocks.



Figure 9: the Evangecube in its package sitting on the medical consultation table

This is what she said:

The Evangecube is something that is important to me because my husband is a pastor and I am Christian. This is why I have a strong motivation for patients to become stronger; not only their struggles with HIV, but also that, they become children of God. This is a very strong desire for me.



Figure 10: A Picture of the Evangecube outside of the package

Another day, late in the afternoon, we sat in Suster Nari's kitchen chatting about the lack of healthcare and HIV/AIDS in Wamena. From everything I had seen and heard in Wamena, I was not surprised to hear she does not trust the medical system. She told me that when family members are sick she tries to help them with her own skills and prefers to avoid the hospital and the Indonesian doctors. Her experiences at the clinic and her own beliefs about care needing to be spiritually-based act as encouragement to continue treating patients her way and with her skills as opposed to sending them to the hospital or to doctors that she believed did not have much to offer.

Suster Nari's view of ODHA was expressed very empathetically. She points out that upon receiving the HIV test results, patients usually want to talk about spiritual matters or at least they are more open to a spiritual discussion. She also references a

turning back to God: “They sometimes change. They are in a place of acceptance. So, sometimes if they already know about HIV they are ready to return to God, or they return to a lifestyle which is not good.” She interpreted the patient’s vulnerability as an opportunity to give the patient something more. This shows Suster Nari believes the better and safer choice is to return to God rather than to an old lifestyle. She defines the old lifestyle as being ungodly and a significant factor in the initial contraction of HIV. Suster Nari’s case reminds us that some healthcare providers use Christianity as a way to differentiate good from bad in general experiences of HIV and AIDS patients. She also shows that the experiences of some healthcare providers are weighed against their Christian beliefs and can lead to both empathy and judgement. For her, there is a personal investment in the inclusion of Christianity and she believed Christianity could have a greater impact on the whole of the person than what medications could offer patients.

In summation, Lia and Suster Nari associate HIV/AIDS with deviation from religious commitment. While I only focused on three specific examples of this association, I observed many other interactions where this link was made. I heard Mantri John express a long-standing tradition of contacting pastors in the face of illness, and HIV/AIDS is no different. Christianity can give strength to discrimination and stigma because Christianity resonates deeply with the community. Stigma is disguised as an important part of community maintenance, rather than as practices that stop people from accessing HIV/AIDS treatment and care.

Assessment: Skirting the Real Issues

The previous examples offered evidence of how Christian morals and medical goals are intertwined, support, and undermine each other. They show the ease with which

ideas can become interchanged, such as the enabling attributes of alcohol developing the idea of alcohol being a cause of HIV/AIDS. A network of enforcing values begins to emerge as Christian morals are expected to save people from HIV/AIDS, even when the explanation Christianity offers for HIV/AIDS does not directly correlate to the health problems and practices people are experiencing in the HIV/AIDS epidemic. The ease with which the lines are blurred between Christian morals and medical morals should warrant greater attention to Christianity and religious syncretism in current discussions of HIV/AIDS-related stigma.

Evidence from this chapter strongly supports the claim by Varas-Diaz et al. (2010) that religion affects how healthcare providers view stigma, and the claim by Herdt (2001) that the ways stigma is regulated are just as important as what the stigma is. It is clear that treatments and options for HIV/AIDS patients in Wamena are minimal. This is one reason healthcare providers encourage patients to look to God for help. Another reason is Christianity is a marker that separates Papuans from Indonesians. In Wamena, Christian reliance is connected to Papuan resilience and identity. The results in this chapter show that the moral claims grounded in Christianity line up well with the medical claims that are offered in Wamena but with little support or medical infrastructure, Christianity easily becomes the sole message. This is one reason why so many practices that would be considered HIV/AIDS-related stigma are hidden. The practices and views are sheltered by the Christian messages that offer a simple explanation of the community's experience of the AIDS epidemic in Wamena. The messages along this vein were preached in churches and counselled in clinics. The cause and effect scenarios that healthcare providers see in their patients are clear and are supported by the church's

expectations of moral behaviour.

Christianity's role in Papuan healthcare provider practices is an important issue and shows that again, there are connections and complexities in healthcare provider practices that cannot be summed up with a simple explanation of cause and effect for HIV/AIDS-related stigma. The next chapter will focus on a different aspect of local patterns of stigma: racial politics. I show the distrust of Papuans towards Indonesians, and discuss how these relations affect the view of HIV/AIDS in Wamena and ultimately, impact HIV/AIDS-related stigma.

Chapter 5: Racial Discrimination and Counter-Stigma

A Trip to the Hospital

In the hospital bed lay a screaming 4-year-old Papuan girl. Her mother sat next to her, squeezing her hand as tears streamed down her face. Her family quickly gathered to the hospital and into the emergency room as word spread about the accident. She had been hit by two Indonesian men on a motorcycle. Her left leg was visibly deformed and protruding out to the side of her body. Her leg was obviously broken and her head and arms were covered in bruises and scratches. Her moaning and screaming filled the room as a frantic Papuan nurse tried to decide what to do.

All the while, a plump Indonesian doctor sat talking to two Indonesian visitors in the adjoining examination room. Nobody was being examined and neither of the visitors looked to be in pain. The doctor ignored the commotion going on in the emergency room and did not seem to have any interest in the current emergency. About ten minutes passed before she finished talking to the Indonesian pair in her office. She walked her well-dressed patients to the front entrance, past the frantic family members, past the two Papuan families in the waiting area, and into the sunshine.

The two Papuan families in the waiting area offered a stark contrast to the Indonesian visitors who had managed to monopolize the attention of the doctor. The Papuan families were not well dressed, nor looked well fed, and the families out front were in tattered and worn clothes. The children had runny noses and dirty hands and one boy was sucking on some rusty metal scissors while his siblings wrestled each other for the last bite of candy. The two mothers looked exhausted while waiting in the hot sun. All of a sudden, a police truck pulled up and both Papuan women pulled their children close.

Four policemen hopped out of the truck. Three of the men were Indonesian and one was Papuan. All the men were carrying rifles. They had come to address the motorcycle accident. One of the Indonesian policemen spotted me sitting next to one of the Papuan women in the waiting area and attempted to make flirtatious eye contact with me. I heard the woman beside me whisper to her son to be afraid of the policeman and I gave only a cold stare in return. The screams were getting louder and I was angry the policemen were making everyone uncomfortable by milling about and accomplishing nothing.

Returning to the scene in the emergency room, the Papuan nurse found some scissors and material to immobilize the girl's leg. He unsuccessfully and timidly tried to realign the leg and, it was clear he was not confident in his skills. Even though we were in a hospital, the X-ray machine was either not working or not made available to this family. A foreign missionary nurse, telephoned by the family, came to assist. The missionary and a family member cut off her pants, secured her leg to a splint without moving the leg and continued to monitor the girl. The doctor on duty at this point was doing paperwork behind a glass window in her office.

The missionary located a spinal board from a source outside of the hospital and a few of the men in the family raced off to find plane tickets. The missionary made it clear to the family that if he were going to be involved in helping, they would need to fly to Jayapura for further care. In the end, the family was forced to spend a lot of money on flights and healthcare interventions in the capital and their young girl's femur was never set. Five weeks after the incident, when I was leaving Wamena, the leg that had been in a loose cast had still not set properly.

The hospital did not help the family, and the predominantly Indonesian police who showed up made people anxious and did not appear to accomplish anything. The Indonesian doctor did not take any interest in this emergency, and if it were not for the families connection to a foreign missionary, the patient might not have received fundamental care until some time later. These events, I was told, were not unusual occurrences.

In previous chapters, I have discussed AIDS-related stigma within healthcare provider practices by looking predominantly at stigma within the health care provider-patient relationship. This chapter aims to counter earlier chapters that have focused on the negative aspects of healthcare providers' relationships with their patients. I show in this chapter the protective role healthcare providers can play in countering stigma by others. I include racial tensions between Indonesians and indigenous Papuans as an important aspect of HIV/AIDS-related stigma in Wamena because racial tensions were identified by a number of healthcare providers, community members, pastors, educators, missionaries, government employees, and housewives as an important factor in HIV/AIDS-related stigma.

This chapter will look at the issue of racial tensions from the perspective of the healthcare providers as a relevant but under-acknowledged issue in understandings of HIV/AIDS-related stigma. I will describe how healthcare providers explain Papuans' fear of healthcare as a fear of genocide, evidenced by the increasing numbers of Papuan deaths. Fear of racial discrimination and genocide were the main reasons offered for people not seeking care at the hospital and government clinics, as well as a belief that Indonesians were deliberately infecting Papuans with HIV. The healthcare providers I

interviewed spoke passionately about protecting Papuans against racial discrimination, and while racism is not generally associated with overt discrimination against people living with HIV/AIDS, respondents say racism seriously affects the services provided to ODHA and the relationship between ODHA and the healthcare system in Wamena. This suggests that current approaches to HIV/AIDS-related stigma are too focused on the HIV virus and, as a result, conceal the role of racial discrimination in HIV/AIDS-related stigma, as well as the work healthcare providers undertake to protect their patients from stigma. In this chapter, I describe racial tensions and show they contribute to stigma in the following ways. First, I show that the fear of genocide through HIV/AIDS elevates the virus to a political issue and a medical issue. Second, I show how this forces Papuan healthcare providers to act as protectors, sometimes in opposition to the healthcare system and Indonesian doctors.

The story about the young Papuan girl and her experience in the Wamena hospital shows that even in regular everyday experiences at the hospital, racial discrimination is a large aspect of the quality of care received. Many Papuans relate to this experience. Scholars have also identified racial tensions as a social issue in Papua and as a serious factor in HIV/AIDS-related issues (specifically, Suter, 2001; Kirsch, 2010; Tebay, 2007). King (2002) notes that Papuans feel the only reason the Indonesian government wanted Papua to be a part of Indonesia was to gain access to resources and land, having very little interest in the Papuans. Neles Tebay (2007) argues that the process of marginalizing Papuans is supported by the healthcare system in Indonesia. Tebay writes, “the death of large numbers of Papuans due to the poor health care service is a frequent occurrence in remote and isolated villages where the populations are exclusively indigenous Papuans.

...The government pays no attention to such cases, blames local cultures for their deaths, and deliberately neglects the provision of health care for indigenous Papuans” (Tebay, 2007 p. 343). Butt and Morin (2010) found that the wealthier Indonesian migrant was privileged over the indigenous Papuan in medical care. Racial inequalities permeate the healthcare system to such an extent that the majority of Papuans do not trust the services. The first section will describe the racial and political aspects of care in detail in order to show the importance of including race in HIV/AIDS-related stigma. The second section shows that there is a form of counter-stigma engaged in by healthcare providers.

Fear of Genocide in Wamena

A group of students at IALF introduced the idea to me that HIV is a form of genocide. Racial discrimination and genocide against the Papuan population are serious claims. I will describe the interaction between the students and myself to show that the idea of racial discrimination is at the forefront of discussions about HIV/AIDS. The group of students who spoke about this, and I, were on a break from language classes together in the cafeteria in Denpasar. The group consisted of four Papuan men. One of the men was from Wamena and the other three were from Jayapura. While we sat in a public area, our discussion was quiet to ensure any people passing by would not hear us. Our discussion progressed out of an explanation about my project and the reasons I was heading to Papua.

They explained to me that HIV/AIDS in Papua is a modern form of genocide, one that can fly under the radar of most Human Rights organizations. They explained that the Indonesian government was secretly relocating HIV-positive prostitutes to Papua (Butt, 2005). This point especially brought broad agreement among the men as they leaned into

the table expressing the importance of this point. They felt that by killing off Papuans with HIV/AIDS, the Indonesian government would be able to enact genocide on Papuans while avoiding the attention of the international community. They believed the Indonesian government wanted access to resources in Papua without having a responsibility to the people. The men explained that guns and violence would garner too much unwanted attention, but people dying of HIV/AIDS was a much less noticeable issue. As far as the men were concerned, the government was successful in this endeavour and this was why their generation was severely threatened. After arriving in Wamena, I noticed multiple other examples of Papuan fears of genocide through HIV/AIDS.

While Suster Nari, Suster Debi, and Suster Dessi all spoke about the generation of Papuans who were dying because of AIDS in various casual conversations, I will describe the concept of losing a generation of Papuans from the perspective of two healthcare providers. The first comments are from an Indonesian healthcare provider, Mantri David and the second example is from Mantri John, a Papuan healthcare provider. I have chosen these two healthcare providers to show that the urgency of dying Papuans is felt across racial lines, but the suffering and fear of genocide represents the sentiments of the Papuan population.

In Wamena, the association of HIV/AIDS with the loss of Papuan people is discussed by healthcare providers and patients. This example is from an Indonesian nurse and shows that the fear of genocide is common in the minds of his patients. Mantri Rian is one of the younger men working in the Main Clinic but he holds a lot of responsibility. He is tall, slim, and confident in his skills as a healthcare provider. While this nurse did

not believe the sentiments expressed by his patients personally, he suggests many patients are concerned about discrimination:

So, I don't think that ARTs are the only important factor in treating HIV. It is just frustrating that Papuan patients come to the clinic with STIs and we want to give them medication but they don't want to take the medication. They think that there is currently a program to exterminate Papuans. So they think the government has created this program to destroy the Papuan people in Wamena. I don't think this is true though.

This quote shows that many Papuan patients do not trust the healthcare system and Indonesian medical recommendations about treatment because they are scared of a government plan to wipe out Papuans. Even though Mantri Rian believes that genocide is not the reason for all of the dying Papuans, he is aware that many of his patients believe genocide is the main goal and this makes it difficult for him to treat his patients.

Mantri Rian explained the fear of genocide as being more of a coincidence or misled belief. Mantri Rian admits the lost generation is an immediate problem, but he does not place the blame with the Indonesian government or as a program with racist origins:

In Wamena and perhaps for the mountain people more, the loss of a generation is coming. This is because so many people that are HIV positive are in the reproductive ages, about 17 years old to 35 years old. That is a lot of people. So yes, we fear that a generation is going to be lost.

Regardless of where Mantri Rian places the blame, this Indonesian healthcare provider is cognizant of the idea of a lost generation and places considerable importance on this belief as a hindrance to HIV/AIDS care. Mantri Rian's observations of the patients and the patient's reasons for being sceptical show that HIV/AIDS is perceived as both a medical and a racial issue.

My observations at the Papuan Clinic also support what Mantri Rian is saying about patient fears regarding Indonesian motives towards Papuans. The Papuan Clinic is the only clinic that does not have any Indonesians on the payroll. Every time I visited this clinic, there was a long line up of Papuans waiting to be seen by the nurses here. The lines were much longer than the lines I saw at the other clinics, even though this clinic only deals with STIs, Tuberculosis, and HIV/AIDS. The three other clinics deal with all ailments. Many people I spoke to said the long lines at the Papuan Clinic are because there are no Indonesian workers here so the Papuans feel safe. This point was supported by all of the healthcare providers working at the Papuan Clinic but also by Pak E, my Papuan host, a prominent pastor, and Suster Debi, who works at the government clinic.

There is a rule at the Papuan Clinic that a patient must be able to walk into the clinic unaided by friends or family. If they are unable to do this, they must go to the hospital instead because they are too sick for the clinic to handle. The first week I was in Wamena, a man was brought to the clinic by his friends who tried to make it look like he could walk but was actually unable to. The healthcare provider who saw him responded to this incident saying:

I have heard many excuses from the fact that they have very poor quality of care in the hospital, that the doctors will not examine them because they (Indonesian

doctors) can't stand the smell of them. For some of the older Papuans, it is too traumatic to have an Indonesian work on them when they remember all the military and police have done to them (i.e. human rights violations). Many flat out just don't trust them! They feel that if they go in they will be carried out dead. Either from neglect or flat out planned murder. I have heard all these stories, but have yet to confirm the latter. Neglect, I can confirm!

There were multiple stories like this one about people who were afraid to go to the government clinics and hospital. Earlier that month a Papuan man arrived so sick at the Papuan Clinic that the staff insisted he go to the hospital. The family refused to go and demanded to be seen by the missionary nurse, but by the time the nurse got to the taxi, he was already dead. This shows that people are risking their lives to avoid treatment by Indonesian healthcare providers and prefer to be seen by Papuan or international doctors and nurses or not at all. Patients were focused on the threat Indonesian healthcare providers can present but some Papuan healthcare providers more clearly made the association between genocide and HIV/AIDS.

In contrast to Mantri Rian, Mantri John (the nurse who sells condoms to sex workers) maintains that the Indonesian government is the instigator for HIV/AIDS in Wamena. In his view, HIV/AIDS is elevated from a virus to a political issue that threatens the survival of the Papuan people. The following quote is about how HIV/AIDS is intertwined with political goals for independence. Mantri John is commenting on the government's role in the HIV/AIDS crisis, again expressing the belief that Indonesians are partly responsible for the lost generation:

Papuans say HIV was sent here by the Javanese people. They sent women infected with HIV, two hundred of them were sent to Papua to transmit HIV. It happened once but they talk about the program as if it continues today, now it is not true. The topic continues because of political interest.

Mantri John situates the actual sending of sex workers as something that happened some time ago that does not necessarily continue today, but did happen and just continues to be dredged up. HIV/AIDS can be used as a tool for political gain. This is an important point because it further intertwines medical and political public debates making it hard to talk about HIV/AIDS without addressing the reason many Papuans believe HIV/AIDS came to Papua.

Healthcare Providers Advocate for Patients

Within this medical and social context, Papuan healthcare providers try to protect Papuan patients. This section will focus on the ways Papuan healthcare providers react to the healthcare system and Indonesian doctors. I will look at ways healthcare providers subvert protocol and provider expectations in order to secure a standard of care that does not threaten the existence of Papuans. The following three examples will show how healthcare providers make personal judgements to cope and adapt to the healthcare system in Wamena, a healthcare system that they do not trust. Stigma manifests in the form of fear and avoidance of healthcare facilities. The following case study highlights the discrimination enacted towards indigenous Papuan patients and why so many healthcare providers try to position themselves and some patients to circumvent larger stigmatizing experiences.

In the first example, many Papuan healthcare providers treat their family and friends on the side to avoid interactions with Indonesian doctors. Suster Dessi often treated family members who were sick on her own time. On one occasion, we visited a family whose two children were becoming increasingly sick but did not want to visit a doctor. The two children had sores on their feet that had become infected. One of the child's sores had become so infected he had red lines of infection reaching from his ankle to his hip. That infection was too severe for Suster Dessi's skills but still, the family would not go to the doctor without her. Suster Dessi explained to me that her expertise would help ensure they would not be duped or mistreated. Suster Dessi successfully treated the younger child's infection. Working outside of the healthcare system with family members is one way Papuan healthcare providers protect each other from discrimination from doctors taking advantage of Papuan patients who need medical treatment.

In another example, Pastor Oli reported racial discrimination was common in the hospital. He stated very bluntly that discrimination is common in the hospital. Pastor Oli explained to me that Pastors are always called on when a member of his church is sick. One of the reasons he and others visit the hospital so much is to help support the patients, but also to keep an eye on their care. Advocating for patients was an important responsibility for him.

Advocating for patients is an important tool for Papuan healthcare providers, but there are times when advocating for the patient is not enough and the healthcare provider must take action secretly. Lia relayed a story about Suster Dessi regarding the lengths they go to ensure Papuan patients are cared for responsibly. Lia explained there was a

very sick Papuan man in the hospital but the doctor was refusing to give the patient a blood test and the medicine that Suster Dessi believed that patient needed. To solve the problem Suster Dessi smuggled out a vial of the patient's blood to a friend working at the Papuan Clinic and got the lab technician to test the patient's blood. Once the HIV test was confirmed positive, Suster Dessi acquired the proper medicine and treated the patient herself. This all happened behind the back of the Indonesian physician.

Lia cited this story, and other admissions of foul play by local health care providers as important reasons why she could never work for the government and why they need to look out specifically for Papuan patients. Lia had numerous stories about how Indonesian doctors often held back medications at the hospital, encouraging the patients to visit them at their private clinic later, so they could make money off of the prescriptions that would otherwise be cheaper at the hospital. These stories about less than honourable doctors made Lia feel the importance of protecting her friends and family. Stories of Indonesian healthcare providers like this made it acceptable for Papuan healthcare providers to work behind the backs of the Indonesian doctors and to sneak drugs from the Papuan Clinic after hours to help their own families avoid treatment by other Indonesian doctors. I viewed this practice on more than one occasion, and heard about many other instances.

Circumventing the Indonesian healthcare system resulted in better care. A friend of Lia's broke her arm and Lia accompanied her friend to the hospital for an X-ray but brought her back to the Papuan Clinic to have the bone set by the foreign nurse. Even though broken bones are not on the list of medical issues the clinic deals with anymore, Lia and their friends were not willing to risk seeing hospital staff set the bone poorly. The

bottom line for Lia is that the Indonesian healthcare providers just cannot be trusted. I pushed Lia on the topic of trust and this was what she said:

It is necessary that the straight hair doctors [Indonesians] come and help the people that are sick but still... I really don't trust them. Also, if they know the patient is sick with HIV, they won't help. Surely, the patient will die. The doctor just goes to see patients that do not have HIV. That is sick and sad. Why don't they help? We are the same as Indonesians but they act like this. They have small hearts, that's what I think... There is a big difference between the people that migrated here and the Papuans. It is a big difference. That is what gives us courage to try at the Papuan Clinic. Therefore, we only serve the Papuans, the people that are originally from Papua. We want to help our people.

The next case study provides a fuller example of the protective nature of Papuan healthcare providers towards Papuan patients.

Case study: Suster Debi and counter-stigma



Figure 11: Suster Debi, a nurse at the Secondary Clinic

Suster Debi is 32 years old and tells it like it is. She likes to chew betel nut and smoke cigarettes; two practices discouraged by the local church. She prefers not to wear the customary white nursing uniform in the Secondary Clinic where she works. Instead, she wears baggy camouflage pants and large hooded sweatshirts usually with the hood up, diminishing slightly her heavysset frame. She identifies herself as a protestant Christian and regularly attends two churches. Going to two churches allows her to still attend church even when she might be fighting with a family member who also attends one of the same churches. She says:

I cannot go to church when there is a problem with another family member. My usual problem is with my older brother. I want to go to church every week but when there is a problem with my brother, I can't go to the same church as him. If

there isn't a problem, surely, I will go to church. In one month, I usually go to church at least three times.

Suster Debi was a challenge to track down. She did not attend work regularly and often left work early due to a headache or some other ailment. Co-workers would hint at her irresponsible nature but they also applauded her success with patients. She had a reputation for a blunt attitude and demeanour that seemed not to care about what other people thought and this was considered an asset in her job. The following story she told expresses her fearlessness and her ability to protect patients in the healthcare setting:

Yes, in our clinic we have a different doctor now, the change is recent. The first [Indonesian] doctor, his personality was hard, very hard. He was authoritative and we had to follow him in everything he wanted. I was always negative towards him. I did not accept him as my boss. There was this one time I had a patient and the doctor was very rude to the patient I was working with. I was counselling the patient in the room here, and the doctor opened the door and entered without knocking. He entered the room and left the door open, he did not close it again! So, I slammed my fist on the table at the doctor. Then I said, "Go outside and close the door because a person is sitting here, don't make him feel like an animal!" He [the patient] has feelings just like me; he is Papuan just like me. The patient was shy, he felt shy and was scared other people would see him in the HIV counselling room.

This example shows that Suster Debi is both an advocate of patients and because of her job, holds a great deal of power over patients and treatment opportunities. While

she exhibits stigma towards patients in the ways described earlier in the thesis, she is also able to clearly articulate the counter-stigmatizing practices that she engages in to protect her Papuan patients.

Banding Together for Family and Papuan Survival

The next example about counteracting racial discrimination arose from a discussion with Suster Nari and Eli. Eli works at the Papuan Clinic. They shared with me their preference for treating family members themselves rather than seeking advice from Indonesian doctors. Suster Nari mused, “I always wonder why they [Indonesians] work so little. I think they should work as we do and examine the patients better. They need to do full examinations to find all of the problems in the patient.” She believed the examination skills of the Indonesian doctors and healthcare providers were not good, a point I had heard before, as well as untrustworthy. She believed that in the few times Indonesian doctors used their stethoscopes on patients, they would only listen to one spot and even she, as a nurse with less training than the doctor, knew that was not sufficient to properly diagnose patients. She further explained that Indonesian healthcare providers rarely touch patients and often make their diagnoses without ever touching the patient. These points of frustration for Suster Nari show that she does not trust the Indonesian doctors based on her assessments of their skills. To protect her family and friends from this, she medically treats her family as best she can without consulting a doctor. Papuan healthcare providers act in ways that protect themselves and their families from the Indonesian healthcare system.

The last example of protecting Papuan patients I offer, describes a meeting that resulted from this last conversation with Suster Nari and Eli. This meeting I describe

below shows how seriously the racial tensions are felt in Wamena and filter into various aspects of society. First, I will explain the events that took place after this discussion because it describes the atmosphere of this event. The order and the content of this meeting are important to understand the seriousness of racial tensions for the people I worked with in Wamena.

After meeting with Suster Nari and Eli, I was approached by Pastor James to go out for dinner with his family. Previously, I had spent many evenings at his house with his wife and his sister. Pastor James was usually away on business and we rarely had the chance to talk. He is a kind looking man and very attentive to his children. I was a little intimidated by him. He is tall and a little on the heavy side. When he speaks, other people listen. Pastor James is an important man in the community. There were always people meeting with him and at church, he always sat with the other leaders in the honoured place at the front of the church.

That evening at a restaurant, our meeting became secretive about mid way through dinner, Pastor James leaned into the table and in a hushed voice said that there was something very important that he needed to tell me before I left Wamena. We could not talk about it in the restaurant though we would talk about it before he dropped me off. It was already dark when we crossed the street and entered the van after dinner. He instructed me to sit in the front passenger seat. It was important for him that I had extra light so I could write down what he was about to tell me. It was all a little eerie, as we sat in the van on the deserted street. It felt like I had entered a spy novel of sorts. Pastor James did not waste any time and told me he was going to tell me eight reasons why all Papuans desire independence from Indonesian rule. I will very briefly describe the points.

Point number one is so that Papua can attain freedom and more people want this than they let on. Many Papuans in high levels of the government want independence, they are just afraid of the Indonesian government and therefore must tread very carefully.

Point two: no one has forgotten the years of torture at the hands of the Indonesians. The wound is still very fresh. Pastor James is only alive because when he was young his uncle, who had been mortally wounded by an Indonesian raid on their village, helped get him and his cousin to the forest before dying. Pastor James said his uncle had to hold in his spilling entrails to get them there. Women were being raped right in front of their husbands and children and there was nothing they could do to help.

Point three: there is no trust between Indonesians and Papuans and this goes both ways. There will never be trust because of their history.

Point four: the Indonesians come to Papua but they only take and do not give back. They do not help with anything; they only make things worse for the Papuans. There are very few, if any, Papuan doctors, there are no Papuan pilots, and all the good jobs and funding goes to the Indonesians.

Point five: the Papuans are proud of their history with famous missionaries and this is something that all Papuans celebrate together but the Indonesians come and destroy churches.

Point six: the transmigration programs look and feel more like a take-over.

Point seven: the Indonesian government has had a large project to send HIV positive prostitutes to Papua. It is their plan to bring HIV/AIDS to Papua along with pornographic material, and a culture of illicit sex.

Point eight: all of the land is being bought up by the Muslim people. All of the programs aimed at helping youth only goes to Muslims and nothing supports education and opportunities for Papuan people.

This long list puts the HIV/AIDS epidemic as one of the key reasons for the fight for Independence. Pastor James summed up this conversation by saying, “They come to kill us.” To Pastor James, this is why he works to protect the Papuan people. This is the reason he supports the Papuan Clinic that serves only Papuan people and has a strict rule that no Indonesian person ever be on the payroll. He enforces this rule with conviction and passion. The secretive yet purposeful approach Pastor James took to share this information with me stresses the importance of racial discrimination in Papua.

Assessment

This chapter departs from earlier discussions of interpersonal relations of the healthcare providers and their patients. The issue of trust is a central theme in this chapter. Papuan healthcare providers do not trust Indonesian healthcare providers. They see where Indonesian healthcare providers fall short in standards and choose to keep family members away from the system as much as possible. Healthcare providers are also aware of their patient’s mistrust of them as practitioners. In these conditions of diminished trust, the health care relationship revolves around the relationship between Indonesians and Papuans and because of this, the healthcare system is strongly affected by racial discrimination.

The fear of genocide is inextricably linked to HIV and most treatment for HIV/AIDS is located in places where Indonesians are predominantly in places of power and Papuans do not feel safe. The actions and observations of the Papuan healthcare providers show that wariness of the medical system is warranted. Suster Debi’s actions

highlight some of the ways healthcare providers can stand up for patients who are being mistreated.

Papuan patients do, however, trust Papuan healthcare providers over Indonesian healthcare providers. They rely on family members with biomedical training to safeguard them and their families when they must deal with the medical system. Papuan healthcare providers actively protect patients through access to secret tests and medications. Papuan pastors were also shown to provide support to indigenous healthcare providers and patients in this area.

This chapter has shown the importance of the counter-stigmatizing practices of healthcare providers. I am not arguing that racial discrimination and macro level inequalities are more important than the stigma that healthcare providers can enact in their interpersonal relations. Rather, I suggest that in Papua, the act of countering race-based stigma by healthcare providers is as important to understand as are the stigmatizing practices they can display. Race and the actions of healthcare providers should be included in any approach that attempts to deal with stigma in Wamena. AIDS-related stigma in Wamena is influenced by political, religious, personal, and historical circumstances. Current international concern with stigma that revolves around generic plans and universal goals does not come close to addressing local needs and concerns unique to Wamena.

Chapter 6: Conclusions and Observations

Summary of Findings

At the beginning of this project, I set out to look at healthcare providers and their contributions to HIV/AIDS-related stigma in Wamena. I expected to find a kind of cause and effect relationship that revolved around obvious markers of stigma between healthcare providers and their patients, with healthcare providers describing abuse, neglect, violence, anger, disgust, fear of contagion, etc towards patients that was specifically related to physical manifestations of the HIV virus or full-blown AIDS. My results however, did not confirm my initial limited expectations. Upon exploration, I found contradictions in the actions of healthcare providers pertaining to stigma. On the one hand, many routinely stigmatized; on the other hand, the same healthcare providers actively countered the stigma of others and tried to protect their patients from discrimination and dangers. This finding complicates any simple assessment of stigma.

In the preceding chapters, I have shown that HIV/AIDS-related stigma is an issue in Wamena but not in the same way that the AIDS Industry depicts stigma. The AIDS Industry focuses predominantly on HIV and describes stigma towards ODHA in limited ways that do not fully consider the importance and effect of local contexts on HIV/AIDS-related stigma. This thesis has shown that the perspective of HIV/AIDS-related stigma that centers around the physiological aspects of HIV/AIDS is insufficient in Wamena because of wider cultural, religious, and political circumstances that shape the practices of healthcare providers.

In chapter three, I showed that stigma is present in beliefs and practices of healthcare providers. Stigma revolves around assumptions about patients and HIV/AIDS

as well as expectations about religious adherence and marginalized groups. Practices that emerge from judgements about patients contribute to the maintenance and perpetuation of stigma. These stigmatizing practices continue because the way healthcare providers are treating their patients is not necessarily a reaction to HIV/AIDS but to wider community expectations. HIV/AIDS-related stigma is about local beliefs and experiences. Stigma is subtle in Wamena, but powerful.

In chapter 4, I showed that Christianity is a very important aspect of the syncretic belief structure in Wamena and is one of the main influences that affect healthcare provider practices in Wamena. I found that healthcare providers are strongly influenced by their faith and this contributes to the kinds of judgments made about patients and further affects patient access to treatment. Christian beliefs are incorporated into treatment protocols along with medical judgments about patients. The healthcare providers decide how a good or bad Christians, as well as a good or bad patients, should act. Approaches to HIV/AIDS-related stigma need to recognize the role of religion in perpetrating stigma within the patient-provider relationship. The application of Christianity within the healthcare provider and patient relationship also had notable positive outcomes. The Christian values that focused on compassion for the sick and undervalued people in the community worked against stigma. The approach to ODHA and working within the HIV/AIDS sector taken by healthcare providers such as Suster Nari and Lia showed the positive role of Christianity to make positive changes for ODHA and reducing stigma. Highlighting and utilizing aspects of Christianity like compassion and forgiveness could reduce stigma in interactions with HIV and AIDS patients as well. The current approaches that ignore the relevance of Christianity in the daily lives of

healthcare providers appears to only reinforce the idea that stigma among healthcare providers does not exist.

In the fifth chapter, I discussed the role of race in HIV/AIDS-related stigma in Wamena. Racial inequality and the importance of the Papuan identity is something that is evident in everyday life in Papua (see figure 12). The fear of genocide led healthcare providers to protect patients and family members from the healthcare system. Racial tensions proved more important and prominent in interviews than fears about acquiring HIV/AIDS. The results in this chapter showed that stigma can serve both as an inhibitor of HIV/AIDS services and as a form of protection for patients. The list presented by Pastor James and the examples of Papuan healthcare providers circumventing, and at times challenging, the medical system shows that HIV/AIDS, and stigma, are wrapped up in the problem of racial inequality and cannot be easily separated. I argued that HIV/AIDS-related stigma, as a term, be reworked to include and acknowledge that healthcare providers are subverting the medical system and HIV/AIDS initiatives in an attempt to protect themselves, patients, and their families. In Wamena, healthcare providers discriminate against patients but they also protect patients. Expecting stigma to be a purely negative occurrence conceals the scope of actions taken by healthcare providers to counter risks to patients.

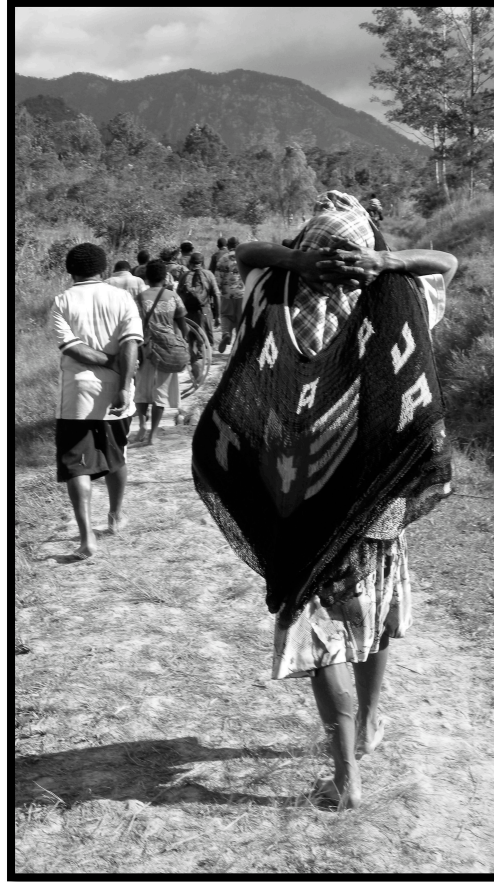


Figure 12: A women wearing a traditional bag emblazoned with the Papuan flag.

Limitations of the Study and Recommendations for Future Research

This study is limited by the time constraints placed on research by the Indonesian government. I was not permitted to be in Indonesia for more than 60 days at a time. The effect of this short time frame is that case studies used in this research are only short excerpts of the healthcare providers' lives. Other limitations consist of the small sample size, political tensions in the area, and language barriers experienced throughout the fieldwork phase. These constraints limited the ability of this project to be generalized widely because travel and other activities are tightly controlled.

The extensive use of triangulation in this project however allows some claims to be generalized to areas where similar local belief structures, strong Christian presence, and experiences of racial discrimination are evident. While I limited discussions of

HIV/AIDS-related stigma to religion and racial tensions, there were more areas that influenced how people viewed HIV/AIDS-related stigma in Wamena that were beyond the scope of this thesis. Discussing gender, international interventions in Wamena, and traditional healing beliefs, would have allowed for a fuller understanding of the whole picture of stigma and influencing factors in Wamena.

A focused study on current stigma reduction programs in Papua, combined with an assessment of how healthcare providers internalize this information in education sessions, would provide important information about whether or not the approach of focusing on healthcare providers is as beneficial as the AIDS Industry purports. Healthcare providers are extremely limited by medical resources and do not get continued access to patients because of geographical constraints. A further study could explore whether it would be more beneficial to address the unique social and geographical environment of Papua that affects access, rather than maintain reliance on external ideas and values in stigma training.

Utilizing Christian networks for stigma reduction is another important recommendation that has emerged from this research. Doing so would provide greater access and support for healthcare providers working with ODHA as well as the wider community. The community's respect for pastors and involvement with churches in the area is a pre-existing platform that currently has great influence in the community. Working within these groups, rather than outside of these groups might have the potential to affect greater change than current efforts. A more purposeful merging of medical interventions and Christianity could mitigate the current reality that a supernatural, be it

animist or Christian spiritual intervention, is the only resource available to alleviate suffering for ODHA in Wamena.

In sum, this research project is a rare glimpse into a group of healthcare providers navigating the diverse landscape of healing practices and biomedical interventions in a politically and environmentally challenging locale with few medical resources. None of the people I spoke with lived only within the boundaries of a biomedical approach to HIV/AIDS, nor did they only adhere to Christian expectations. Everyone was a little bit different, treated their patients a little differently, and understood their role within their community a little differently. There is no simple solution to HIV/AIDS-related stigma in Wamena but there are factors that influence peoples' actions and practices in the workplace, and these factors are not limited to implementing a simplified rendering of HIV/AIDS as taught in training sessions. If there is any hope to change the current direction of the HIV/AIDS epidemic in Papua, it is going to have to begin with creating an environment where Papuans are safe and their beliefs and practices are acknowledged and incorporated into the solutions being implemented.

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Appendix A

Guiding Topics for In-depth Interviews

Name, Age, Hometown, School level, Relationship Status, Children

When did you become a nurse/ staff/doctor?

Where did you go to school?

Did this job require special training and if yes where?

How did you become as nurse/aid/doctor?

Why did you choose this job?

Is there anyone or anything that encouraged you to become a nurse?

What does this job allow you to do that another job might not?

Tell me about your job? This can be feelings, patients, friends, specific tasks...

Please explain HIV/AIDS to me.

How much contact do you have with HIV/AIDS-related cases?

Where did you learn about HIV/AIDS and treatment practices? school, workplace, friends, organizations

Can you share about some of your experiences with HIV/AIDS care and treatment?

What do you think the strengths and weaknesses are in the approach to HIV/AIDS?

Do you work with any NGO or FBOs? If so in what capacity, what is the level of involvement?

How has working with these organizations changed your practices or knowledge of HIV/AIDS?

How do you feel about their involvement? Can you elaborate?

Are there any ways these organizations hinder your work?

Appendix B

Stigma Scale in English

Adapted from S.C. Kalichman & L. Simbayi. (2004). Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. *AIDS CARE*. 16(5):572-580.

The Stigma Scale used in this project was adapted from Kalichman and Simbayi's article. The questions are intended to detect repulsion of HIV-positive people and to assess social sanctions. The questions are listed below:

People who have AIDS are dirty

People who have AIDS are cursed

People who have AIDS cannot be trusted

People who have AIDS should be ashamed

People who have AIDS have nothing to feel guilty about

Most People become HIV-positive by being weak or foolish

It is safe for people who have AIDS to work with children

People who have AIDS must expect some restrictions on their freedom

A person with AIDS must have done something wrong and deserves to be punished

People who have AIDS should be isolated

I do not want to be friends with someone who has AIDS

People who have AIDS should not be allowed to work

Appendix C Stigma Scale in Indonesian

Skala Stigma Umum

Nama Sandi responden: Pekerjaan Umur
 Kategori lain
 A: Setuju B: Tidak Setuju

1. Orang yang sudah kena HIV/AIDS adalah seorang kotor
 2. Orang yang sudah kena HIV/AIDS adalah seorang terkutuk
 3. Orang yang sudah kena HIV/AIDS pasti merasa malu
 4. Orang yang sudah kena HIV/AIDS harus diterima seperti orang biasa
 5. Orang yang sudah kena HIV/AIDS mengalami diskriminasi dari keluarganya
 6. Orang yang sudah kena HIV/AIDS bisa menjaga anak-anak
 7. Orang yang sudah kena HIV/AIDS harus menerima pembatasan pada perilaku mereka
 8. Orang yang sudah kena HIV/AIDS mengalami kekerasan
 9. Orang yang sudah kena HIV/AIDS boleh berpartisipasi dalam kegiatan sosial
 10. Orang yang sudah kena HIV/AIDS mengalami penolakan dari teman-teman
 11. Kelakuan orang yang sudah kena HIV/AIDS pasti salah dan pantas menerima hukuman
 12. Orang yang sudah kena HIV/AIDS harus diasingkan
 13. Orang yang sudah kena HIV/AIDS sudah tidak dihormati lagi oleh masyarakat
 14. Saya tidak mau berteman dengan orang yang sudah kena HIV/AIDS
- Orang yang sudah kena HIV/AIDS tidak bisa bekerja