

LEPROSY

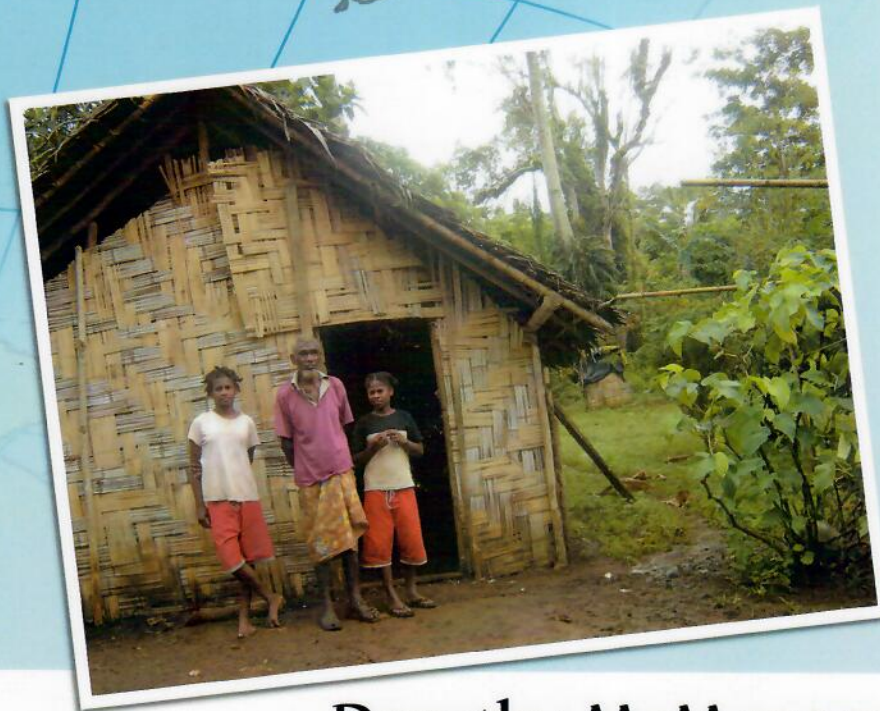
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STIGMA

IN THE

SOUTH PACIFIC

**A Region-by-Region
History with First
Person Accounts**



Dorothy McMenamin

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Preface

How leprosy and its stigma impacted on the lives of those who suffered the disease is explored in five South Pacific nations visited by the author — namely, Fiji, New Caledonia, Samoa, Tonga and Vanuatu. Oral histories were recorded with elderly leprosy sufferers, many of whom suffered decades of isolation at various leprosaria in the Pacific islands. One New Caledonian interviewee had been in residence at a leprosarium for over seventy years. Introductions were facilitated through the Pacific Leprosy Foundation, a charitable organization founded in 1939 in Christchurch, New Zealand. With the assistance of their staff at the leprosy hospital in Suva, Fiji, as well as agents, volunteers and sisters of the SMSM who helped leprosy sufferers in the islands, the author was driven to the homes of the interviewees, often in remote villages, to record the interviews.

The personal testimonies reveal the heart-rending experiences of being diagnosed with the disease, removed from their families, shifted into isolation, their medical treatment, and eventual discharge back home. But the return home was sadly not always to be a happy one. Descriptions of these events implicitly disclose levels of stigma that prevail in the island communities. What becomes evident is that where there is openness and knowledge about the minimal risk of leprosy contagion and the availability of a cure, as has occurred in Fiji and Vanuatu, lower levels of stigma exist. Nevertheless, even in these countries, prior to the availability of an effective cure, fear and horror of the physical effects of leprosy often caused the victims to be cast out or voluntarily leave their homes. This segregation led to groups of leprosy sufferers banding together beyond their villages to help care for each other.

Following the implementation of the policy of isolation in leprosaria by medical officials from the early 1900s despite the initial hardships of separation, it was found that leprosy patients benefited from the better medical facilities available, and particularly enjoyed the opportunities for friendships and camaraderie at leprosaria.

However, if conditions at leprosaria were miserable and the movements of residents restricted by fences visible to the public, as in Samoa and Tonga, leprosy stigma prevailed and was heightened. It was evident that perceptions of stigma varied from region to region and even person to person. In New Caledonia higher levels of stigma were evident because leprosaria had been located at former prison sites and strict isolation enforced. High stigma also prevailed in Tonga because from the earliest days officials linked leprosy with old biblical strictures that asserted leprosy sufferers should be treated as unclean and cast out of their homes and villages. It is important to emphasize that due to the specific focus on the personal experiences of those who suffered leprosy, it is beyond the scope of this research to evaluate stigma in the islands in connection with other diseases and physical deformities.

Following the availability of sulphone treatment in the 1950s, and the improved MDT medication in the 1980s (now freely available worldwide), the disease no longer need be physically disfiguring or disabling when diagnosed and treated early. Thanks in part to the generous donations raised by the PLF to fund medical services at the central leprosy hospital in Fiji and directly assist leprosy sufferers in the Pacific Islands, the huge limitations and corresponding leprosy stigma of the past are fading. As one contributor to the project said, "The time of darkness is ending."

Introduction

A common response by most people when asked about leprosy and its stigma is that leprosy is a disease of the past which caused terrible physical deformities, but because the disease is no longer prevalent, stigma is not an issue. However, if told that they are to meet someone who had leprosy, fear of contagion arises, magnified by fear of the awful physical disabilities associated with it. This fear is unfounded and particularly inapplicable since the mid-twentieth century with the availability of a medical cure that ends contagion by killing the disease-causing bacillus. Early diagnosis, followed by treatment, prevents any possibility of ensuing disabilities.

This fear of contagion and disability lies at the heart of leprosy stigma throughout the ages. It has been perpetuated in the 20th century by images of leprosy sufferers imbedded in the public mind by films such as the epic *Ben-Hur*, which portrayed scenes of a family afflicted by the physical ravages of the disease. More recently the film on the life of Che Guevara, *The Motorcycle Diaries*, vividly dramatized the mutilated appearance of residents at a leprosy colony. These images are horrific, especially in the modern world where physical disabilities are routinely transformed by plastic surgery so that the worst physical deformities are eliminated from public view. In such a world the impact of grotesque physical appearances and any perceived risk of deformity exaggerate and sustain leprosy stigma.

In the past leprosy has often been described as a "fate worse than death," and in today's societies, which thrive on cosmetically contrived beauty, it is hardly an exaggeration to say that gross physical deformities are still viewed as tantamount to a "fate worse than death." Adding to the unfortunate lot of leprosy sufferers, the common use of the word "leper" as an analogy refers to outcasts of society and conjures up notions of ostracism and misery. Greater public awareness about leprosy and its cure (and the realization that global mobility means the disease exists in most countries, but that the risk of contracting it is minimal) is the way to diminish old stigmatic attitudes towards

the unfortunate people who have suffered the disease. This research reveals how leprosy affected its victims in five South Pacific nations from the early twentieth century until the present day, and how the discovery of sulphone treatment revolutionized these people's lives. But due to old, ingrained attitudes and ignorance about medical treatments, stigma continues.

This book seeks to extend the battle against stigma by broadening the knowledge and understanding of how the disease and its stigma impacted upon the lives of the victims and their families. In order to locate primary sources and record oral histories with leprosy sufferers, especially the very elderly who experienced isolation prior to the availability of an effective cure, the author visited Fiji in the South Pacific, the Polynesian islands of Samoa and Tonga, and the Melanesian islands of New Caledonia and Vanuatu between 2004 and 2008. The research was initiated and funded, in the main, by the International Leprosy Association Project, Global Project on the History of Leprosy (funded by the Nippon Foundation), Welcome Unit for the History of Medicine, University of Oxford, referred to hereafter as the Oxford Project.¹ Introductions to the individuals who had suffered leprosy were facilitated by the Pacific Leprosy Foundation (PLF), a charitable organization in Christchurch, New Zealand, and its liaison personnel resident in each of the islands. So apart from widening the understanding of the personal experiences of leprosy sufferers, this book forms a useful guide to future researchers utilizing the historical archives deposited at the Macmillan Brown Library, Christchurch, New Zealand.

The oral histories were not recorded with stigma in mind, and it was not the main focus of the questionnaire. However, while recording the interviews, notions of stigma associated with leprosy became evident, and the characteristics that constituted stigma varied from place to place and, sometimes, person to person. It can be argued that stigma, being a reflection of the subjective and possibly even subconscious attitude of the stigmatizer, is more susceptible to psychological than historical enquiry. Nevertheless, various writers have identified historical events and practices as being the causes that have given rise to leprosy stigma, and these events and practices are examined within the South Pacific context. The factors identified as the cause of stigma are:

(1) Biblical texts and teachings conveyed and perpetuated by Christians and missionaries who aligned leprosy with earlier ideas of sin and uncleanness, resulting in those with the disease being considered outcasts from society.²

(2) Fear of contagion and the mutilating and disfiguring physical characteristics that occur, especially at advanced stages of the disease.³

(3) Fear induced by twentieth century medical policies that advocated isolation, which involved the removal of patients from their families and incarceration at leprosaria.⁴

The collection of oral histories has allowed the issue of stigma to be examined more widely — for example, through personal experiences describing the conditions at leprosaria — which has permitted analysis of the impact of these conditions and other associated factors that might have caused stigma. The object has been to set aside preconceptions and, relying only on the oral testimonies of the leprosy sufferers, to examine the degree to which the three above causes contributed towards leprosy stigma in Fiji, New Caledonia, Samoa, Tonga and Vanuatu.

As two of the principal causes of stigma identified above involve isolation of leprosy sufferers at leprosaria, where care was provided by religious orders, leprosaria are an important focus. Accordingly, a section on a few leprosaria worldwide provides a contextual basis for comparison with the central South Pacific leprosarium at Makogai, Fiji. The Makogai leprosarium will in turn be assessed against smaller leprosaria visited in the Pacific islands to ascertain whether these leprosaria caused stigma. To provide an understanding of leprosy sufferers' experiences of the disease, and how it was treated and perceived by the medical fraternity, health care workers and local communities, long extracts of testimonies are quoted to convey the personal dimension of the sufferers' traumas.

The Disease and Its Brief History

Leprosy was more precisely identified and named Hansen's Disease in 1873, after Gerhard Henrik Armauer Hansen of Norway, who identified the disease-causing bacillus, *Mycobacterium leprae*. The *M. leprae* bacillus is related to the bacillus causing tuberculosis, *Mycobacterium tuberculosis*, which attacks the lungs. In leprosy the bacilli attack and damage the nerves under the skin, which can result in paralysis, the loss of sensations, and degeneration of muscles and bone, leading to highly visible progressive disabilities.⁵ *M. leprae* attacks the nerves in cooler areas of the body, which are, in the main, the peripheral nerves close to the surface of the skin.⁶ This gives rise to visible patches and rashes on the skin, a flattening of facial features, visual problems and loss of facial hair.⁷ As a consequence of nerve damage in the limbs, unfelt injuries, especially to the hands and feet, lead to severe physical disabilities aggravated by accidental injuries and repetitive actions in everyday life.⁸ Fingers and toes are most easily damaged, and the loss of these digits is a notorious sign of leprosy. The simple repetitious action of walking with anaesthetized leg nerves leads to the later chronic problem of plantar ulcers on the soles, which are extremely difficult to cure and frequently lead to complications that result in amputations.⁹ Because the nerves cannot recover, disabilities occur

long after the disease has naturally arrested or after medical treatment. For this reason early diagnosis and treatment of leprosy are imperative to prevent nerve damage which later leads to severe physical disabilities.

The long incubation period of leprosy can extend from a few months to twenty or even fifty years, and, together with the varied symptoms associated with different forms of the disease, this has made diagnosis exceedingly difficult historically.¹⁰ The most serious form of leprosy is now clinically identified as multi-bacillary leprosy, also known as lepromatous leprosy, which is a multi-bacillary invasion of the skin, nerves and internal organs.¹¹ Pauci-bacillary leprosy, also known as tuberculoid leprosy, is the opposite end of the spectrum, where internal organs are not attacked, and the skin and nerves are affected by a solitary or few bacilli.¹² In between these poles lie a varied mix of different presentations of the disease, depending on the degree of specific immunity.¹³ Medical classification of these vastly varying forms is defined by the Ridley-Jopling scale.¹⁴ Many cases of leprosy spontaneously cease to be infectious and become inactive, which are commonly referred to as “burnt out cases.”

Since Hansen’s identification of the leprosy-causing bacilli, it became possible to identify the presence of bacilli in skin samples, confirming a diagnosis of leprosy. Laboratory tests and procedures show the presence of *Mycobacterium leprae* in skin tissues even at the earliest stages of the disease.¹⁵ However, despite extensive research towards the end of the nineteenth century, no successful treatment of leprosy or any form of inoculation had been discovered. At the First International Leprosy Conference in Berlin in 1897 the disease was declared virtually incurable and isolation practices recommended.¹⁶ Various remedies had been tested in an attempt to combat and ease the symptoms of the disease, such as chaulmoogra oil. The oil is extracted from the *Gynocardia odorata* tree and used by early Indian Ayurvedic medical practitioners; it became the treatment most commonly adopted by the British and other medical practitioners for the treatment of leprosy.¹⁷ Chaulmoogra oil was administered orally and later via injections, but its success was very limited.¹⁸ Its taste was most disagreeable, and the injections were administered with thick needles that were so painful as to deter patients. It was not until the revolutionary discovery of antibiotics — in particular, sulphones in 1941 at Carville in the USA — that an effective treatment was eventually found.¹⁹

By the late 1940s, dapsone, also known as DDS, became the most successful sulphone treatment in the majority of leprosy cases, producing remarkable results and removing the earlier visible marks and skin lesions, although nerve damage remained irreversible. Leprosy was eventually able to be contained, rendering a patient non-infectious, although some patients could not tolerate the prescribed high dosage of sulphones, and relapses did occur. By the 1970s, evidence of serious resistance to dapsone, associated with relapses

of leprosy, surfaced worldwide, and the treatment was adapted to counter the problem.²⁰ The present treatment of Multiple Drug Therapy, MDT, was produced in the 1980s, usually comprising a combination of dapsone, clofazimine and rifampicin. MDT has been proven to effect a more stable and permanent cure, avoiding the earlier problems of drug resistance, and was adopted by the World Health Organization for treatment in their worldwide strategic plan to achieve the elimination of leprosy.²¹

Despite extensive research, the actual mode of transmission of the bacilli is still not definitively identified, although it is medically accepted to be via droplet and/or airborne infection.²² It has been suggested that a breakthrough in discovering the exact mode of transmission may be helpful in understanding the contagion of AIDS because of the commonalities between leprosy susceptibility and the HIV virus with tuberculosis *Mycobacterium*.²³ Irrespective of the precise mode of transmission of *Mycobacterium leprae*, it is held that leprosy may be a disease of high infectivity but low pathogenicity, thereby suggesting that older ideas of prolonged close skin-to-skin contact necessary for infection might no longer be sustainable.²⁴

Dr. Roland Farrugia, retired WHO leprologist and current PLF leprosy consultant, suggests that some societies are more susceptible to leprosy than others, and that ninety-five percent of most societies have differing levels of natural immunity to leprosy; the remaining five (or perhaps ten) percent having some genetic defect that makes them susceptible to leprosy when exposed to the bacillus.²⁵ This susceptibility, being a genetic weakness, is often passed from parents to their children, and inevitably some children are more prone to contracting leprosy, although leprosy itself is not hereditary. Dr. Bruce Mackereth, in charge of a leprosarium at Lolowai, Vanuatu, in the 1960s, conducted an epidemiological study of leprosy patients. In line with findings from other studies, he noted a strong hereditary factor in that children and siblings of infectious cases were much more likely to be infected and more likely to contract the same form of leprosy than the spouses of leprosy sufferers.²⁶

A salient feature of leprosy, with profound impact upon its associated stigma, is that leprosy in itself is not a terminal disease.²⁷ Even prior to any effective cure being available, leprosy sufferers could live well into old age, but with increasingly serious and outwardly visible debilitating deformities, with death usually attributable to other causes. As explained by the chairman of the PLF Medical Advisory Committee, Dr. Brian McMahon, “People tend to die with it [leprosy] rather than of it.”²⁸ As such, leprosy stigma is due to its epidemiological and etiological characteristics as a mutilating, disfiguring and progressive disease.²⁹

Inevitably and historically, the complexity of leprosy led to mystery and

public confusion about the disease. As the author Edmond suggests, the western public have remained haunted by past images of the fearful appearance of its physical deformities in advanced cases, frequently portrayed in fictional literature and films.³⁰ These images are influenced by medieval sumptuary laws which required people with leprosy to signify their presence by various means, such as special clothing and the ringing of a bell. These practices engendered horrific images of leprosy that were perpetuated by images in literature and the media to the public, who in the main were relatively ignorant about the disease. Twentieth century policies of segregation and isolation, intended to prevent contagion, made leprosy a disease out-of-sight-and-out-of-mind, leaving it shrouded in mystery and, in the public mind, often perceived as a disease of the past which no longer existed.³¹

The western medical fraternity, colonial officials and missionaries, right up to the 1950s, were, in fact, fairly ignorant about leprosy also, and their fears of contagion and ideas of segregation influenced the perceptions of South Pacific islanders. The general lack of public knowledge about leprosy, its containment, and its connection with continuing disabilities has contributed to leprosy sufferers remaining objects of dread and, accordingly, objects of stigma in many parts of the world, including the Pacific. Public attitudes towards medicine have been, and still are, molded by medical and scientific knowledge.³² Once a scientific breakthrough is achieved on the exact mode of transmission, the publicity generated might lead to greater public awareness about leprosy overall and hopefully diminish fears of contagion, which would reduce stigma.

The arrival of leprosy in Polynesia is reported to have been in the mid-nineteenth century and blamed on Chinese immigrants, although these claims are largely unsubstantiated, and there is a lack of evidence to make any definitive claims.³³ It has been suggested that leprosy was prevalent in parts of Melanesia and Micronesia prior to this time, and that the movements of Pacific islanders within the region contributed to the spread of leprosy.³⁴ It was not until the introduction of western ideas of health and medicine, through missionary activities and colonization, that the incidence of leprosy and its increase was recorded in the Pacific region.

It is not really possible to know how leprosy was viewed by Pacific islanders in the late nineteenth and early twentieth century. The oral history testimonies reveal attitudes towards leprosy sufferers during the mid-twentieth century that likely reflect earlier attitudes. But it is important to note, as pointed out previously, that attitudes of leprosy stigma vary from place to place and even person to person. Another limitation to the overall assessment of stigma in the islands is that the attitudes towards other diseases are not available for comparison. Whether attitudes differed according to the severity

of different diseases, and/or are the same as attitudes towards leprosy, lie outside the scope of this research.

There have been very few cases of leprosy diagnosed in New Zealand, and from 1925 until the discovery of sulphones, these cases were transferred to the leprosarium established on the island of Makogai in Fiji.³⁵ Even prior to the advent of sulphones, with isolation and the level of care available at Makogai, Dr. Austin, the medical superintendent at the leprosarium from 1930 to 1951, reported that the incidence of leprosy in Fiji had fallen, and the increased numbers of patients discharged annually from Makogai by 1948 were "good propaganda" for leprosy.³⁶ This is in contrast to the Hawaiian situation, where it was reported that the incidence of leprosy continued to rise despite compulsory confinement.³⁷ The subsequent dramatic improvement in the treatment of leprosy and fall in incidence of cases worldwide since the availability of sulphones in the 1940s and MDT treatment in the 1980s led the World Health Organization (WHO) in 2000 to aim for an elimination level of leprosy at less than one case per 10,000 population in the five year period leading to 2005.³⁸ As will be shown, this level of elimination has been achieved in most of the South Pacific region, although not yet in many other parts of the world.

Historiography

There has been a recent burgeoning interest in the historiography of leprosy worldwide, which to a large extent has been propelled by the Oxford Project to locate and retrieve archival material. Similar oral history projects and explorations for archival records have resulted in parallel research worldwide, which has contributed to a flourishing of leprosy historiography.³⁹

The research initiated by the Oxford Project in the South Pacific region has encompassed hitherto unexplored areas of historiography in Tonga and Vanuatu, and extends the boundaries of earlier works on leprosy in Fiji, New Caledonia and Samoa. An enormous contribution to the historiography of leprosy in Fiji was provided by Sister Mary Stella in *Makogai: Image of Hope* (1978) and Sister Joan Morris' dissertation *They Came to Makogai* (1966), both of which provide a background to leprosy in Fiji. In 1999 a documentary video produced by Bob Madey and Larry Thomas recorded the recollections of leprosy sufferers as they journeyed to re-visit Makogai.⁴⁰ Articles by the author and Jane Buckingham have provided accounts of a visit in 2004 to the leprosy hospital in Suva, Fiji. However, this research builds a much wider and more detailed perspective than that available in those initial articles.⁴¹ Although stigma is not specifically addressed in all these works, the lives of

the leprosy sufferers and descriptions of differing events implicitly indicate attitudes of stigma.

A collection of the memoirs (in French) of leprosy sufferers in Ducos, New Caledonia, was edited by Maryse Crouzat and Nicole Forrest, *L'Hymne à la vie: des pensionnaires du Centre Raoul Follereau: Une page d'histoire calédonienne*, which was published and launched at the time of the visit to Ducos in August 2006. Access to these memoirs has been limited by lack of a full translation. Nevertheless, reports and documents obtained from Dr. Crouzat, and filed in the Macmillan Brown Library, provide the background to leprosy in New Caledonia, with details of the recent period being supplemented by the oral histories obtained through the Oxford Project. Likewise, the dissertation of Safua Akeli in 2007, *Leprosy in Samoa 1890 to 1922: Race, Colonial Politics and Disempowerment*, has been utilized to summarize the early policies relating to leprosy in Samoa.

Other publications relating to leprosy in the wider Pacific region are John Miles' *Infectious Diseases: Colonising the Pacific* and Anne Perez Hattori's *Colonial Dis-Ease: US Navy Health Policies and the Chamorros of Guam, 1898–1941*, but these do not focus solely on leprosy nor stigma. An autobiography by Dr. John Valentine provides details of his time at the leprosarium at Tinian in the Northern Mariana Islands, and an oral history with him has been archived at the Macmillan Brown Library relating to this work.⁴²

Earlier twentieth century historiography of leprosy in the north Pacific region focused on the Hawaiian experiences of leprosy sufferers isolated at Molokai, and the life and death of Father Damien. These seminal events in Molokai shaped the later historiography of leprosy and have been the focus of numerous subsequent publications, but will not form a center of debate in this research.

More recent historiography has looked at western and colonial politics of segregation, and institutions of confinement, such as prisons for criminals and asylums for the mentally insane, as well as leprosaria for the containment of leprosy sufferers. Jane Buckingham, in *Leprosy in Colonial South India: Medicine and Confinement*, argued that the British government was limited in its powers to confine leprosy sufferers, and that the fragmented nature of colonial authority and penal hospitalization was a source of conflict and compromise, where even the weakest could resist. Differences and similarities in the attitudes of traditional Hindu and western cultures towards leprosy were discussed, but no definitive investigation of what comprised the varying notions of stigma itself was explored. Other publications examining the role of colonial powers in terms of public health and internment include David Arnold's *Colonizing the Body: State Medicine and Epidemic Disease in Nineteenth Century India*, Megan Vaughan's *Curing Their Ills: Colonial Power and*

African Illness, Alison Bashford's *Imperial Hygiene: A Critical History of Colonialism*, and, most recently, Rod Edmond's *Leprosy and Empire: A Medical and Cultural History*.

This work does not encompass or examine the limits of colonial powers in the South Pacific region, but provides narrative accounts of the experiences of leprosy sufferers and the care provided for these people by colonial governments and independent governments in the Pacific from the 1930s into the twenty-first century. It considers how the various institutions of confinement of leprosy sufferers established in Fiji, New Caledonia, Samoa, Tonga and Vanuatu, as well as the role of missionaries at these institutions, impacted upon local attitudes so as to contribute towards an understanding of stigma as it manifests in the South Pacific.

The testimonies included here add to the historical understandings revealed through the African voices reported by Eric Silla in *People Are Not the Same: Leprosy and Identity in Twentieth Century Mali*, where a collection of nearly two hundred life histories were used to elaborate the perspectives of leprosy patients.⁴³

Silla spent a year in Mali talking to patients and engaging with the political and social dynamics that shaped the lives of the patients; whereas this research only permitted brief visits to the specified Pacific nations, with no time available for in-depth evaluation of the intricacies of national political and social life upon the lives of leprosy sufferers. Nevertheless, the resilience and vibrancy found among the individuals in Mali have much in common with the lives of leprosy sufferers in the South Pacific region, in that the onslaught of the disease in both regions was followed by isolation within home and local communities by health authorities. In these situations the patients formed their own support groups, which led to the establishment of separate communities.

In 1989 Gussow published a socio-historical study, *Leprosy, Racism and Public Health: Social Policy in Chronic Disease Control*, which traced the values and institutional climate in which leprosy was embedded internationally, and the contemporary forces that were replacing established ideology regarding leprosy care. This publication followed on from earlier articles in 1970 and 1971 by Gussow and Tracy, based on their research with leprosy sufferers and workers at the leprosarium at Carville in Louisiana, USA, which concluded that contemporary ideas relating to the stigma of leprosy was a myth that had emerged in the early twentieth century.⁴⁴

These and other propositions by Gussow and Tracy will be discussed further in the following section on stigma; and, in particular, this research will explore to what extent these ideas are applicable to the lives of leprosy sufferers in the South Pacific region.

Brief History of Leprosy Stigma

Stigma is defined as “a mark of disgrace associated with a particular circumstance, quality, or person.”⁴⁵ The heart of the cruel stigma associated with leprosy and the attitude towards those suffering from the disease is exemplified in the word “leper” which, when used as an analogy in other contexts, makes explicit the sense that a person is shunned or ostracized from society. No other disease has such a derivative cognate as leper, indicating that that person has a specific disease, apart perhaps from the term HIV-carrier in association with AIDS. Like leprosy in the late nineteenth century, AIDS in the mid-twentieth century gave rise to hysterical fears of contagion and created stigma towards the unfortunate victims. In reviewing public health posters on the risks of AIDS contagion, Sander Gilman reproduced the advertising images used, which attempted to prevent the transference of the virus while at the same time avoiding the creation of stigma towards individuals, as in a poster slogan “It won’t kill you to spend time with a friend who has AIDS.”⁴⁶ If the lessons of history are learned in relation to contagious diseases where death is not imminent, such as in AIDS and leprosy, it should be remembered that in the fight against contagion there is a need to avoid ostracizing the victims so as not to increase their suffering.

In support of a worldwide agenda to de-stigmatize leprosy and remove connotations of those having the disease being ostracized from society, the word “leper” is avoided, apart from its use in specific circumstances (as above and in direct quotations). However, it should be kept in mind that some qualities inherent in stigma are present with all medical conditions that put others at risk through infection, such as influenza and the recent publicity regarding possible pandemics of bird and swine flu. Most people, where possible, would avoid putting themselves at undue risk of contagion, and this was the case with leprosy. The fact that the signs of the disease remained visible on leprosy sufferers who had not been diagnosed nor treated at the early stages but survived into old age wrongly raised fears of continuing contagion. Until leprosy was clinically understood, and medical tests confirmed the presence of active or inactive bacilli, neither the leprosy sufferers themselves nor those around them knew whether there was a risk of contagion or not. Findings from the oral histories suggest that the visible signs, and ignorance about the disease and its transmission, lie at the heart of the stigma of leprosy, rather than biblical proscriptions against leprosy.

Nevertheless, connections persist between what is referred to as leprosy in the Christian Bible and the clinical diagnosis of the disease in the twentieth century, and this has been blamed as the source of stigma. Etiological explanations have testified that the word leprosy in the Bible, and modern classifi-

cations of leprosy, refer to different conditions.⁴⁷ Browne has shown that the Old Testament Hebrew word *šāra’at* and later Greek word *lepra* are complex and untranslatable terms which embraced concepts impossible to interpret into single words in modern languages, but eventually came to be translated simply by the generic term leprosy, which included several skin diseases.⁴⁸ The Hebrew word *šāra’at* originally signified a state of ritual uncleanness or ceremonial defilement characterized by visible surface blemishes, on a par with the ritually unclean who handled corpses or with menstrual uncleanness.⁴⁹ Most references to *šāra’at* were in a ritual context, and to the Israelites, *šāra’at* was a condition amenable only to divine intervention, requiring ritual cleansing rather than a medical cure.⁵⁰ The Greek word *lepra* referred to the generic concept of scabiness, either scaly skin or sometimes even scaly walls, with no suggestion of the ritualistic defilement incorporated into *šāra’at*; but in the New Testament *lepra* came to be the equivalent of *šāra’at*.⁵¹ Thus the two words coalesced and were translated simply as leprosy into English and other translations of the Bible. Leprosy remained a generic term until the specific disease was precisely delimited clinically in 1847 by Daniellssen and Boeck.⁵² The serious prejudice associated with the generic term leprosy was reinforced by transfer of the corpus of *šāra’at* beliefs to the innocent victims of newly identified mycobacterial disease, clinically identified by Hansen as leprosy.⁵³

Dr. Desmond Beckett, one of the later medical superintendents at the leprosarium at Makogai in 1960s, had earlier been involved in the care of leprosy sufferers at Makondane leprosarium on the island of Pemba, Zanzibar, and at the Jos Plateau in Nigeria. He clearly points out that the biblical references to leprosy and “leper” were not necessarily the same medical condition as that recognized as leprosy today, although it was probably one of the conditions included in the generic use of the term.⁵⁴ Nevertheless, Beckett considers that “the morbid interest in leprosy and the instinctive dread of the condition that is almost universal in the non-medical world, stems from this biblical indoctrination.”⁵⁵ This view supports the opinion of Brody that the “stigma of leprosy is thus the product of a long tradition.”⁵⁶

The level of stigma encountered in the South Pacific, predominantly Christian nations, is reported to be less severe than in some other countries — for example, Japan, which is not a predominantly Christian country and where stigma cannot be blamed on the Bible and Christian attitudes. But it was not until 1996 in Japan that a law enacted earlier in 1953 finally abolished forced segregation, putting an end to enforced isolation of leprosy sufferers in sanatoria.⁵⁷ Researchers in the Ryukyu Islands have demonstrated that younger Japanese generations are more likely to take a benign view of leprosy because they no longer witness the deformities caused by advanced leprosy. But older

groups believed that leprosy patients should be permanently isolated because they had personally observed the deformities of victims and could not accept that the patients were no longer infectious.⁵⁸ This Japanese research suggests that early diagnosis and treatment of leprosy, which avoids later physical deformities, should finally result in the diminishment of stigma. The finding is one that will be shown to be supported by this research. The high level of stigma in Japan, particularly among the older generation, has been attributed to the stringent public policies of isolation, so much so that in May 2001, \$17 million were awarded to leprosy sufferers as compensation for their ordeals, and the then prime minister, Junichiro Koizumi, publicly apologized for the wrongs of the previous governments.⁵⁹ This compensation implicitly recognizes that isolation of leprosy sufferers contributed to the high stigma. A Japanese benefactor, Yohei Sasakawa, through the Nippon Foundation, has made a commitment to provide the medical treatment MDT to leprosy sufferers worldwide free of charge.⁶⁰ The benefit of free medication and efforts to ensure early diagnosis and treatment of all leprosy sufferers should result in the gradual elimination of the awful visible symptoms of advanced leprosy cases. If the conclusion of the Japanese research is correct, this, in turn, will lead to a corresponding diminution of the fears that sustain stigma.

The modern use of isolation as a recognized health practice developed in western societies through the public health in the nineteenth century, which focused on sanitation, hygiene and preventative medicine. Practices incorporating quarantine and isolation had been effectively used to combat highly infectious tropical diseases — so much so that at the First International Leprosy Conference in 1897, in view of the lack of any effective treatment or inoculation, and with the backing of Hansen, segregation was advocated for the confinement of leprosy cases.⁶¹ This was in opposition to the earlier findings in India of the Leprosy Commission in 1893 which considered isolation impractical, with compulsion likely to lead victims of the disease to hide from authorities, as had already been evident with compulsory isolation in Hawaii.⁶²

The British medical fraternity and National Leprosy Fund, who were aware of isolated cases of leprosy in Europe and especially in Norway, recognized that the disease was not highly contagious and that the public risk was so low that isolation was impractical, unnecessary and even cruel.⁶³ Nevertheless, the outcry to segregate leprosy sufferers persisted in the public domain, especially in newspapers and even through literature. Elements of the exotic, bizarre and even horror inflamed the imagination.⁶⁴ It is a very basic human trait to fear anything that can cause gross physical harm to the body. Leprosy in western society and literature embodies this horror; yet it also inspires fascination and fantasy regarding the limits of societal taboos.⁶⁵ This fascination in fantasy and fiction, it is suggested, has compounded western ideas of stigma

and leprosy, the latter being a word steeped through antiquity with morbidity.

With isolation practices advocated for leprosy sufferers, in the twentieth century leprosy stigma became associated with the terrors of being removed from one's home and incarcerated far away without any means of self-sufficiency, as has been suggested was the case initially at Molokai, Hawaii. The section below on leprosaria provides a contextual basis for comparison and an assessment of the leprosarium at Makogai, Fiji. The lack of public health resources to support government policies of isolation and segregation, meant that leprosy sufferers became not only wards of the state, but victims dependent upon the goodwill and philanthropic generosity of individuals. The plight of leprosy sufferers spawned the growth of charitable organizations such as the Leprosy Mission, and in New Zealand the Pacific Leprosy Foundation in Christchurch.

Missions and Stigma

From the earliest days of leprosaria in the South Pacific, most people were reluctant to work with leprosy; only the religious orders were willing to do so, as they saw it as part of their duty to help those in need. It has been suggested by various researchers, including Edmond, that the high level of missionary involvement in the provision of care at leprosaria worldwide contributed to a revival of old biblical stigmatic attitudes.⁶⁶ Edmond went on to suggest that the missionaries simply “palliate[d] the worst effects of crude and harsh quarantine,” and that patients were merely “educated to accept their life-sentence, abandon all other identities and wait for better things in the afterlife.”⁶⁷ The oral history testimonies of leprosy sufferers in the Pacific Islands do not indicate that the nuns running the leprosarium at Makogai or other leprosaria gave particular emphasis to the connections between leprosy and biblical ideas of sinfulness or divine wrath. Some interviewees were aware of biblical texts and referred to the fact that leprosy was mentioned in the Bible, but displayed no knowledge that their condition might, in fact, have been different from that referred to in the texts. Others acknowledged that segregation was endorsed by the Bible, which prescribed that those with leprosy should be “sent to the end of the village.”⁶⁸ This idea perhaps fits with biblical prescriptions that the diagnosis of leprosy meant a life sentence away from the community, which in turn sanctioned their own isolation in leprosaria.

Gussow and Tracy have described the ministrations of religious orders at various leprosaria as a “relationship of missionary activity ... bringing to

life of a modern parable⁶⁹—namely, that of the Good Samaritan, which they suggest re-invoked perceptions of older ideas of biblical stigma by the early twentieth century.⁷⁰ Because of this biblical stigma, in the USA from 1920 to the 1940s, a process of destigmatization was pursued, which included renaming leprosy as Hansen's Disease; yet stigma is believed to have persisted.⁷¹ Gussow and Tracy explored these ideas in relation to the situation at Carville leprosarium in the USA, and described the link between the biblical stigma and the present-day ideas of leprosy stigma as the creation of a myth.⁷² They suggest that this myth was created or re-created during the period when leprosy was encountered in colonies in the late 19th century, particularly after the identification of *Mycobacterium leprae* in 1873 and the hysteria surrounding the death of Father Damien at Molokai, Hawaii, in 1888. The latter event had been sensationally reported in the western press, with fears expressed that although leprosy had virtually disappeared in Europe during the sixteenth century, it could re-emerge and be re-introduced into the west because it had afflicted a European, the Belgian priest Father Damien. These fears were exaggerated because Hansen's recent discovery was seen as confirmation that people with the disease were sources of contagion, whereas methods of transmission of the disease had previously been uncertain and often erroneously considered to be hereditary.⁷³

Myth of Stigma and Self-Stigma

The research by Gussow and Tracy at Carville concluded that since the advent of the effective cure by sulphones, fears about the disease and contagion had diminished, replaced with false ideas that leprosy was a disease of the past—so much so that, in fact, prevailing notions of stigma no longer existed in the public mind. It was further noted that the experiences of those suffering leprosy and those involved in the treatment of the disease reflected no consistent pattern of stigma, but that the years of isolation had inflicted a level of internalization of stigma, referred to as “self-stigma,” upon the psyche of residents at Carville.⁷⁴ Self-stigma is the internalization of the public perception that those with leprosy should be excluded from normal society, so that leprosy sufferers felt they needed to be segregated because they were contagious and needed to protect the public from any contagion.

Although the above categories are essentially western ideas, to varying degrees they are evident in the South Pacific, either through early colonial contacts and/or conveyed by western medical personnel and missionaries. The use of lengthy extracts from the testimonies of leprosy sufferers will provide descriptions of the experiences following diagnosis with leprosy and their

internment at different leprosaria. These will also help to show how leprosy sufferers perceived their social acceptance back in their communities, and to what degree, if any, notions of stigma and/or self-stigma existed. A wide range of personal differences were evident, and leprosy sufferers who appear to have internalized stigma tended to isolate themselves and not mix freely in their local communities. Whether this was entirely due to internalized ideas of stigma, or was a reflection of the real attitudes of the local communities, is the vexed and ambivalent issue in the assessment of stigma. The views of leprosy sufferers also demonstrate a responsible and positive attitude in that several interviewees encouraged their family members, especially children, to be checked regularly for early signs of leprosy. This understanding of leprosy, and the simple, effective treatment now available, is changing old negative attitudes towards leprosy in the Pacific islands.

In attempts to deter stigma worldwide, an official day was nominated in 1954 as World Leprosy Day by the French philanthropist Raoul Follereau.⁷⁵ Follereau was the benefactor of leprosy sufferers in several French colonies in Africa as well as New Caledonia, and his initiatives led to the formation of the European Federation for Leprosy (ELEP), which later became known as the International Federation Assisting Leprosy (ILEP).⁷⁶ World Leprosy Day was nominated as the last Sunday in January, and in Tonga, Samoa and Fiji on this day leprosy awareness programs are aired on national and local radio stations. The effectiveness of this and various other awareness programs is not easily assessed in regards to the extent the information is actually assimilated by the public. In the long run, such programs do help raise understanding about leprosy and the efficacy of the treatments, reducing misunderstood fears about the disease and its associated stigma.

Growth of Leprosaria and Missionary Involvement

During the eighteenth century the practice of isolating particular groups of people grew, and planned asylums were built in the U.S. for specialized purposes (such as homes for unwanted children); while in Europe such asylums were often located in what were originally monasteries.⁷⁷ The name “asylum” was derived from the Greek word for refuge, being places inviolable from without. It became implicit that asylums were not considered places for punishment, but places to effect a cure for the ills of society; therefore, being committed did not necessitate any legal process for removal of people to these institutions.⁷⁸ The asylum became a benevolent institution that extended to include places of confinement for leprosy sufferers, earlier referred to as lazarette or lazar homes, utilizing the Christian story of Jesus healing Lazarus

and indicating that these homes were to assist and treat leprosy sufferers.⁷⁹ These leprosaria were also called leprosy stations or leper colonies. The terms colony and station implied self-sufficient places where groups could live and form a functioning community.

This sanction to endorse segregation of leprosy sufferers, particularly in the USA, led to what has been referred to as the "production of a culture of difference"⁸⁰ because the institutions created required staff to care for patients and funding to provide necessary services. In Britain the Mission to Lepers was founded in 1874 and became the prototype for church supported agencies for the care and treatment of leprosy patients.⁸¹ In providing specialized facilities for leprosy sufferers, leprosy became institutionalized, with even a specific name for the doctors — leprologist — and further specialized services developed in line with modern health care practices.

With institutionalization in the twentieth century, leprosy became a zealous and altruistic mission for the church and missionaries, who in turn used their influence and widespread affiliations to raise charitable funding.⁸² Since lay people were reluctant to care for those suffering from leprosy in institutions, especially in remote areas, religious orders undertook the work. The commitment and selfless devotion of sisters from different Christian denominations, who provided daily care, involved spending the majority of their lives in remote leprosaria, examples being the Daughters of Charity of St. Vincent de Paul in Carville, USA, from 1896 to 2005, and the Sisters of St. Paul of Chartres at Culion leprosy colony in the Philippines from 1906.⁸³ For the South Pacific region, the founding pioneers of a Catholic order which came to be the Missionary Sisters of the Society of Mary (SMSM), set out from France. One of these pioneers arrived in New Caledonia in 1864, and by 1892 was tending to the needs of leprosy sufferers.⁸⁴ Additionally, the Anglican Melanesian Mission began operating in the islands in 1849, which in the twentieth century led to the establishment of leprosaria. The activities relating to leprosy in New Caledonia will describe the involvement of the missions, which subsequently led to the SMSM becoming the providers of nursing staff and helpers at the leprosarium established at Makogai, Fiji, in 1911. The research of Joan Morris describes life at Makogai in the 1950s and concludes that the leprosarium was not simply a "polyglot of sufferers" but a colony which had formed into a "well integrated community."⁸⁵ Testimonies of leprosy sufferers who had been isolated at Makogai will be quoted and support Morris' conclusion. These demonstrate that the facilities available at various smaller leprosy colonies and/or wards or wings established at different South Pacific hospitals to isolate leprosy patients contributed to perceptions of increased or diminished associated stigma, dependent upon the conditions at each leprosarium.

The role and activities of the SMSM sisters at the leprosaria in Fiji, and at the Raoul Follereau leprosarium in New Caledonia (as well as the leprosy care offered by sisters in Samoa and Tonga), are examined to assess and refute the claim by Edmond (referred to earlier) that the religious orders simply palliated the needs of leprosy patients and prepared them for the afterlife. Edmond's view fails to recognize the medical and scientific professionalism which has been neglected in descriptions of charitable activities. The role of the Anglican Melanesian Mission staff running the leprosarium at Lolowai, Vanuatu, will be described in this context, and particularly in view of the comparatively low level of stigma evinced in the islands of Vanuatu.

Other Leprosaria

In order to provide a context for comparing the leprosaria in the South Pacific region with leprosaria cited in earlier historiography, a brief description of some of these institutions follows — namely, Molokai leprosarium in Hawaii, Carville in the USA, and the isolation of the Chamorros of Guam at Culion in the Philippines, plus limited comment on leprosaria set up in India and Singapore. Although insufficient details are provided here to make any real overall comparison between these worldwide leprosaria, the descriptions will demonstrate a difference in the approaches to establishing leprosaria in the South Pacific, particularly Makogai in Fiji, and St. Barnabas leprosy hospital at Lolowai in Vanuatu.

Although isolation may have confirmed fears of contagion in the public mind, leprosaria undoubtedly provided a humane alternative for those who could not care for themselves or had nobody else to care for them, as described in the events cited by Edmond.⁸⁶ The ambivalence of isolation is evident with a case of leprosy discovered in London in 1898, the same year as the First Leprosy Conference in Berlin, which had advocated isolation for leprosy cases. Although the *British Medical Journal* noted that there was no need for alarm due to contagion, it pointed out the absence of, and therefore the need for, a dedicated institution to care for those leprosy sufferers who were not able to provide for their own care or had no one else to care for them.⁸⁷ Debates in the press relating to isolation continued for some years, and an anonymous correspondent signed "A Leper," who had apparently worked in an "asylum for seven years and become infected,"⁸⁸ wrote that those infected wished to take every precaution to prevent any spread of the disease, and that "an asylum offered a secure and known world where patients would not be shunned."⁸⁹

In due course, through a charitable donation, a home was established outside London in the village of Woodham Ferrers in Essex. The first few

cases of leprosy were transferred during nightfall to avoid attention, and soon two nurses from a religious order and some monks took up residence to provide care.⁹⁰ These events clearly demonstrate that isolation of leprosy sufferers fulfilled a need by providing a place where those requiring help could go voluntarily, rather than isolation being simply imposed or enforced by the authorities. The sick deserved to be cared for when, on occasion, they were turned out of their lodgings and should not be left to literally rot on the streets. It will be shown that similar needs gave rise to the establishment of small leprosy colonies in the Pacific islands, which later coalesced into larger leprosaria with better medical facilities.

In Hawaii, as early as 1865, the forced segregation of leprosy sufferers passed into law, and the remote and difficult to access location of Kalaupapa on the island of Molokai became the site to which the unfortunate victims were banished.⁹¹ Much has been written about leprosy at Kalaupapa on Molokai, and on the conditions and manner in which Father Damien devoted his energies to help those suffering from leprosy; these debates will not be entered into here. Nevertheless, it is important to note that from the earliest days when leprosy sufferers were brought to Molokai, they were unable, for various reasons, to become self-sufficient, partly because the land supposedly available for planting was disputed by locals.⁹² Living conditions were miserable, as widely reported after the death of Damien, and in the main the patients had to fend for themselves. The horrors reported worldwide regarding the conditions at Molokai and the horrific plight of the unfortunate victims exacerbated fear of being diagnosed with leprosy, which led to patients resisting or hiding from health authorities.⁹³ This inevitably increased the stigma associated with leprosy. In Fiji, as will be discussed, a large leprosarium was established on the island of Makogai much later, in 1911; in contrast, it was well planned, with good facilities available, prior to the arrival of patients. The whole island of Makogai was dedicated to improving the living conditions of the residents, who from earliest times took part in gardening and fishing to support a self-sufficient and useful lifestyle — because a life sentence was envisaged on the island.

The first institution in the U.S. devoted solely to leprosy was the Louisiana Home for Lepers in 1894; in 1896 the Daughters of Charity of St. Vincent de Paul came to tend the patients.⁹⁴ The Louisiana leprosy station on the banks of the Mississippi River, not far from New Orleans, was a remote and poor region, and patients were brought from distant places and segregated far from their families. The poor district and tyranny of distance put fear into the minds of leprosy sufferers and their families. Because of the strong stigma of leprosy, an atmosphere of stealth and secrecy prevailed in the early years at Louisiana, where the first batch of patients were brought up-river under the

cover of darkness to avoid discovery of the purpose of the dwelling by locals.⁹⁵ The conditions were such that the patients and sisters had to contend with ignorance and prejudice against the disease that “rendered the stigma even harder to bear than the physical suffering.”⁹⁶

By contrast, in Fiji and other Pacific islands, small leprosy colonies had initially been set up nearer the homes of leprosy sufferers, often with impoverished conditions, and the patients were gradually transferred to the larger leprosaria, enabling them to benefit from the wider range of facilities available. In these circumstances, removal by force was unnecessary, although stigma was evident in the problems encountered to secure transportation for the patients. Rather than secret transportation, a few boats agreed to carry such patients, but would signal the presence of leprosy patients by flying a special flag; and the boats were disinfected after the patients disembarked.⁹⁷ Hoisting a flag on boats carrying sick or quarantined people was a common practice in colonial ports.

The advantage of establishing larger leprosaria is evinced by the purchase of the Louisiana station in 1921 by the U.S. Government, whereupon conditions improved and it became the national hospital for leprosy in America, commonly known as Carville, the leading center for research into leprosy and rehabilitation of leprosy sufferers. It was here in the 1940s that the phenomenal breakthrough was made — the successful treatment of leprosy by sulphone drugs.⁹⁸ This discovery and the commencement of an effective treatment for the disease made a revolutionary improvement in the lives of patients, but the stigma was reported to be harder to eliminate.⁹⁹ The stigma attached to leprosaria remained, as Dr. Beckett pointed out, partly because the location of Carville remained where it had been deliberately positioned — between the male and female State penitentiaries, as a means to prevent intermingling.¹⁰⁰ Such geographical locations are naturally perceived as locations for outcasts from society. The location of leprosaria in distant, often impoverished areas, or, alternatively, in prisons (as occurred in New Caledonia), impacted on public perceptions of stigma associated with leprosy sufferers and leprosaria. Fortunately, with the more recent effective treatment of MDT, leprosy is gradually being treated as just another disease at ordinary hospitals, and specialist care specifically for leprosy is situated within the walls of general health providers. Thus the association of leprosy with separation and outcasts from society should cease in the public mind which will bring relief to the victims themselves.

Another example of the tyranny of distance and fear contributing to the perceived stigma of leprosy is seen in the treatment of the Chamorros of Guam, who were transferred to the leprosarium at Culion in the Philippines, which was established in 1901 and became the largest leprosarium in the

world.¹⁰¹ Leprosy sufferers were forcibly gathered by the U.S. Navy in Micronesia, including Guam, and taken to the distant island of Culion. In 1902 the Chamorros were initially segregated at the nearby island of Tumon in Guam, the colony being surrounded by high, barbed wire fences. Iron bars were placed on windows and the doors padlocked at night; but many inmates managed to escape, and family members managed to enter the barricades (which, in fact, perhaps, made the segregation tolerable).¹⁰² Hattori notes that a language reflecting the “criminalization of the ill”¹⁰³ is evident in government records, not only in the manner of capture but in living arrangements, which would have confirmed ideas of exclusion and unacceptability in the psyche of patients.¹⁰⁴ Finally, in 1911 it was deemed more expedient to transfer the “inmates” at Tumon to the distant Philippine island of Culion, despite the awareness by officials that the Chamorros appeared accustomed to the disease and were opposed to isolation.¹⁰⁵ The fear of banishment was so great that, it is reported, a blind man with leprosy carried a woman who could not walk on his back, and together they escaped transportation by the Navy and evaded detection for over a month.¹⁰⁶ Exile to Culion continued until 1924, at which time the surgeon at Guam decided that the expulsion policy resulted in worse health conditions for the Chamorros; cooperation was needed for health programs to succeed, and the fear of exile had led leprosy sufferers and other patients to avoid American doctors and hospitals.¹⁰⁷ Leprosy sufferers were returned from Culion to the Tumon colony where patients continued to be segregated. These events demonstrate that banishment and exile contributed to the fearful reputation of leprosy, which is also evident in South Pacific regions, raising fears and stigma. The use of force to remove patients undoubtedly aggravated perceptions of stigma in Guam, which did not occur further south in the Pacific, apart from some evidence of forcible confinement in New Caledonia.

Some patients in Guam indicated they took pride in accepting banishment because their action avoided the risk of being the source of contagion to their own families.¹⁰⁸ This double-edged sword of leprosy demonstrates that a level of humane segregation was acceptable to patients; but however brave the idea of pride in accepting exclusion and distant exile may have been, exile raised stigma. Significant stigma is evident in the fact that leprosy patients hid rather than seek medical attention because of the consequences of a diagnosis of leprosy. These findings are partially reflected in the experiences of those in Tonga, where patients who returned from isolation at Makogai faced stigma through exclusion in their own homes — either because they continued to be perceived as a risk for leprosy contagion, or due to ingrained attitudes in their village communities.

Another instance of the conditions of incarceration which would have

perpetuated ideas of exclusion and stigma is Buckingham's description of the high walls specially placed around a leprosy hospital built by the British government in Madras, India, ostensibly as a place of voluntary residence.¹⁰⁹ Here patients had to wear red caps, as did criminal prisoners; so instead of being seen as a charitable and benevolent institution, which was at least in part the intent of the medical officer working there, the hospital came to be seen as “a place of terror.”¹¹⁰ Nevertheless, Buckingham suggests that it was the hospital which was stigmatized, not the leprosy patients, as their families continued to visit at the hospital. Another leprosy hospital was established at Port Blair on the Andaman Islands, a well known British penal colony¹¹¹ — yet again linking leprosy with the outcasts from society. In New Caledonia, the leprosarium at Ducos was previously a prison, and the stigma of leprosy appeared greater in New Caledonia than in neighboring Vanuatu. The perception of leprosy patients being treated the same as those who were outcasts from society appear to have contributed to a higher level of stigma.

Although leprosy confinement was not compulsorily enforced in India, and institutions were altruistically intended to be places of refuge rather than places of detention, the geographic situation of institutions at penal colonies with high fences around them, and particularly the stipulation of wearing caps like those worn by state prisoners in Madras, would have contributed to the perception of an unwanted people, unworthy and barred from ordinary society. During the earlier days of isolation in Samoa and Tonga, high fences were erected at the end of hospital grounds to contain leprosy sufferers in special buildings, segregating from the main hospital; these areas were viewed with some degree of fear and horror by the general public.¹¹² Buckingham indicates that in India this culture of difference produced feelings of shame in families with leprosy but mainly the poor and homeless were segregated into the leprosy colonies, while those with families who could provide care were frequently hidden from public gaze in their homes to avoid being shunned by their community.¹¹³ Despite segregation of the poor, Buckingham suggests that patients retained the power of resistance and negotiation, and viewed the leprosy hospital in Madras more as an institution for care and treatment than a place of forced confinement.¹¹⁴ These findings run counter to the view that leprosy sufferers were merely confined for the public good. Additionally, it demonstrates that leprosaria served the interests of advanced leprosy cases both before and after the availability of sulphones in India and the South Pacific.

In 2005, Loh Kah Seng interviewed elderly leprosy sufferers in Singapore, many of whom had been segregated for several decades, and was told by patients who lived at the leprosarium that because they bore visible scars and disabilities, they had been unable to convince family, friends and the public

that their leprosy was cured.¹¹⁵ It was further noted that following the discharge of large numbers of patients soon after the first sulphone treatments, many of those discharged demanded to be readmitted because they had been rejected by their families and had nowhere to go.¹¹⁶ This supports the proposition that the physical manifestations of the disease form one of the core constituents of stigma, and that leprosaria fulfilled a need for leprosy sufferers with physical disabilities. Furthermore, these attitudes cannot be ascribed to Christianity because Singapore is not predominantly Christian.

There are commonalities between the British colonial governments in Singapore and the Pacific Islands. In Singapore a Lepers' Ordinance was passed in 1897 — two years earlier than a similar ordinance implemented in Fiji in 1899, both of which restricted the occupations that leprosy sufferers could hold.¹¹⁷ There are various parallels within the history and approaches to containment of leprosy in Singapore and the Pacific Islands, although in the Pacific Islands confinement was not enforced by the authorities like in Singapore. Centralized leprosaria came to represent places fondly remembered as a home for the residents, providing friendships and a sense of community spirit.¹¹⁸ The Singapore interviews indicated that although their “lives are bad” due to leprosy and disabilities that prevented them from returning to ordinary life, their “luck was good” because they had received care and a place that had become home to them, despite societal rejection.¹¹⁹ This sense of cheerful irony is somewhat echoed by interviewees at Twomey hospital in Suva, Fiji, after the closure of the leprosarium at Makogai; residents were concerned because their hospital was being increasingly used for non-leprosy patients, and they felt at risk of losing their home.¹²⁰

These attitudes of leprosy sufferers, however, can be interpreted differently — that is, as a dependence on institutions reflecting a continued expectation of an entitlement to free care and medical support. This care and ongoing support is available to elderly leprosy sufferers who underwent isolation and had lost support of families and their communities, as well as cases with severe physical disabilities who are residents at various leprosaria in the South Pacific. Certainly the PLF continues to offer support to these people. But with MDT treatment, patients can now be rendered non-infectious within forty-eight hours,¹²¹ and such expectations can no longer be taken for granted, as new cases of leprosy fall within the realm of ordinary diseases. This view is reported by Silla in his research in Mali, where the French leprologist Pierre Bobin, who had previously worked in New Caledonia, noted that in both countries “former patients ... had grown accustomed to receiving free medicines, quality care for ailments unrelated to leprosy ... and considered themselves entitled to these benefits.”¹²² Silla's research demonstrates how leprosy sufferers in Mali viewed themselves as a separate group, with their identities

rooted in the disease.¹²³ He describes how these people formed an association to fight for their rights to obtain charitable grants donated by the Association Raoul Follereau, little of which had been seen by Malians. Also, when the government sought to take over land earlier allocated as a leprosy village by the former colonial government, the residents fought back, revealing their collective participation in civic life, which Silla suggests demonstrated “the capacity of the disease to define identity as forcefully as more common attributes rooted in languages, religion or ethnicity.”¹²⁴ Silla reports that Dr. Bobin viewed suggestions of a collective identity of leprosy patients as an anachronism, as opposed to Silla's contention that scientific advancement and medicine had failed to eradicate the disease and its stigma.¹²⁵ However, Silla also observed that leprosy no longer prevented marriages or caused social isolation, but concluded that stigma “still permeates the society in which they live.”¹²⁶ Silla does not specifically identify what constitutes stigma, but suggests that stigma derives from the incurable and chronic nature of the disease.¹²⁷ This tends to support the proposition by Bobin that the separate identity of leprosy sufferers, centering on the disease, was indeed an anachronism in the late twentieth century, since leprosy was virtually curable. Alternatively, identity associated with leprosy could be interpreted as reflecting elements of internalization or self-stigma, as observed by Gussow and Tracy, drawing together a community with close common interests and past experiences.

These historical descriptions of life at some worldwide leprosaria demonstrate that although isolationist policies imposed fear and emotional hardships of separation from loved ones on leprosy sufferers, leprosaria offered opportunities for friendships without any fear of being the source contagion. Living at leprosaria developed a spirit of camaraderie and community. A leprosarium was a place where patients felt they belonged, and for many it became home and a place where some friendships resulted in marriage and family. These findings are paralleled by leprosy sufferers in the South Pacific, and these testimonies will be explored to discover whether, apart from the benefits of leprosaria, leprosaria per se and/or the nursing mission sisters contributed to the idea of stigma.

The Interviews

My first visit was made to Fiji in 2004, followed by visits to Samoa, New Caledonia, Vanuatu and Tonga in 2006, and a further visit to Vanuatu in 2008.¹²⁸ The PLF liaison personnel in the islands usually approached individual leprosy sufferers prior to my visit, and personally escorted and introduced me to the interviewees. A general questionnaire was utilized at the interviews,

seeking details of the interviewees' childhood, parents, siblings, schooling, lifestyle, their own adult experiences, occupations, marriage and children, with a focus upon their health. Questions were not specifically directed at experiences relating to the stigma of leprosy, but stigma was implicit in the life stories recounted. Interpreters were frequently used because of my lack of Pacific languages.

The experience of interviewing leprosy sufferers is not easily conveyed, especially the warmth of their reception to a foreigner arriving in their homes, not only enquiring into but recording various private aspects of their lives. I am obliged to recognize that the warmth of my reception may have been linked to the presence of the PLF liaison personnel who facilitated the introductions, having driven me to remote village homes to enable the oral histories to be recorded. The interviewees might have felt beholden to the PLF representatives, who provide assistance from the PLF and report back to Christchurch concerning future needs. In the main, the interviewees appeared pleased and excited to have their stories recorded and were happy to pose for photographs. Matters relating to physical disabilities were indirectly raised by enquiring what problems were experienced later in life due to leprosy.

The first interviews were conducted with thirteen leprosy sufferers living at P. J. Twomey Memorial Hospital in Suva, Fiji, in August 2004. Two of the residents had previously been filmed for a documentary about life at the leprosarium at Makogai and the residents appear to have been happy with the result. There was no apparent apprehension about having their personal life stories recorded.¹²⁹ My concern was in doing justice to each interviewee given the restraints imposed by limited time — trying to squeeze in all thirteen interviews and visit other leprosy sufferers in their homes within five days.

Three visits were made to leprosy sufferers in their homes and villages in Fiji. Although prior arrangements had been made to record the oral histories, family members were present in the home, often young children who played nearby and interjected at times. The homes, frequently built with the assistance of PLF donations, were simple two or three room houses close to neighbors or plantations. The open style of homes could not prevent the sounds of trucks clattering past, neighbors talking, radios outside nearby, dogs barking and cocks crowing or fighting. The ideal oral history interview environment of a quiet room with no interruptions was never available in the island homes visited. Conducting oral histories with casual interpreters meant there was little control over what was actually asked and how accurately answers were interpreted. Careful phrasing of questions in English, and innuendoes in the replies, were probably lost through the use of casual interpreters.

The second series of interviews took place in Samoa in January 2006. Sister Marietta SMSM, originally from Christchurch, was the liaison contact

and facilitated the meetings with the leprosy patients. A PLF truck, shared with the doctor in charge of leprosy patients, was available to Sister Marietta to drive us to their homes around the island of Upolu. The majority of interviews took place in Samoan homes — *fale* — which are literally open walled buildings with pillars and a roof. The roof provided protection from the sun and rain, and the supporting pillars allowed the cool breeze to circulate through the home. Conducting interviews in these surroundings again meant no possibility of excluding unwanted sounds. The interviewees were very forthcoming with their stories, providing vivid accounts of their experiences, particularly in Samoa. Sometimes the manner of speech was difficult to follow for an outsider new to Samoa, but the majority of interviewees spoke good English.

On the visit to New Caledonia in September 2006 it was discovered that the leprosy sufferers at the Raoul Follereau leprosarium at Ducos, near Noumea, had already had their stories recorded for a French publication, launched during my visit. It was not deemed appropriate by the authorities and care givers that further recordings be made. New Caledonia had stopped receiving funding from the PLF, and the French government provided the care for leprosy sufferers, so there was no PLF contact on the island. A visit to the SMSM mission headquarters in Port Vila, Vanuatu, enabled a meeting and interview with a local SMSM sister, Noëllie, who had worked with leprosy patients throughout her life of service. She then arranged a visit and interview with one of the longest term residents at Ducos leprosarium.

Tonga was visited in November 2006, and Sister Joan Marie SMSM ran a nursing clinic and was the PLF liaison contact at Maofanga on the main island. She made time during her busy surgery hours to introduce me to the doctors who worked with leprosy patients, and arranged for her assistant to facilitate the interviews around Nuku'alofa, who also acted as interpreter. The homes of the interviewees were small *fale*-type buildings, with materials provided by PLF, most homes being relatively remote from nearby villages. On a visit to the northern island of Vava'u, four leprosy sufferers, and a matron of the hospital to which the Fale'ofa leprosy station was annexed, were interviewed. Sister Goretti SMSM was the PLF contact in Vava'u and drove me to meet the interviewees, also serving as interpreter. While visiting Tonga, the research had to be curtailed due to civil political action, resulting in the central section of the capital city Nuku'alofa being burnt down, which I witnessed from small aircraft returning from the northern island of Vava'u to Maofanga. Electricity supplies to the island failed, all businesses and government departments closed, access within the city was restricted and airports were closed to flights for several days.

The visit to Vanuatu in October 2006 permitted only interviews in Port

Vila with staff who had worked at the leprosarium at Lolowai and now resided in Port Vila, together with an interview with Dr. Roland Farrugia, the visiting PLF consultant and former WHO leprologist. Names were obtained of staff of the leprosarium who retired back in Auckland, New Zealand, and subsequent interviews were conducted with Sister Betty Pyatt, and Dr. and Mrs. Mackereth. In 2008 a visit was made to a northern island of Vanuatu to record interviews with leprosy sufferers in Espiritu Santo. Tony Whitley, of Rowhani Baha'i School in Santo and a PLF liaison contact, organized a driver and another fellow Baha'i worker, Carren Bough, to act as guide and interpreter to enable interviews with leprosy sufferers both nearby and deep into the island.

The Melanesian homes were very different than the open, *fale*-styled Polynesian homes, as they were often tall, tapered, windowless huts with dark, cool interiors. As it was the "winter" season in the tropics, and overcast outdoors, interviews were conducted inside the huts where very little light penetrated. Small wood fires were lit on the open ground of the interior for warmth and light. These home conditions revealed how easily leprosy sufferers with anesthetized limbs injured their feet and/or hands while warming themselves beside the embers.

Despite the lively tales and vivid details of the memories of the interviewees, dates and western ideas of time were quite vague in many cases in Vanuatu. Birthdays were often unknown; and with older participants, to obtain an idea of dates, such as when leprosy was contracted and visits to leprosaria occurred, it was useful to ask whether these events occurred "before or after the war," and whether they were children or adults at the time. World War Two had made a huge difference to life in the islands, and several personal accounts were recorded. Other means of dating events involved jogging memories about medical staff at the leprosaria. This lack of personal detail is uncommon among westerners, but it would be quite wrong to assume a corresponding lack of understanding or connection with modern-day life by the Melanesians. Although there was no electricity in many of the homes, with meals being cooked on open fires nearby, comprehension was not an issue. This is particularly evident when the nephew of an interviewee, Mary Alma Namtatak, joined the photograph session. Immediately afterwards he asked for the memory stick from my digital camera and a few moments later produced the photographs downloaded on his computer. Comprehension and ability were no problem, especially when modern technology was available.

An important feature of this book is that the interviewees are identified and often shown photographed with their families. It is felt that using the real names of the interviewees brings an authenticity, integrity and proper appreciation of the adversity that leprosy sufferers had to overcome — plus

the realization that leprosy had not prevented most of them from raising normal, healthy families. The openness with which the life stories were told, whether it involved tears recounting painful separations or joy in witnessing the good health of their offspring, is more likely to dispel ignorance about leprosy and, accordingly, its stigma. It is believed that ending the secrecy previously associated with leprosy will result in an understanding and recognition that anyone who contracts the disease in this day and age no longer need fear or re-live the painful experiences of the past.

The descriptions that follow relating to the conditions at each of the Pacific nations commence with a pithy historical introduction to provide some idea of the differences between the island nations. This is followed by an overview of the history of leprosy up until the period encompassed by the oral histories gathered. Long extracts of individual testimonies provide vivid and detailed descriptions of the lives and experiences of leprosy sufferers, implicitly voicing the level of stigma encountered at various points in their lives. Comments by medical workers and lay people are quoted to give a greater understanding and perception of the conditions and stigma encountered in the islands.

The long-lasting effects of leprosy are still evident in various parts of the world. This book details the personal experiences of people in Fiji, New Caledonia, Samoa, Tonga and Vanuatu, the majority of whom contracted leprosy as children. It recounts how they were subjected to prolonged isolation in various leprosaria as the first effective cure for leprosy only became available after 1949. Oral histories are utilized and verbatim extracts demonstrate the degree to which the disease stigmatized those who suffered from it. Topics covered include the exact nature of the diagnosis, removal from one's family, the experience of isolation, and the reaction of family and villages upon the individual's return to community life.

Dorothy McMenamin lectures on various aspects of Indian history, particularly modern South Asian history, through the University of Canterbury, Christchurch, New Zealand. She has published broadly in journals on topics relating to marginalized communities. This is her second book.

On the cover: Rere Abana and his granddaughters outside their home (photograph from author's collection); background © 2011 Map Resources



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