Kalaupapa 2002-2005

Summary Report of the Kalaupapa Ethnographic Project

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Charles Langlas Kaohulani McGuire and Sonia Juvik

2008

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Prepared for the National Park Service

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Cover photo from painting of Elaines Place The Bar courtesy of Jim Kingwell

Maps prepared by Cynthia Phillips University of Hawaii at Hilo

Preface

This document is summary report of the results of the Kalaupapa Ethnographic Project carried out 2001-2005 The main goal of the project was to describe the community that now exists at Kalaupapa consisting of former Hansens disease patients the Hawaii State Department of Health workers who serve them and the National Park Service workers of Kalaupapa National Historical Park Although our work lasted until 2005 our most intensive period of research was the summer of 2002 We describe the settlement through the period from 2002 to 2005 but we focus particularly on 2002 in giving the figures for the number of people in various categories and in describing the specifics of activities

It is necessary to say something about the terminology used in the report For the most part we have used those terms for social categories that are used within the Kalaupapa community Thus we use patients for those who have had Hansens Disease but who no longer have an active case of the disease we use kokuas for the workers at Kalaupapa and we use haole for Caucasian There has been some controversy over which term is more appropriate for the disease Hansens disease or leprosy The State of Hawaii moved to exclusive use of the term Hansens disease in 1949 and abandoned the term leprosy because that term carries with it undesirable connotations of horror and stigma For the same reason we have decided to use the term Hansens disease in this report even though many of the patients themselves do not object to the term leprosy

We feel fortunate to have stayed at Kalaupapa among the patients and workers of the community many of whom we now count as our friends Many of the patients in particular opened their hearts and their minds to us and helped us to understand Kalaupapa In 2002 the time setting for this description there were 44 patients on the Kalaupapa/Hale Mohalu Registry and 35 of them were living at Kalaupapa As of June 2008 their number has been reduced to 26 on the Registry with only 20 still living at Kalaupapa In particular we mourn the recent passing of our friends patients Clarence Naia Olivia Breitha Richard Pupule Peter Keola Nellie McCarthy Paul Harada and Elaine Remigio

The views expressed in this report do not necessarily represent the official position of Kalaupapa National Historical Park or the National Park Service as the report is the result of work done by team contracted to perform the work and not by park service staff Likewise although we have referred frequently to the oral history work done earlier by Anwei Law that generalizations made by us do not necessarily represent her ideas

Note on Names and Quotations

Names of informants who are quoted or whose interviews are cited have been used only if the individual agreed In the case of an individual who wished to remain anonymous number or pseudonym has been assigned to him or her Longer quotations have been presented as block and placed in italics to set them off from the rest of the text Most of the quotations are taken from interviews carried out for the project as indicated in text references by the abbreviation mt Those interviews were transcribed and then informants were asked to sign release form granting use of the transcript to the team The interview from which given quotation is taken is indicated by the name of the informant or by pseudonym or number if the informant wished to remain anonymous and the date of the interview e.g Boogie Kahilihiwa 3/30/06 Int few quotations are taken from an earlier research project carried out by Anwei Skinsnes Law abbreviated as ASL Quotations from her work are indicated by the name of the informant ASL date of the volume of collected interviews number of the interview and page number for the quotation e.g Richard Marks in ASL 1985-87 1030

The language used by our informants in many of the quotations is local English commonly called pidgin or sometimes Hawaiian Creole English Pidgin is the vernacular language used by most people who grew up in Hawaii and by the majority of those who live at Kalaupapa both patients and workers It is rich and flexible language in its own right and deserves respect from the readers of this report We have preserved the pidgin language used by our informants knowing that our primary audience the people of Hawaii will want to hear the informants in their own vernacular language We have not thought it necessary to translate the pidgin quotations believing that even the reader without pidgin can adequately comprehend what is said

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CHAPTER 1. INTRODUCTION

This is a summary report of the results of the Kalaupapa Ethnographic Project. Kalaupapa Peninsula on the Island of Moloka'i is the place to which Hansen's disease patients were sent by the Kingdom of Hawai'i, then by the Territory and the State of Hawai'i until the state ended the practice in 1969. A number of former Hansen's disease patients still live at Kalaupapa today, along with State Department of Health (DOH) workers who serve them. There are also National Park Service (NPS) workers at Kalaupapa. In 1980 the federal government established Kalaupapa National Historical Park at Kalaupapa, with the understanding that the patients and the DOH workers would continue to live there.

The project was carried out between March, 2001 and September, 2005 by a team of three researchers, cultural anthropologists Charles Langlas and Ka'ohulani McGuire and cultural geographer Sonia Juvik. Langlas took the lead role in project management. For a short period early in the research (July 2001 to February 2002), we were joined by cultural anthropologist Jennifer Cerny, who subsequently became the chief of cultural resources at Kalaupapa National Historic Park. Our research was carried out under the supervision of Dr. Fred York, NPS Regional Anthropologist based in Seattle, Washington. The original idea for this project came from Dean Alexander, the superintendent of Kalaupapa National Historical Park from 1996 to 2001 and he obtained the funding for the research. He was the one who first oriented us to Kalaupapa in December, 2001.

Broadly, the goal of the project was to describe the community that now exists at Kalaupapa and how that community has evolved over the last few decades. The scope of work for the project directed the project team to describe all three segments of the community--the former Hansen's disease patients (henceforward called "patients"), the state Department of Health (DOH) workers, and the staff of Kalaupapa National Historic Park (both sets of workers referred to henceforward as "*kokua*"). We were directed to pay particular attention to four areas: (1) the current life of the patients, (2) the current relationships between the three segments of the community, (3) how the community changed after the NPS became established at Kalaupapa in 1980, particularly how life changed for the patients, and (4) how the patients view the current management of the park by the NPS. We were also directed to begin our inquiry with the year 1970, so that we would have some idea of what the community was like before the NPS came to Kalaupapa to compare with what community life is like in 2002-2005. What has happened to the patients since 1970 is clearly very important. However, we found the idea of limiting our inquiry to 1970 and the years thereafter too restrictive. It was 1969 when the law was repealed that required Hansen's disease patients to be isolated at Kalaupapa. The patients' attitudes to many things— to authority, to the landscape of Kalaupapa, to God, and to outsiders—were formed to a large degree by the nature of their lives at Kalaupapa during the years before 1970, while they were forcibly "incarcerated" there.[1]

The report gives a brief history of Kalaupapa in Chapter 2, then continues with three additional chapters on the Kalaupapa community as we found it. Chapter 3 describes the social organization of Kalaupapa community. Chapter 4 describes a set of themes unique to the culture of those who live at Kalaupapa, especially the patients. Chapter 5 describes Kalaupapa as a cultural landscape, focusing on those elements of the landscape that were singled out by patients and workers and the meaning of those elements to them. The final chapter speaks of the future of Kalaupapa, and to the hopes and fears of the patients about what will happen there.

Researching Kalaupapa

The general nature of our research was the classic ethnographic fieldwork method of immersion in the life of the community, using participation-observation of community life, as well as interviews of community members and fieldtrips onto the land with them. However, our fieldwork was only an approach to immersion, because our stays at Kalaupapa were always short, two weeks at most. In the early "exploratory" phase of our work we began with participation-observation and then informal interviews of the most forthcoming individuals (usually tape-recorded) in order to formulate ideas about how the community worked. The nature of such informal interviews is to begin with a few broad questions and then let the interview go where the answers lead, without trying to direct the informant too much. As we moved into the later "testing" phase of our work we formulated several standardized interview guides in order to test our ideas systematically with a larger group of informants. These interviews might be categorized as semi-formal. There was a standard set of questions to structure the interview, but we did not stick rigidly to the pre-designed questions. Rather, we acted to re-word a question if the informant was confused, or to ask follow-up questions to get a fuller answer, as necessary.

Our first objective was to get to know the patients and try to establish a degree of acceptance by them. When we first went to Kalaupapa in 2001, we expected that it would take a considerable time to establish relationships of trust with the patients and that is what we found. The patients have a history of being rejected by non-patients or of being regarded as objects of curiosity. They were suspicious of us, as they are suspicious of any newcomer not invited by a community member. We introduced ourselves in several ways. On our first trip, we talked to the Roman Catholic priest, the Congregational minister, and the Mormon church leader, and asked each of them to introduce us at the Sunday church service and bless the project. On our second trip a few months later, we met with the Kalaupapa Patient Advisory Council (which advises the DOH on management of Kalaupapa community) and asked the council for their permission to carry out the project. The council agreed, but they and the other patients maintained a reserve toward us for some time. It took six months to a year longer before the patients warmed toward us and we were able to begin interviewing a substantial number of them. Some patients became friendly, but never did agree to be formally interviewed. We continued going to the church services regularly. It has always felt important to us to share that social and spiritual connection with the patients and other members of the community who go to church. Pina Ramos, the wife of a patient, commented that our attendance at church "really softened the hearts of the patients" toward us.

From the beginning, the team divided the work up roughly between us. Each of us was to do some interviewing of the patients, because that was to be the most important part of our project. However, McGuire was to concentrate on participant-observation of the patients and interviewing them about their life. Langlas was to concentrate on participant-observation of the workers and interviewing them about their social relationships with patients and with each other. Juvik was to concentrate on learning about the "cultural landscape," how both patients and workers felt about aspects of the natural and constructed landscape.[3]

Figure 1. Researchers McGuire and Juvik with Patient Friend "George"

McGuire was the one who first established a solid connection with the patients. That was partly because she spent the most time at Kalaupapa during the first year and partly because of who she is. Most of the patients are local people, raised in Hawai'i, and the majority are Hawaiian. McGuire is a Hawaiian, raised on Moloka'i and O'ahu, and that made it easier for her to connect with the patients. Langlas and Juvik have both lived in Hawai'i for many years, but it is still obvious that we come from outside Hawai'i. McGuire soon discovered that she had an auntie among the patients. That gave her a more valid standing at Kalaupapa as the relative of a patient, rather than merely an outsider researcher. Moreover, her natural *aloha* was clear to everyone and that soon endeared her to the patients.

Langlas had some difficulty in his efforts to interview the workers. Many of them did not make themselves available. Unlike the patients, they work on weekdays and many of them leave on the weekends. Like the patients, many of the workers are local people and they were suspicious of a *haole* (Caucasian) outsider who came asking questions. They are protective of their own privacy and also protective of the patients. That said, many of the workers did eventually agree to be interviewed. Some of them provided crucial insights to our analysis, including Lon Rycraft (the Congregational minister), Albert Pu and Randall Watanuki (the NPS and DOH maintenance supervisors), Lucy

Whiting (NPS administrative clerk) and DOH nurses Fe Austria-Schwind and Julie Sigler.

Figure 2. Patient Paul Harada Teaches Researcher Langlas How to Collect Salt

After our first year and a half of fieldwork, we developed interview guides to use in several areas of our research. A "Patient Biography Schedule" was developed to collect detailed material from patients on their past and present life. A "Worker Relationships Survey" was developed to interview the workers on their social relationships. We also developed a "Park Management Questionnaire" in order to ask the patients about how they viewed the NPS management of the park.

We did in fact spend more time interviewing the patients than the workers. As time went on, each of us developed special relationships with certain patients as a result of personal chemistry and concentrated on interviewing those particular patients. We believe that the length of our fieldwork at Kalaupapa contributed greatly to the depth of our work. The project was originally planned to last only three years, from 2001 to 2003. Because we each had other work commitments, we had to extend our work at Kalaupapa until 2005. In the case of some of the patients, it was only in the last two years that they trusted us enough to share fully their personal stories.

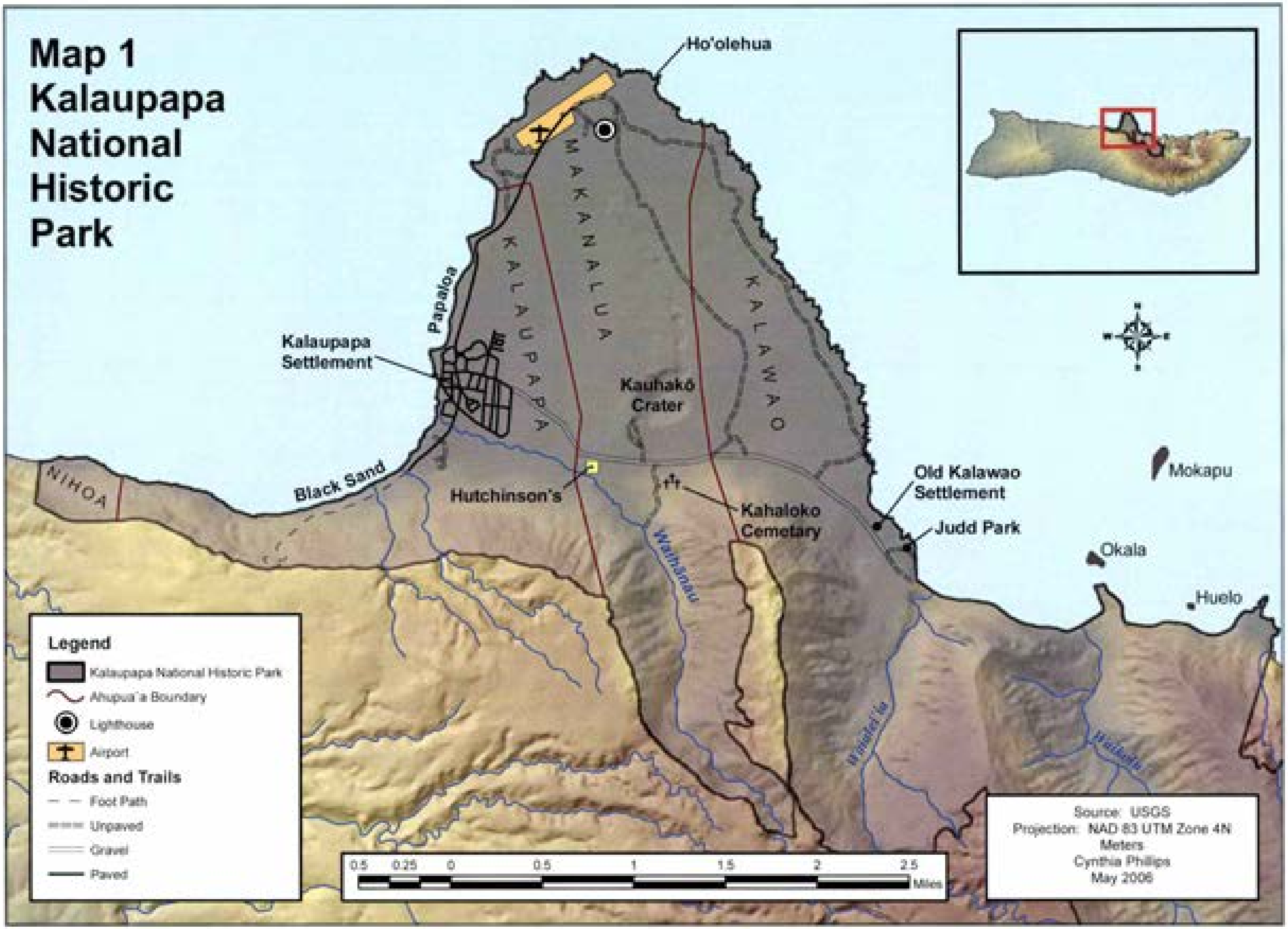
Orientation to Kalaupapa National Historical Park

The boundary of Kalaupapa National Historical Park today is much the same as the historical boundary of the "Kalaupapa Leprosy Settlement"[4] maintained by the Territory of Hawai'i and then by the State of Hawai'i prior to the creation of the park.

The boundary of the park is largely the same as that of Kalawao County as well, except that the county does not include the small section called Nihoa on the west end of the park.[5] Physically, the most obvious features of the park are the low, rather flat peninsula that projects from the north coast of Moloka'i, the steep pali (cliff) that towers above it to the south and effectively separates "Topside Moloka'i" above from Kalaupapa Peninsula below, and the valleys which lie to the east side of the peninsula. (See Map 1.)

Figure 3. Kalaupapa from the Air, 2005. Photo by Lori Tango

Generally when people say Kalaupapa they mean the peninsula. On the leeward (eastern) side of the peninsula is Kalaupapa Settlement proper, containing the residences of Kalaupapa patients and workers and the DOH and NPS administrative offices and other buildings. The leeward side of the peninsula has a sand beach, shallow water offshore and a broad reef. North of the settlement proper on the leeward side, seaward of the road to the airport, in the area known as Papaloa, is a large graveyard.[6] This graveyard is currently in use for burial of patients. Further north is a group of beach houses built and owned by patients and often used by them to house their visitors. The paved road ends at the airport, although there is a track that leads further, all the way around the peninsula. From the airport on east around the windward side of the peninsula there is no reef; the water at the shore is deeper and rougher. On the east side of the airport is the old lighthouse (Moloka'i Light Station) and the beach area called Ho'olehua. The lighthouse and a couple of nearby houses are owned by the federal



Map 1 Kalaupapa National Historic Park

Source: USGS
Projection: NAD 83 UTM Zone 4N
Meters
Cynthia Phillips
May 2006

government and administratively they are not part of Kalaupapa Hansen's disease settlement, although they are now part of Kalaupapa National Historical Park. Ho'olehua beach is the location of many saltwater ponds where salt is harvested in the summertime. The remainder of the windward coast of the peninsula is traveled mainly by fishermen and by visitors to Kalaupapa who are being shown "around the island" by their hosts.

A second road leads inland from Kalaupapa Settlement proper, east to Kalawao. On the way to Kalawao, the road passes north of "Hutchinson's," the former home site of Ambrose Hutchinson, an early administrator at Kalaupapa. Most of the interior of the peninsula is covered with lantana and Christmasberry, which forms a nearly impenetrable scrub forest on both sides of the road. A turnoff on the south side leads up to Kauhakō Crater (the remains of a small extinct volcano), with a cross at the top marking the spot used until recently for Easter sunrise services. On the road up to the crater are some tombstones and masonry tombs. We were told there are many unmarked graves in the area as well. Continuing east along the main road, the traveler comes to three large, old water tanks, then to an old, tree-shaded cemetery called Kahaloko. Farther east the road reaches the old settlement of Kalawao, where the first Hansen's disease patients were sent in the nineteenth century, although there is at first little obvious evidence of the settlement. The road comes into forest at the place known as Hanging Tree, famous for being haunted. After emerging from the forest the road reaches the old Siloama Congregational Church and the old St. Philomena Roman Catholic church, with the tomb where Father Damien was buried. Here too there are many graves, marked and unmarked. The road ends at Judd Park, often used for picnics. The park is named for the former Settlement Administrator Lawrence Judd, who earned the gratitude of the patients as the first administrator to begin to overturn some of the physical barriers that segregated patient from kokua (non-patient worker).

On the southwest side of the park, where the peninsula tapers off, there is a long black sand beach traversed by the trail used by Kalaupapa workers and tourists to travel up and down the pali (cliff). Once the trail begins to climb the pali it is quite steep and has been constructed with 26 switchbacks. Further west is a table land named Nihoa that juts out from the pali and is used primarily as a place for gathering the limpet opihi. On the southeast side of the park, three valleys cut back into the pali, the Waihānau, the Waiale'ia, and the Waikolu. Of these, the Waikolu Valley is the biggest and is the only one with a stream that flows constantly into the sea. The Waiale'ia Valley was said to have a stream that always flows, but does not reach the sea except during winter storms. Both valleys are said to have the remains of old *lo'i*, pond fields for growing the Hawaiian staple taro. In the early part of the twentieth century patients still grew taro in Waikolu along the stream. The stream was the source of the water piped into Kalaupapa Settlement proper for many years, until the NPS drilled a well in lower Waihānau valley and brought the first reliable, high-quality water into the settlement from the well.

CHAPTER 2. KALAUPAPA HISTORY

Early History

In 1865, the Kingdom of Hawai'i passed a law (the Act to Prevent the Spread of Leprosy) authorizing the government to acquire land to isolate those found to have Hansen's disease. The land at Kalawao on the east side of Kalaupapa Peninsula was acquired by the kingdom and the first group of patients were sent there in January, 1866. Later in the nineteenth century the kingdom acquired the rest of the peninsula. The first patients were landed with difficulty at the mouth of the Waikolu Valley farther east and had to walk over the rocky beach to get to Kalawao. The early patients were almost entirely Native Hawaiians. They belonged to the three major Christian denominations established in Hawai'i by that date, Congregational, Roman Catholic, and Mormon. Within a few years, they built churches at Kalawao, in 1871 the Siloama Congregational Church was built, in 1873 the St. Philomena Roman Catholic Church, and sometime later a Mormon church. In 1873, Father Damien arrived to lead the Roman Catholic congregation. The other two churches were led by Native Hawaiians, the Congregational church by the pastor and Hansen's disease patient Hoolu and the Mormon church by elder Jonathan Napela, who had come as a helper to his wife, who had the disease.

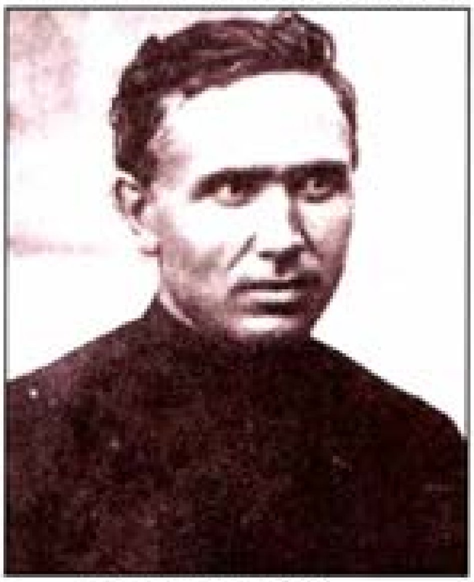
<u>Father Damien and Mother Marianne</u>

Many Roman Catholic priests, nuns, and lay brothers have labored at Kalaupapa to serve the patients. The best known of these are Father Damien de Veuster and Mother Marianne Cope, both of whom have recently been beatified. At the close of every service the Kalaupapa Catholic congregation offers a prayer for each of them that they may be elevated to sainthood.

Father Damien was born in Belgium in 1840. As a young man, he volunteered to join a group of missionaries of the Congregation of the Sacred Hearts of Jesus and Mary who were to travel to Hawai'i. In 1865 he began serving as a priest on Hawai'i Island. In 1873, he volunteered to stay at Kalawao and serve the Catholic patients there. He continued working at Kalawao for the rest of his life — contracting Hansen's disease and dying of complications related to the disease in 1889. He labored energetically at Kalawao, preaching and striving to reform the people morally, helping the patients to build houses and set up a water system, and seeking additional financial support from the Hawaiian government and from private contributors in order to improve the living conditions at

Kalawao. He lived among the patients as one of them, setting aside any fear of their disease. In an early letter to his brother, he wrote, "…I make myself a leper with the lepers to gain all to Jesus Christ. That is why in preaching, I say 'we lepers'; not my brethren…;"

Father Damien was buried at Kalawao, next to St. Philomena Church, which he had built and where he preached. In 1936, the long process of his elevation to sainthood was initiated. He was declared Venerable, and his body was exhumed and returned to Belgium. In 1995, he was beatified as "Blessed Damien" when the church recognized the first miracle performed by him in healing a nun who had prayed to him. At that time, Damien's right hand was returned to his original gravesite at Kalawao in a major ceremony. Today, visitors from around the world make pilgrimages to his grave and church at Kalawao to honor him. Patients of all denominations venerate him because he dedicated his life to them. For years, the Kalaupapa community has held an annual Damien Day celebration on his feast day, April 5.



Father Damien, c. 1863

Cake Made for a Combined Celebration of Damien Day and the Eightieth Birthday of Father Joseph Hendriks in 2002

Mother Marianne came to Kalaupapa in 1888, just before Damien's death. In 1883 she was the Provincial Superior of the Order of St. Francis, located at Syracuse, New York, when she received a visitor from Hawai'i asking for nurse-sisters to work with Hansen's disease patients there. The request touched Mother Marianne's heart and she answered the request in a letter, writing, "I am hungry for the work and I wish with all my heart to be one of the chosen Ones, whose privilege it will be to sacrifice themselves for the salvation of the souls of the poor Islanders.... I am not afraid of any disease, hence, it would be my greatest delight even to minister to the abandoned lepers. That same year she led a group of six nuns from her order to Honolulu to work there. In 1888, she came to Kalaupapa with two other nuns to supervise the new Bishop Home for Girls there. Mother Marianne continued her work with the patients at Kalaupapa until her death in 1918. She was buried on the grounds of Bishop Home. In 2003 she was credited with a miracle and beatified. Her body was exhumed in 2005 and returned to Syracuse for reburial. Blessed Marianne's feast day is celebrated annually by the community on January 23.

Mosaic of Mother Marianne. by Karen Lucas.The mosaic was created with the help of several patients from ceramic fragments found at Kalaupapa, and is mounted outside St. Francis Catholic Church, Kalaupapa.

In 1887, Damien had dormitories built for the orphan boys at Kalawao with materials supplied by the government Board of Health, which had responsibility for the settlement. Later on Henry P. Baldwin gave $5000 to enlarge the complex, which became known as the Baldwin Home for Men and Boys. It was staffed by lay brothers of the Roman Catholic Order of Sacred Hearts. Bishop Home was built at about the same time at Kalaupapa. In 1888, C.R. Bishop gave $5000 to establish the Bishop Home for "unprotected" girls and women (those without husbands). The Home was built on the west side of the peninsula and included dormitories, a convent and chapel. Once built, the Home was supervised by nuns of the Roman Catholic Order of St. Francis.

The late 1880s marked the beginning of a shift from Kalawao Settlement on the east side to Kalaupapa Settlement on the west side. The Native Hawaiians who still lived on the Kalaupapa side were convinced to leave, so that there would be no contact between them and those with Hansen's disease. About 1886, the Board of Health had a pier constructed on the Kalaupapa side, which greatly facilitated embarking and disembarking by boat. By 1895, there was a substantial community on the Kalaupapa side as a result of migration from Kalawao, including churches for each of the three congregations, houses, a dispensary, and Bishop Home. Before long, two additional group homes were built for patients, Bay View Home in 1901 and McVeigh Home in 1910. In 1932 Kalawao was finally abandoned when the boys living at Baldwin Home moved to Kalaupapa to a new Baldwin Home built there.

From Prison to Sanctuary

Up until the mid 1940s both patients and outsiders saw Kalaupapa as a prison, a place to which those with Hansen's disease were consigned for the rest of their lives to prevent their disease from spreading to others. Today the patients see Kalaupapa very differently. They see it as a safe and happy place, as their beloved home. Now it is a refuge from the outside world, which often seems to them a difficult place. The following quotations from patients illustrate this shift in their perception.

"George," came 1940: *Today this is a nice place. But before it wasn't nice. Especially when you see the patients with all their sores, you scared. It was a gruesome place.* (3/28/02 Int)

Catherine, came 1942.
A lot of things went on in Kalaupapa: lot of nice things. We had fishing during the day, and then at night we had a big dance in the hall. Well I thought that it was a land of milk and honey.

Some people think that we don't have a life here, and we do. Life is good here. I don't want to live anyplace else in this world but Kalaupapa. It's my home. I would like to live here and die here. And be buried here. And I hope they will never tell us to leave. That will kill a lot of us. (5/23/02 hn)

Ku'ulei, came 1950-1958.
That is what Kalaupapa is to me. I would never want to leave. It's paradise! Where can you find someplace like this? There is nowhere in the world you can go where you can feel secure, where you know that everyone around you is just like you, your guard is not up. (7/13/02 hn)

Pauline, came 1962
We like to go holoholo [traveling], whatever, but there's no place like home. We love the place. You don't have horns blaring or sirens blowing or what, you know, in this place. I'm always happy to come back home after being away. (7/10/01 hn)

Kalaupapa Peninsula was chosen by the Hawaiian Kingdom in 1865 as the place to settle those with Hansen's disease because of its geographical isolation. The only access to Kalaupapa by land was a steep trail down the cliff face (pali) from Topside Moloka'i. The isolation of Kalaupapa made it seem very much like a prison for many years. Today there is an airfield at Kalaupapa and daily flights come in from Honolulu and from Topside. Kalaupapa is less difficult of access physically, but the DOH still limits visitation to Kalaupapa Settlement by outsiders. Both patients and workers describe Kalaupapa today as a refuge from the outside world. It is a place without hustle and bustle, without traffic noise, without crime. For the patients it is also a refuge in the sense that they do not need to worry about being stared at if their appearance has been altered by the disease. Nor do they need to fear being stigmatized and rejected when outsiders learn that they come from Kalaupapa. However, when patients were brought here in the 1940s their feelings were very different. Often they were brought to Kalaupapa against their will, having been torn away from their families. When they arrived they were confronted with patients in an advanced stage of Hansen's disease, and they saw in them what would happen to them as well – alteration of the facial features, loss of fingers and toes, blindness, and in a few years death. Kalaupapa then was a place to which they were consigned by the government of Hawai'i. Kalaupapa was to become their prison and then their burial place.

The patients' sense of Kalaupapa has been transformed from prison to sanctuary today, partly because they are no longer forced to remain at Kalaupapa, and partly because they came to dread the outside world. The state's isolation policy was ended as a result of the introduction of antibiotics which put the disease into remission. Today those with Hansen's Disease are treated on an outpatient basis, since it is recognized that those being treated with antibiotics are not infectious to others. (In fact the majority of individuals are not susceptible to developing Hansen's Disease in any case.) The first sulfone antibiotics were introduced in 1946, when the use of these drugs was still experimental, the dosage uncertain. It took about ten years of taking the drugs for most patients before they were pronounced "inactive" (as determined by testing of body tissue for the bacterial agent) and were placed on "temporary release."[14] Those on temporary release could then leave Kalaupapa and even get a job outside. In 1969, the state officially ended its program of forced segregation for those with Hansen's disease. Some of the Kalaupapa patients left after they were released, but many chose to stay. Those patients who moved out sometimes had a difficult time adjusting to the complications of life outside. They had become used to their institutionalized existence at Kalaupapa, where life was circumscribed and the necessities for living were provided.[15]

Gugelyk and Bloombaum carried out the first social science project at Kalaupapa in the 1970s. They were interested in understanding why the majority of patients chose to remain at Kalaupapa. They concluded that it was "due to prolonged tenure in the institution, disfigurement, and stigma imputed by the patients to the general [outside] community."[16] In interviews done by them, patients revealed their fear that outsiders would reject them (despite the fact that the disease had been rendered inactive by the antibiotics and they could no longer spread it to others). Some patients told of having been rejected by family members; others told of trying to make it on the outside and getting fired from a job when the employer discovered they had had Hansen's disease. Conversely, many patients spoke of Kalaupapa as "heaven" or "paradise," and as the place where their closest ties were now. Those same sentiments are still echoed by patients today — the fear of being shunned by outsiders, the feeling of being closer to people here than to family outside, and the sense that Kalaupapa is home.

Prior to 1946, the patient population at Kalaupapa Settlement was in flux. Although some patients that came to Kalaupapa lived a long time, many died after only a few years. As they died, they were replaced by new patients from outside. After 1949, the population was more stable. As a result of the introduction of the sulfone antibiotics, patients lived longer. Consequently, the Board of Health (of the then Territory of Hawai'i) set a policy that no new patients be sent to Kalaupapa except at their request.[17] Henceforward, patients were normally to be treated at Hale Mohalu, a facility set up in Pearl City. Up to 1969, a certain number of patients at Hale Mohalu were allowed to transfer to Kalaupapa on request, but the number of new arrivals was small. After 1969, no new patients were admitted. Since then, the population has dwindled as the patients get older and die. (See Table 1.)

As the patients have aged they have become less able to take care of the work of the settlement and the proportion of non-patient workers has increased. In the early 1960s most of the work of the settlement was done by patients. In 1961, 131 out of 217 patients living in the settlement were employed (counting both full-time and part-time workers).[18] In 1965, there were 209 patients and only 65 DOH workers.[19] Thus the number of patient workers was about twice the number of DOH workers in the 1960s. In recent years the situation has changed radically. Only a few of the patients are still working full-time today and most of the work of the settlement is being done by government workers employed by the DOH or the NPS. In 2002 there were 44 patients and 40 DOH staff. There was also an NPS staff of about 20, which was doing part of the work of the settlement. Putting both staffs together, the 60 workers outnumbered the 44 patients. That shift is felt even more by the patients because some of those 44 lived primarily outside.

even though they were still listed as residents on the Kalaupapa registry and maintained a house at Kalaupapa.

Table 1 Number of Resident Patients at Kalaupapa, 1940-2006[6]

Year	**Active Patients**	**Released Patients**	**Total Patients Resident**
1940			About 400
1946			328
1956	90	134	224
1960	81	139	220
1965	59	136	195
1970	30	125	155
1975	1	135	136
1980			124
1985			101
1990			90
1995			72
2000			47
2002			44
July 2006			33

The Rules of the Settlement

"The Rules" have long been important at Kalaupapa. Rules for how the settlement would be run were established by the territory at the beginning of the twentieth century and later by the state. Before the sulfone drug therapy was introduced, rules were enforced to maintain segregation between patients and non-patients (both workers and visitors). These rules were ostensibly set up to prevent contagion, but they also had the clear effect of teaching patients to know their place. For the most part the segregation rules were still in effect into the mid 1960s.[7] The fundamental rule was that non-patients and kokuas could not mingle outside of work. Often patients and state workers were part of the same work team, and the state workers could enter a patient's house to do work there. Contact was allowed in the context of work, but not outside of work. The kokuas were not allowed to go to the patient bar to drink or buy beer and they were not allowed to go to a patient's house after work. Many of the kokuas did sneak to patient houses to drink and party in the evening, but if they were caught they would be fired. The onus was on the kokuas in this case, because there was little that could be done to effectively punish the patients. They were already incarcerated at Kalaupapa. Instead, they were kept in line by a more subtle system of social control that inculcated feelings of inferiority.

A set of social barriers was set up which embodied the segregation between patient and non-patient. At the airport, there was a pipe running through the waiting room to separate patient from non-patient. (Patients on temporary release sat on the non-patient side.) And there were separate restrooms labeled "patient" and "kokua." At Paschoal

Hall, where social events were held for the settlement, the patients sat downstairs to watch movies and the kokuas sat upstairs. When dances were held at the hall, a barrier of plants was placed down the middle of the floor to separate the patients from the kokuas. At the Damien Day dinner celebrated annually at the hall, the kokuas were served first and were not allowed to sit next to patients. At the churches too there was one area for patients to sit and another for non-patients. In St. Elizabeth Chapel at Bishop Home, run by the Catholic Sisters, there were separate railings set up for patients and nonpatients to take communion next to the altar. At the old Siloama Congregational church at Kalawao the separate outhouses built for patients and kokuas can still be seen. (See Figure 4 below.)

One street of the settlement was known as Staff Row, where the houses of the settlement administrator and doctor and a dormitory for the nurses were located. All of these were surrounded by a fence and patients were not allowed inside the fence. If a patient had some reason to see the occupant, it was necessary to ring a bell on the gate and wait until the occupant came out. Likewise at the front entrance of the hospital, there was a line on the floor of the hall which led to the doctor's and nurse's offices and patients were not allowed to pass that line.

Figure 4. Separate Patient and Kokua Outhouses,
Siloama Congregational Church, Kalawao

Although these rules had their beginnings in an attempt to prevent contagion, they became part of a system of social control, a system by which the patients were taught that they were inferior and were to submit to authority. Several of those interviewed, both by us and by Anwei Skinsnes Law in 1984-87, spoke revealingly about the rules, showing that they did not really prevent contact between patient and non-patient, but they did inculcate strong feelings of inferiority and stigma and often an unquestioning attitude to authority.[22] As the quotations below indicate, patients often didn't think to question authority, and if they did were afraid to do so.

> *Wherever we went in Kalaupapa, or in Kalihi Hospital, there were signs telling us where we could or could not go and what we could not touch or whom we must not touch. Once we were declared a patient, our minds became the property of the system, for awhile anyway. Then, for a few years we were brainwashed.*
>
> Olivia Breitha (1988)[23]

> *You get program that [you] no do this, no touch that, no go over here, no go over there. You become so program, you know. Hey, I no can do that. Why? We never questioned that. "Why? Who told you?" Well, I know you guys told me, but I never ask you how come I no can. Or why I no can. Or what they going do if I am do em. You know?*
>
> Boogie Kahilihiwa (3/30/06 Int)

> *The priest or the minister or the doctor could enter my house; there was no problem, but I could not enter theirs. My house where I could sleep and live for years and breathe all the germs in the world—that was okay for them to visit, but for me to go into their house for ten minutes was illegal.*
>
> *You were a leper, they made sure you never forgot it. All those little things, you know. Many of our people learned over the years to keep your mouth shut. You wanted a job, you wanted a house, you put your name on the list and shut up. You never criticized, never talked back, and I could never live that way, so I was always in the dog house.*
>
> *I got into a hassle with one of the nurses about that [about not crossing the line to the doctor's office in the hospital] and I was told, "When are you patients gonna learn your place?"*
>
> Richard Marks (in ASL 1985-87, 1:4-5).

This of course was the context which created patients who were afraid to leave Kalaupapa, fearing that they would be stigmatized on the outside as they had been at Kalaupapa.

Even in the 1960s, when most of the patients had become inactive cases as a result of the drug therapy, the DOH staff generally remained resistant to relaxing the rules. In 1947-49 Lawrence Judd, a former governor, became the settlement administrator at Kalaupapa. Although he was still concerned about preventing contagion, Judd took it upon himself to remove some of the "unnecessary" segregation barriers because he saw them as psychologically damaging to the patients.[24] For example, he removed the high fence that surrounded the Visitor's Quarters where relatives of patients stayed when they came to visit. He felt the fence served to emphasize needlessly the separation between patients and visitors, since relatives were at that time allowed to go out under escort and visit the patient at home. After Judd left, however, there was little further change until 1968-69. Dr. Robert Worth explained that it took drastic action to force change on the conservative Dr. Hirschy, then head of the Communicable Diseases Division in charge of

Kalaupapa Settlement.[25] Worth showed in a 1968 article that patients on sulfone drugs were not contagious, but Hirschy still would not budge on ending segregation until a special committee was appointed by the governor to review the whole state Hansen's disease program. It was only as a result of that review that the legislature finally acted in 1969 to repeal the law and end the enforced segregation of Hansen's disease patients. In some ways the segregation between patients and kokuas continued even after 1969. For example, volleyball teams were still restricted to be either patient teams or kokua teams in the 1970s, according to patient Gloria Marks.[26] Only in the 1980s were mixed teams formed.

Today, the DOH no longer maintains rules to restrict the patients, but there is still an elaborate set of rules that restricts the kokuas. It was always true that the rules restricted the workers as well as the patients. The rules really only privileged the administrators. Into the mid 1960s, the laborers all lived together in a camp and were not allowed to have pets.[27] They had to leave the settlement on weekends, when they didn't work. After 1968 workers were allowed to visit patient houses after work, but they had to go to the office and get a pass.[28] Incredibly, as late as 1981 they still needed to get a pass even though it was only "a formality".[29] As late as 1989 the laborers were not allowed to stay at Kalaupapa on days they were not working.[30] In the 1950s the patients were allowed to hunt with rifles, but the kokuas were not allowed to hunt until the 1990s.[31]

The most important of the rules which still affect the kokuas are those that exclude their spouses and children. For many years the workers – other than the administrator and the doctor – lived in separate male and female dormitories, not houses. There was no place for their families. Now most of the workers live in houses, but there are still rules which generally prevent their family from living with them. Neither DOH nor NPS workers may have their spouse living with them at Kalaupapa unless the spouse is also working (either working for pay or doing volunteer work). They may not have their young children living with them either, because there is a rule that children under 16 may not be in the settlement. Both of these exclusion rules derive from the earlier segregation policy of the territorial and then state administrations, which prevented anyone from living at Kalaupapa other than patients with Hansen's disease and workers to maintain the settlement. When the patients at Kalaupapa today were brought there, their spouses could not come. Under the law of that time a spouse could be granted an automatic divorce from a patient placed in isolation for Hansen's disease. The children born to patients at Kalaupapa were taken out of the settlement soon after birth to be raised outside.

Now the exclusion rules are kept in place because of pressure from the patients. The settlement administrator and the park superintendent would like to get rid of the rules to make life easier for their workers. Paradoxically, the Kalaupapa Patient Advisory Council now pushes to maintain them, backed by most of the patients (though not all). The patients give various reasons for not wanting workers to have their spouses or young children at Kalaupapa. Some still fear that children might be infected with Hansen's Disease if they lived at Kalaupapa. Some are sensitive about the physical effects they exhibit from the disease and are afraid that children might stare or laugh at them. Some patients say that they weren't able to have their children here, and they had to leave their spouses behind when they were brought to Kalaupapa. Why should the workers get to have their children and their spouses here? Some fear that with the dwindling of their numbers, they would be swamped by an influx of outsiders. (See p. 46 for a fuller discussion of this issue.) Whatever the specific reason, it is clear that ending the exclusion rules would mean a drastic change in the nature of the community and they resent any such change.

Patient Activism and the Establishment of the National Park

The establishment of Kalaupapa National Historical Park in 1980 is connected with the rise of patient activism in the 1960s. The patients became more assertive about claiming a role in decisions made for them during the 1960s. That new assertiveness can probably be linked to the effect of the sulfone antibiotics. As the antibiotics rendered their disease inactive, the patients gained hope for the future and they began to see the segregation rules as unnecessary. At the same time, they feared that the state might decide to abandon Kalaupapa Settlement and force them to leave. They worked for the establishment of the park at Kalaupapa because it gave them better assurance that they would be able to continue living at Kalaupapa Settlement.

The Kalaupapa Patient Advisory Council was formed by 1960, with the approval of the Director of Health, as an advisory body to the Department of Health for matters concerning the Hansen's disease patients under its care.[32] In 1968 Bernard Punikaia was elected as chairman and he served from 1968-1972, and again from 1977-1979.[33] Under Bernard the council became more assertive than it had been earlier, particularly when the state made a decision to close down the facility for Hansen's disease patients at Hale Mohalu in Pearl City. Hale Mohalu was established as a facility for Hansen's disease patients on O'ahu in 1949 when the former O'ahu facility, Kalihi Hospital, was closed down. Hale Mohalu was used to receive incoming patients, and to house Kalaupapa patients who needed medical care on O'ahu, including dialysis patients and those recuperating from surgery at one of the O'ahu hospitals. In January 1978 the state closed Hale Mohalu at Pearl City and shifted the patients to a facility at Le'ahi Hospital in Honolulu, against the wishes of both Kalaupapa and Hale Mohalu patients. A 1977 survey of patients by Gugelyk and Bloombaum showed that 86% of the patients opposed the closing.[34] The patients were used to the expansive grounds and comfortable buildings at Hale Mohalu and felt that the Le'ahi facility was too much like a hospital. (The Le'ahi facility was later named Hale Mohalu, just like the old one.)

The patients reacted to the closure by protesting. Most of those at Hale Mohalu were taken to Le'ahi, but a small group of patients, including Bernard Punikaia, Clarence Naia, Richard Pupule, Frank Duarte and his wife, Catherine and Jubilee Poahala stayed. They occupied Hale Mohalu for six years. Eventually the DOH administration turned off the electrical power and water and finally the governor had them removed forcibly. They were joined by some non-patient protestors and were supported by many of the Kalaupapa patients, but not all. As Bernard noted in 1979, it was not an easy thing for most of the patients to challenge the government.[35] They had been conditioned to do what they were told. Patient Paul Harada says that Hale Mohalu was a turning point for him and others.[36] It led them to begin to question authority, whereas before they had just accepted what they were told to do.

Some of those at Hale Mohalu felt that Kalaupapa was also in danger of being closed.[37] In fact there had been whispers even before 1970 that the state might pull out of Kalaupapa and sell the land to a developer, according to Patsy Mink.[38] Already in the late 1950s, patient Richard Marks began to write letters pushing for Kalaupapa to become a national park, because he feared the state might pull out.[39] Then about 1970 a group called Citizens for the Preservation of Kalaupapa was organized in Honolulu to prevent commercial development of Kalaupapa. Richard Marks finally managed to connect with Patsy Mink, Hawai'i Representative to the U.S. Congress, who became the main legislator responsible for getting Congress to approve the creation of Kalaupapa National Historical Park. Mrs. Mink went to Kalaupapa to talk to the other patients there and convince them that it would be good for them, and in 1973 she introduced the first bill to establish the park.[40] When that bill failed, she introduced a second bill in 1975 for a locally-based advisory commission to study the issue. The commission recommended the establishment of the park and in 1980 Congress passed the enabling legislation (Public Law 96-565).

Development of the Park and Patient Reaction

Henry Law began work as the first park superintendent at Kalaupapa National Historical Park in 1982 and he hired the first permanent maintenance worker in that same year. A long-time DOH worker who first came to Kalaupapa in 1982 described to us how well the NPS was liked by the patients during his tenure (1982-88).

> *The people [patients] loved the NPS, Henry Law and Anwei during the time she was here. It saved the peninsula from the clutches of Japanese corporations which would have created a tourist island development here.* (Douglas Seldmates, DOH worker 24, February, 2002)

The park staff increased slowly over the years, but it always consisted primarily of maintenance division laborers. Beginning in the 1990s the park began to hire staff in the protection and resource management divisions. The size of the various divisions over time is shown in Table 2 below. (Often the permanent staff has been augmented by seasonal workers, limited term workers, and casual workers contracted to work at the park by the Pacific Cooperative Studies Unit of the University of Hawai'i,[41] so it is difficult to give unambiguous numbers. All of these temporary workers have been included in the numbers.) When the park was first established the DOH had a large maintenance division to take care of the settlement. The park's maintenance division was more concerned with the rest of the peninsula outside the settlement. Gradually the state's maintenance division has been reduced as the number of patients has declined. When the present settlement administrator (Mike McCartney) came in 1993 there were 60 state positions. That number was reduced to 19 by 2002, with most of the losses in the maintenance division.[42] Concurrently, the DOH turned over much of the maintenance of the settlement to the NPS. In 1988, the park drilled a well in Waihānau Valley and began to provide water to the settlement from that well, in place of the DOH system which had piped water in from Waikolu Stream, two valleys east of the peninsula. The old water pipe required frequent maintenance, because it ran right under a cliff at the edge of the ocean and was subject to breakage when rocks fell from the cliff. By 1992 the park took over the care of the plumbing system for the settlement. In 2002 the park took over the mowing of most of the public area within the settlement, leaving for the state crew only the yards of the patient houses and the DOH buildings.

Table 2. Staffing at Kalaupapa National Historical Park[43]

Year	Adminis-tration	Maintenance	Protection	Cultural Resources	Natural Resources	Total
1982	1	1 + 3 seasonal				5
1986	2	3 + 5 seasonal				10
1992	2	5	1	1		9
1994	2	8	1	1	1	13
2000	2	8 + 5 term	1	1 + 1 casual	1	19
2002	2	7 + 5 term	2	2	2	20

In general, our conversations with patients have shown that they are appreciative of the NPS for its role in preserving Kalaupapa Settlement from being eliminated by the state. They appreciate too what the NPS has done to take care of Kalaupapa physically. In particular they pointed to the improved water system that the NPS put in, to its role in clearing out the scrub trees which had taken over the cemeteries at Papaloa and Kahaloko by the 1970s, and to its clean up of Judd Park and the old settlement area at Kalawao. In the park management interviews we did with patients, all of them felt that the NPS is still doing a good job of maintaining the cemeteries and the settlement ground. That overall gratitude does not, however, preclude patient complaints about specific issues. (A number of patient grievances with the NPS are considered later on.)

When he was interviewed in 1985, Richard Marks felt that the park administration was at that time much more open to patient input than the Department of Health.[44] That was likely true then, when the first park superintendent Henry Law was in charge. Talks with patients have indicated that Henry Law was particularly well-liked and many of them see him as the superintendent most concerned with patient welfare. More importantly, the park staff was small then and its impact was limited, so most patients have little complaint about the park during the early period. However, since that early period, the park has grown considerably, both in terms of staff size and activities. The growth of the park staff is seen in itself as threatening by the patients, because it is an element in their becoming outnumbered and less important at Kalaupapa. The impact of the park at Kalaupapa is also much greater today than it was during Henry Law's time and there is naturally much more potential for NPS actions which can lead to patient criticism.

Over the years since 1980 there has often been tension between the patients and the park superintendent in power, just as there has been with the settlement administrator. Both individuals have considerable power over what happens at Kalaupapa and the patients have a difficult relationship to authority as a result of their history during the period of segregation, when they were allowed no voice in what happened to them. Some never learned to confront authority, but others became quick to do so. Bloombaum's analysis of the situation in 1979 is still apt today.

> *Of course, the patients want more than to have their records preserved. They want to be assured and reassured frequently that Kalaupapa will be theirs as long as they want it. They want to be involved in deciding what is to be done with the peninsula after they are all gone.*
>
> *They want to be a force in their own lives, and to move continuously away from the essentially paternalistic treatment of which they have been the recipients since 1866.*[71]

The patients were socialized to a paternalistic regime that required them to obey and as a group they easily came to resent those in authority. Generally they are suspicious of authority and super-protective of their own interests. They generally see change as threatening and tend to resist it. If they are to be comfortable with the actions of either the federal or the state regime, they need to be involved in decision-making and to be assured that decisions will not be taken unilaterally against their interests. Our interviews with patients have indicated that some settlement administrators and park superintendents have listened to the patients and tried to involve them in decision-making; others have ignored patient concerns and that has often led to confrontation with the patients.

CHAPTER 3. THE COMMUNITY

Social Categories: Patients, Kokuas, Callers, and Others

The most basic social division at Kalaupapa is between patient and non-patient. Non-patients fall into two main groups, workers and visitors. At Kalaupapa, the term "kokua" (plural "kokuas") is used for any non-patient worker, whether DOH or NPS and it is used with that meaning in this report. Patients are those individuals once diagnosed with Hansen's disease. If they are on the Kalaupapa Registry, they have the right to reside at Kalaupapa so long as the state's Kalaupapa Settlement is in existence. Workers do not have that right: if they lose their job they lose their right to stay at Kalaupapa. Some of the patients still work for the state in civil service jobs, but most of them are retired. A patient who holds a civil service job with the state might be called a worker, but not a kokua. Visitors who are guests of a patient or worker are usually termed "callers." Callers usually stay at the state's Visitors' Quarters (also called the "Caller House") or at one of the beach houses, but they must be hosted by a particular patient or worker, and formally registered with the DOH administrative office. By DOH regulation, a visitor's stay at Kalaupapa has (until very recently) been limited to seven days (six nights) at a time, and to 13 days per quarter. A visitor also may not roam the peninsula outside the settlement unless accompanied by his or her host. (See pp. 45-46 for further discussion of the rules which restrict visitors. Changes were made in May 2005 and further changes were being discussed in June 2005.) An individual patient or worker is limited to a maximum of six callers at a time.

All three terms – patient, kokua and caller – derive from the past and they are problematic today in various ways as a set of social categories. The latter two terms cannot easily be stretched to cover the range of non-patients who come to Kalaupapa now, who include tourists and volunteers. The tourists are clearly different from callers, who come as guests of someone living at Kalaupapa. The tourists come for the day and are picked up by Damien Tours. (There is no other way to come to Kalaupapa as a tourist.) They are sponsored by Damien Tours and must stay with the tour. Although they do get off the bus at certain locations, they remain with their driver guide and may not move around the settlement on their own as the callers can. The categorization of volunteers is more ambiguous. There are long-term volunteers under both the DOH and the NPS who fit easily into the category of kokuas, because they are part of the community and are seen to perform a regular service at Kalaupapa. But there are also short-term volunteers who do not fit so easily. They are free to walk around the settlement, unlike the tourists, but they are not like kokuas who are part of the community and perform a regular service.

Volunteers

A volunteer is someone who comes to Kalaupapa to "serve" the patient community, the community-at-large, or the park, by helping out with special projects. Usually this is done on a short-term basis, over a week-end or a period of one to two weeks. Most often volunteers come together in groups or clubs, but occasionally individual volunteers come in alone. Volunteers may be sponsored by the DOH, the NPS or by individual patients or workers. Quite often volunteers are also sponsored under the auspices of one of the churches. Church sponsored projects might include painting, minor building or repairs, yard work, sewing and mending clothes, washing windows, or doing just about anything that needs to be done.

Volunteers Planting Native Plants

The National Park Service Volunteer-in-Parks (VIP) program at Kalaupapa is geared more specifically toward work projects to protect cultural or natural resources within the park. Groups like the Sierra Club, various community and high school groups come to Kalaupapa to work on service projects such as seed collection, working in the plant nursery, replanting of native species out on the land, cemetery clean-up, building fences, repairing the pali trail and so on. A group of veterinarians returns annually to conduct a feline spay and neuter program to control the large Kalaupapa cat population. Groups of student archaeologists often come in the summer to do archaeological survey work.

The emphasis is on service to the patients and their surroundings. In exchange, the volunteers get an inside glimpse into the community and culture of Kalaupapa that they would not see if they came as tourists, just for the day. In addition, there is the camaraderie and dynamics among the volunteer group itself, group meals and interaction that contribute to the overall Kalaupapa experience. A huge benefit to the volunteers is that they usually get to spend time with patients by hosting them for meals, talking story, playing music and socializing with them. Over the years strong bonds have been created between patients and volunteer groups who return year after year, especially with churches who continue to send work groups to Kalaupapa.

Both terms patient and kokua are rejected by some people at Kalaupapa today. What people say about using those terms is revealing about their attitudes toward others. The term kokua was originally a Hawaiian word used for someone who came to Kalaupapa to care for a family member sent there as a patient, most often a husband or wife. That practice was allowed during the nineteenth century. The term derives from the Hawaiian word *kōkua* meaning "to help", or "helper" and originally it meant one who came to help out of aloha, not as a paid worker. At some point, the term got extended to the Catholic nuns and lay brothers who cared for patients at Kalaupapa and then to the territorial, later state workers who were paid to care for patients. By the 1940s, family members were no longer allowed to accompany a patient sent to Kalaupapa.[illegible] By then, the term was used mainly by non-Hawaiian speakers at Kalaupapa and meant simply "non-patient worker" (personal communication from Paul Harada, August 2007). Today it is a local English word at Kalaupapa, pluralized as "kokuas." When the park was established in 1980, the patients called the NPS workers kokuas as well, to differentiate them from patients and callers. In general the NPS workers are not as directly involved in caring for the patients as the DOH workers, but they have always had a role in maintaining the settlement infrastructure for the patients, as well as in caring for the rest of the peninsula.

Today the term kokua has a double meaning for some at Kalaupapa. It means "non-patient worker" to the patients, but to local workers who know the original Hawaiian meaning of the word, it can also mean "someone who serves the patients." The Congregational minister told us that, to him, none of the workers today are really kokuas in the original sense.

> *There's a guy named G. [a patient] who died a number of years ago who said there's no such thing as a kokua. They're long gone. A kokua was someone who came and took care of their partner – not for pay. There's a couple people that you might call kokua today— I would – but by and large, there are no kokua. People get paid. There's a couple of people that are married to patients, who live down here who I would consider a kokua, and that's it.* Lam Ryerall 3/15/02 Int

On the other hand, many of the workers embrace the term kokua for themselves. As Gina Sasada said, "I think as far as the kokua themselves go, you know, we pick it up from the patients. Because that's how they refer to us. After you come down, you come here, you live and you work and you pick it up."[illegible] We asked the workers this question as part of a survey: "Would you use the word kokua to describe yourself?" Out of 12 workers surveyed (both DOH and NPS), 11 said they use the term. Some said merely that the term means worker to them. Others said they like the term because they understand the meaning as helper and they feel they are here to serve the patients. A couple of them even said they were honored by the term. On the other hand, one NPS worker complained that he doesn't like being called a kokua. He doesn't call himself that because he works for the NPS and not for the DOH. The settlement administrator has also reportedly said that he does not like the term, stating that the workers aren't kokuas any more, they are civil servants.[38]

During the days of enforced segregation, it was generally only family members of patients who came to visit Kalaupapa as callers, and even they came seldom.[39] That began to change during Lawrence Judd's tenure as settlement administrator, when he helped to establish a Lions Club at Kalaupapa in 1948 and to begin the tradition of annual visits by Lions Clubs from outside Kalaupapa.[40] Today there are many people who come to Kalaupapa to visit the patients as callers, not only family and friends but also groups who come to share in one way or another with the patients. There are a number of church groups that have returned repeatedly over the years to join in services with the patients and to help clean up church grounds. Groups of entertainers often come in to perform at community parties as well. These can all fit within the category of "callers," and they are generally welcomed by the patients. When patients and long term kokuas see someone new walking around, they immediately become suspicious and want to know who it is. If they can connect that person to someone in the community — "Oh that's John's callers" then they are reassured.[41] Many patients come out to party with someone else's callers at the Visitors Quarters. The tourists who come in to take the tour are a different matter. Some patients stay indoors during the time they are riding around on the bus so as to avoid them.[42]

The term "patient" may seem strange to outsiders, inasmuch as the patients have inactive cases of Hansen's disease. However, many of them still have some continuing debilitation from the disease and need continued medical monitoring. For example, many have nerve damage and have lost feeling in hands and feet. For this reason they often injure themselves without knowing and get infections. They also seem to suffer lowered resistance to infection.

The question that naturally arises regarding the term "patient" is why doesn't the term indicate what <u>kind</u> of patient? There is some distaste, apparently, for both the term leprosy and the term Hansen's disease. The State of Hawai'i has decided that it is more politically correct to use Hansen's disease (following the lead of the National Hansen's disease Center at Carville, Louisiana), but many patients seem not to like that term and would just as soon use the term leprosy. One patient makes fun of the term Hansen's disease by saying "handsome disease" instead. In fact the patients usually simply speak of "the disease" or "the sick," without actually naming it. If there is distaste for the term leprosy, it is probably because the term "leper" is so disliked by patients. For example, patient Olivia Breitha wrote in her 1988 book that "... the term "leper" is totally inappropriate and should not be used." Most patients feel the term "leper" has all the biblical connotations of one who should be shunned. They long heard the word used pejoratively to stigmatize them as low and "unclean."

In the past, the patients often used the Hawaiian term *ma'i pākē* (Chinese sickness) for Hansen's disease or for someone who had Hansen's disease. It was still being used in the 1970s when Gugelyk and Bloombaum were interviewing patients. Today, however, it is almost never heard at Kalaupapa. Probably it disappeared from use as the Hawaiian speakers at Kalaupapa passed on. When we began our research at

Kalaupapa, we were told by a staff member of the Pacific Cooperative Studies Unit at the University of Hawai'i, under which we were contracted, that the preferred term for those who live at Kalaupapa because they have had Hansen's disease as "residents." It is true that to the DOH and the patients themselves, only the patients are residents of Kalaupapa, since they are the only ones entitled to live there indefinitely. However, the normal term used by everyone at Kalaupapa is patients, not residents. Only one of the patients told us that he dislikes the term patient and prefers the term resident. Some of the long term workers bristle when they are told that they are not residents of Kalaupapa. They point out that they have no other residence and that they are registered to vote at Kalaupapa.

In 2002, there were several people in the community who were long term members, but who are harder to fit into the three categories. Four individuals had lived at Kalaupapa for a long time, but were not paid employees of the state or the NPS. Three of them were non-patient spouses married to patients and one was a volunteer under the DOH. The volunteer was a retired DOH worker who had been allowed to stay on and was provided with housing as long as he volunteered. All four were considered kokuas by the patients, either because they worked to help the patients in general as volunteers, or because they helped their patient spouses. Three others who did not fit readily into any of the categories were the resident Roman Catholic priest and the Congregational minister and his wife (often called by the pidgin terms kahu and mama kahu).

Social Flow of the Settlement, Summer 2002

During the week (during 2002), the day starts early at Kalaupapa: the settlement starts to buzz about 6:00 A.M. Mass starts at 5:50 at the Catholic church, even before it has gotten light during the winter season. A small group of patients comes to mass every day, together with a couple of kokuas. Some of the patients come a half hour early to meditate before the mass. By 6:30 mass is over and everyone disperses after a few minutes chat. About the same time as the weekday mass, the patients at the Kalaupapa Care Home, usually known as the "hospital," are given their breakfast, having been awakened at 5:00. The hospital serves both as a care home for those patients who can no longer care for themselves and as a facility to provide medical care to all the patients. It has limited facilities and does not serve non-patients except in case of an emergency. Also at 6:00 the DOH cafeteria opens to serve breakfast to the state workers. All of the state workers are entitled to eat three meals a day there.

At 7:00 A.M. the work day starts for many of the DOH and NPS workers. (In summer the NPS maintenance workers start earlier, at 6:00 A.M.) The state maintenance crew can be seen at their building, meeting with their supervisor for a quarter hour or so, who assigns the work for the day. Fifty feet away the NPS maintenance crew can be seen meeting at their building with their supervisor. Soon they scatter — the state crew to do yard work in patient yards perhaps or to pick up rubbish, the NPS crew to mow grass in the settlement grounds perhaps, or to work outside the settlement. Also at 7:00 one of the nurses begins dressing patients at the hospital. The patients often develop infected sores on hands and feet that need debridement and bandaging for many days until they heal. A group of them can be found at the hospital for an hour or two every morning.

At 9:00, the first regular flight into the airport arrives from Honolulu. A number of patients usually go out to the airport to meet it, to pick up the paper or just see who is coming in. The last flight out to Honolulu is at 3:00. There are also flights to Topside and sometimes to Maui. Many of the kokuas spend the weekend out of the settlement, so they leave on Friday afternoon and come in for the work week on Monday morning. The airport is also a favored spot to drive to for a ride early in the morning, especially for those who take their dogs out riding.

Also at 9:00 the Kalaupapa Store becomes a gathering place. A long lanai (veranda) lined with benches stretches across the front of the store, offering a nice view out to the ocean. Regularly at 9:00 about four of the state maintenance workers gather there for their break, to drink soda and sit on the benches to talk story. A couple patients also come regularly at 9:00, but they usually sit separately from the workers. Other patients drop by the store through the morning. Usually they sit for a while on the benches and talk story with others who have come to buy, for anywhere from a few minutes up to a half hour. Except for those few patients who work fulltime, life is slow paced and there is plenty of time to stop and talk.

The store has a limited selection of canned and frozen goods that are generally available. On Mondays and Fridays fresh bread is flown in; on Tuesdays fresh milk is flown in; on Wednesdays fresh poi and vegetables are available (flown in on Tuesday). The patients are given first choice in buying vegetables. The store hours used to be the same as the regular state work hours, 7 A.M. to 3:30 P.M., but they were cut in summer 2002. Now the store is open from 9:00 to 3:45 on Monday, Wednesday and Friday, and from 7:00 to 11:00 on Tuesday and Thursday. The Kalaupapa Store is run by the DOH on a non-profit basis, primarily to serve the patients. Freight costs are paid by the state. Secondarily the store serves the kokuas and visitors to the settlement, but many people at Kalaupapa will tell the nonpatient newcomer that he or she is "not supposed to buy too much there." Kokuas are supposed to order groceries from a store Topside if they want to buy a lot. This is a compromise that allows the kokuas the convenience of buying groceries at the Kalaupapa Store, but prevents the store from running out of items that patients want to buy, according to the acting DOH business supervisor.[53] Prior to 1990 the kokuas were not allowed to shop at the store at all, only the patients.[54]

Figure 5. Kalaupapa Store

At 11:00 the state cafeteria (often called "the kitchen") opens for lunch. Most of the state workers eat there. Generally a couple of tables are occupied by the maintenance crew (all men) and another table by female office staff and nurses. With a few exceptions, there is little interaction between the men and the women. The male maintenance workers eat fast and leave. The maintenance supervisor has made a deal with his workers that if they take short noon hours, they get off early on Friday afternoon when most of them leave the settlement for the weekend. The women take more time at their lunch. At about the same time, lunch is served at the hospital. The NPS maintenance workers go to their homes for lunch at 11:30.

Figure 6. Postmistress Ku'ulei Bell

During this lunch hour period from 11:00 to 12:00, the post office becomes a gathering place of sorts. Mail generally comes in from the airport about 9:15 and gets put into the mailboxes by 10:00 or 11:00. Both patients and kokuas usually drop by to check their mail sometime between 10:30 and 12:00. A number of them regularly take the opportunity to talk story at the window with the gregarious postmistress Ku'ulei (a patient). At 12:00 she closes the window for lunch.

At 3:30 it's "pau hana" (after work) time for most of the workers. The pool hall and the bar become gathering places then. The last meal of the day is served by the state cafeteria at 3:45, but fewer of the workers eat supper there than lunch. The work day ends early so there is time for those workers who take the pali trail every day to get home by dark. Many patients and workers can be seen around the settlement between 3:00 and 5:00. Some have a regular place and time to feed stray cats. Others are riding out to the airport or the old slaughterhouse to give their dogs a ride or just to "catch air" and cool off. Some go swimming at the pier or go fishing.

A group of state workers and patients meet most afternoons at the pool hall, a small building in the area of Bay View Home. It has a pool table and card table inside, a refrigerator for keeping beer cold, and a picnic table and grill outside. Most weekdays there is a paiute game there (a local version of rummy). The game is run by a female kokua, who works as caretaker at the hospital. It often begins about 2:00 after she gets off work and continues to 7:00. A couple of the patients are crazy about gambling and if the kokua who runs the game is in the settlement they usually play paiute there. Otherwise they try to find another venue. There is a group of about four or five state workers that show up regularly about 4:00 to play pool, drink beer, and listen to Hawaiian music CDs. On Saturday night they usually cook out. A few other kokuas and patients may drop by to talk story, especially on Saturday night. But most of the kokuas and patients never go to the pool hall unless there is a party held there to celebrate a birthday or to say goodbye to a worker who is leaving.

Figure 7. The Bar

Another group meets most afternoons at Elaine's Place, usually simply called "the bar." A patient called Elaine owns and runs the bar, which sells ice cream, chips, soda and beer. Neither ice cream nor beer are sold at the Kalaupapa Store, so Elaine's Place is the only source for them. Elaine usually opens the bar around 12:00. When she is out of the settlement or not feeling good, then one of the NPS workers Lucy or Albert opens the bar for her after finishing their work day for the NPS at 2:30 or 3:30. There is a small group of patients who come by regularly to sit and talk in the early afternoon. Another group of kokuas, mostly NPS workers, often meets to drink beer after work. Other patients and kokuas come by briefly to pick up ice cream or beer to take out, since the price is higher to sit and drink beer than to take it out. There is very little overlap between the group that drinks at the bar and the group that drinks at the pool hall. Often the bar closes by 5:00, except on Friday night when Lucy and Albert usually keep it open until 9:00 or so, as long as anyone wants to keep drinking. As many have told us, the bar was a much livelier place a few years ago (1990-1995) than it is today and it was more central to the community. People were there drinking every night, and they brought food and ate potluck.[11] Earlier still when the patients were younger, there was a group that played Hawaiian music and sang most every night. Now the TV is usually on and the talk has to compete with it. The style at the bar has been for people to take turns buying rounds and to push people to drink more by buying the next round. A number of kokuas have said that they started out going to the bar every night, but had to stop because they couldn't keep drinking like that. Most of the patients that used to drink at the bar have stopped drinking for health reasons, so they rarely stay into the evening.

People also gather at various private homes in the evening, most often to play cards. That involves gambling because, as we were told, it's no fun unless there's money on the game. One of the state workers frequently hosts a pinochle game at her house for a mixed group of patients and kokuas. (The game alternates between her house and the pool hall.) A second group, mostly patients, often gets together to play poker for small stakes. Recently one of the NPS workers started hustling them to come to his house to play on Thursday nights for bigger stakes. A third group, consisting of state workers, frequently gets together to play cards or watch videos at one of their homes. Less frequently there are parties at a private house, usually on a Friday or Saturday night. Today these parties are usually given by kokuas, because the patients for the most part lack the energy for it.

In comparison to weekdays, weekends at Kalaupapa seem pretty quiet unless there is some special event going on. There is hardly anyone on the streets early in the morning. There are no workers driving here and there, the DOH office and store and the post office are all closed. Many of the kokuas have left for the weekend. Those who have stayed at Kalaupapa are often off fishing or hunting outside the settlement. In the afternoon the regulars collect at the pool hall or the bar. On Sunday morning, nearly all the patients go to one of the church services. The Catholic priest says mass at 7:00 at St. Francis church and at 9:00 in the hospital for those who are in wheelchairs. The Congregational church holds services at 9:00, the Mormon church at 10:00. Of the kokuas, most of the nurses are Catholic and go to Catholic services. The rest of the kokuas generally do not go to church.

There are a surprising number of special events that go on at Kalaupapa, usually on weekends. Some of these events are put on by the Kalaupapa community and others are brought in from outside. For years the community has held a yearly round of parties - Superbowl Party in February, Lei Day Contest, Mother's Day party and Damien Day in May, the Walk-a-fun walk (with dinner) and Barge Day (with lunch) in July, Lion's Club Charter Day and Fishing Tournament (with banquet) in August, Thanksgiving luncheon in November, Lion's Club Christmas Party, the Festival of Trees craft fair in December, and a New Year's Eve party at the end of the year. These are community events. Almost all the patients come and the kokuas are expected to at least come for a while and "show face." It has become difficult for the patients to put on these events as they have gotten older and the entire burden falls on a few of the younger ones, together with a small core of kokuas. Other kokuas help occasionally, but the majority do not. There are goodbye parties for workers who are leaving and informal parties with church and volunteer groups that come in to the settlement where everyone from the community is welcome. Certain church groups come to Kalaupapa every year. The St. John Vianney Choir from Kailua, O'ahu is hosted by the Catholic congregation every July. The choir holds a formal choral concert and dinner, and they spend the nights singing informally with the patients at the Visitor's Quarters. There are also smaller parties put on by individuals that are basically by invitation, held either at the person's home or at the pavilion across from the gas station. The community is small and news of a party gets around, but several people have told us that they don't go to a private party unless they are personally invited.[illegible] These individually-hosted parties were much more frequent in years past than they are today.

Apart from their personal friendships with certain patients, many of the kokuas respect the patients as a class and give them precedence in much the same way that Hawaiians or Japanese give precedence to elders. At parties the patients are given first choice of where to sit and are given first priority in getting their food from the buffet table. On the narrow roads, they are given a wide birth when patient and kokua meet driving their cars. Long-time DOH maintenance worker Randall Watanuki described his attitude by saying that he privileges the patients: if he meets them on the road in his car, he gives them space; if he meets them fishing, he moves away to give them space.[illegible] In the early 80s, he continued, there were more old folks fishing. If an elder [patient] was fishing, he wouldn't go onto their rock. But if he was fishing on a rock, he would offer his place to the elder. "I'm not sure why — whether it's because they're patients, or because they're older and I was raised to respect elders." In fact, the patients are elders to most of the kokuas, who are of a younger generation than the patients, and that inevitably colors their relationship, especially for local people.

There is also a sense that the patients should be privileged at Kalaupapa just because they are patients. The patients themselves clearly feel that they have a special claim to Kalaupapa and should be given priority over non-patients. The desire to privilege the patients can be seen in what one of us was told by Lucy Whiting, a long-time NPS worker.[illegible] She mentioned that she likes it when occasionally she sees only patient cars at the bar. She felt that it was their time to get together and "talk story" about issues or just "shoot the bull." She said she doesn't go to the bar when there are only patients there, because she doesn't want to intrude.

The sense that the patients should be respected and helped as a group is implicit in the statements made by many long-term kokuas that they worry about how long the patients will be able to stay at Kalaupapa, and that they want to stay at Kalaupapa to help as long as there are still patients here. It is exemplified in the following statement by a longtime DOH worker.[illegible]

But loving them by worship with them, working with them, feeding them, it's a great privilege for me. Not everybody get a chance to come here and work.

I guess it's a test for us working with them, to see how we take them. And I get to see many cases where they deformed. It's really a touching story, because when you hear them talk, the patients, the parents disown them. You know, they don't wanna come in and see them. I mean it hurts me a lot. So they become my family, in other words, so they get somebody to love.

I treat everybody the same. Because I feel why should I choose one very special when all of them are patients. I treat them equally, you know.

DOH worker 18 (2/16/02 Int)

Barge Day

Often described as "Christmas in July," Barge Day is reminiscent of an earlier time in Kalaupapa's history when there was no air freight service to the peninsula and everything was brought in either by boat or on pack mules via the pali (cliff) trail. Barge Day is still the only time of year when large, heavy freight items, nonperishable foods and bulk supplies are brought in to the remote Kalaupapa community. Taking advantage of the calm ocean waves during the summer months, the Young Brothers barge may make anywhere from one to three trips from late June to August or early September, depending on the community's needs. On the return trip to Honolulu, the barge is loaded up with junk cars, rusty appliances, and other discarded items, all headed for scrap metal heaven. Soda and beer cans are sent out for recycling by the Kalaupapa Lions Club. For anyone moving to or moving away

from Kalaupapa, this is the once-a-year opportunity to move containers of household goods and personal items into or out of the settlement. Even today, as Barge Day approaches, anticipation and excitement fill the air—just like Christmas morning when gifts are unwrapped and opened. In a similar fashion, people like to keep their soon to be delivered goods "secret."

Early in the morning people keep an eye on the ocean to the east for the first sight of the incoming barge. The fun comes as everyone gathers down at the wharf as the barge pulls up to dock and then watches with glee as everything is unloaded. Everyone oohs and aahs over a new washer and dryer, a brand new truck, someone's "new" used car, or a new set of furniture. Everything from gasoline and diesel fuel, lumber and utility poles, tires, mattresses and medical equipment to cases of beer, juice and soda for the bar, and bags of rice and other nonperishables for the one and only store at Kalaupapa is brought in on the barge.

The feeling is festive with lots of hustle and bustle as supervisors shout orders, workers scurry to their places and forklifts race about unloading the freight containers. Alongside the pier, like items are organized and lined up neatly together, the State goods in one area, the National Park goods in another, and personal items for residents in still another area. The unloading takes about five to six hours.

The DOH kitchen prepares lunch for the whole community. Everyone is invited, visitors, workers and residents alike, to gather at the Kalaupapa store as lunch is spread out on long tables on the porch in front. There is lots of laughter, talk-story and good old-fashioned kanikapila (singing) as everyone relishes the day's festive air. Like the excitement of Christmas, Barge Day seems to bring a sense of renewal and invigoration to the community. All too soon it is over as the barge heads away from the wharf and out to sea to disappear into the horizon.

Patients

In 2002, 44 patients were listed on the Kalaupapa Registry as residents, nine of them living outside Kalaupapa and 35 living inside. Those who lived outside Kalaupapa included six staying at Hale Mohalu on a long-term basis for medical care. Three others had established a home outside Kalaupapa as their main residence. All three have made independent lives for themselves on the outside, but still maintain their Kalaupapa Registry status and a home at Kalaupapa. Of the 35 patients who lived inside Kalaupapa, three to five were generally at Hale Mohalu for medical care at any given time. Only 24 patients were really able to get around without assistance. Six were in the Kalaupapa Care Home because of disabilities and five others were basically house-bound because of blindness or difficulty in walking. All of these 11 required some assistance to go to the store, to church or to other community functions. Therefore, the pool of Kalaupapa patients who were really mobile and active in the community was limited.

The dates at which the patients arrived at Kalaupapa range from 1923 to 1969, the last date patients were admitted to the registry. They generally spent a couple years first at the O'ahu facility for Hansen's disease patients, at Kalihi Hospital (before 1949) or Hale Mohalu at Pearl City (after 1949). The largest number were transferred to Kalaupapa as children in the years 1940-42. They were shipped from Kalihi after nearby Pearl Harbor was bombed, because Kalihi Hospital lay close to Pearl Harbor and was regarded as too dangerous. Those who came after 1950 were spared most of the effects of the disease, because they received the sulfone drug treatment soon after contracting Hansen's disease. In speaking of Kalaupapa, they often defer to the "old-timers" who came before them and know more about Kalaupapa "in the old days."

The patients on the Kalaupapa Registry are a cross-section of the population of Hawai'i in terms of ethnicity, although Hawaiians (including part-Hawaiians) are over-represented in comparison to their numbers as a percentage of the state population. Hawaiians have always been the majority among the Kalaupapa patient population. In 2002, 26 of the 44 patients were Hawaiian. In 1968, 56% of the patients at Kalaupapa were Hawaiian, compared to 16% Hawaiians in the general population.[61] Apparently Hawaiians have always been more susceptible to contracting the disease than have Asians and Europeans, perhaps because they didn't so much shun those who had the disease[62] or perhaps because the genetic makeup of Hawaiians makes it more likely they will be susceptible to the disease[63]

The patients on the registry in 2002 ranged in age from 61 to 90 some years old, with the largest number being in their seventies. The youngest patients are generally among the most active, as might be expected. However, the group of patients in their seventies seemed remarkably active in 2002, given their age and their disabilities. Many of them worked within the settlement, either fulltime or part time. Three patients were working in forty-hour-a-week civil service jobs, one as the federal postmistress, the second as the supervisor of housekeeping for the DOH, and the third as a kitchen helper for the DOH at the care home dining room. Two other patients, Richard Marks and his wife Gloria, were running Damien Tours, a business which they started some twenty years ago to take tourists around Kalaupapa by bus and talk about its history as a Hansen's disease settlement. Their tour business continues to be quite successful today, as it is the only way tourists can come to Kalaupapa (apart from callers or official government visitors). At one time they employed other patients as drivers, but there are none left today who are able and willing. Consequently, they have had to employ tour drivers from outside, as well as a mechanic. Another patient, Elaine Remigio, owned and was running the bar in 2002. She had bought the business and named it "Elaine's Place" after the previous patient owner died. In 2004, Elaine retired and sold the bar to patient Gloria Marks, who renamed it "Fuesaina's." In addition to these six patients working full time, ten other patients were working part-time in 2002. Some were working for the Arizona Memorial Museum Association, running the Kalaupapa bookstore, which sells books and other items to visitors. Most, however, were working for the DOH under the state's Patient Employment Program (PEP). The PEP was created by the state legislature in the 1980s to give non-working patients something to do. Under the program, patients are hired by the state for 19 hours a week to do various jobs that can benefit both the patient and the settlement.

Figure 8. Patient Ivy Kahilihiwa pumps gas at the Kalaupapa gas station
(her job under the Patient Employment Program in 2007)

As of June 2008, when this report was written, 18 of the patients who had been on the registry in 2002 had died, leaving only 26 on the registry. Nineteen patients were still living at Kalaupapa in 2008. Only 17 of them were still mobile, and only eight of them were still employed.

Most of the patients are retired. The difference among them in their savings and retirement benefits is a result (in part) of changes in the level of pay and pensions for patients working at Kalaupapa. Up through the 1960s at least, patients were doing most of the work at Kalaupapa at incredibly low wages, less than 70 cents an hour. Prior to 1957, the wage span was 40 cents to 55 cents an hour.[64] A patient might do the same job as a kokua, but would be paid less. At some point a group of patients brought suit to force the state to pay them minimum wage. After patients worked for twenty years for the DOH, they could retire with a pension. In 1961, the pension was only $130 to $140 a month,[65] although the patients have always received free housing, free medical treatment, and monthly food rations from the state. Today the lower end of these patient pensions is about $130 every two weeks.[66] Patients say that the state never expected them to live long enough to collect the pension, and that when the first patients retired after twenty years they had to bring suit to collect. The state did not contribute to the U.S. social security system for them, so they did not get social security either.[67] Only after 1958 were patients able to take the civil service exams and get state jobs at regular state pay. One of the patients had a friend in the Hawai'i State Legislature who worked to get a new law passed that patients on temporary release could be hired by the state civil service, and would actually have preference at Kalaupapa.[68] Many of the patients now in their sixties and seventies moved into the civil service system at that time, allowing them to retire in good financial shape since they were vested in both the state pension system and social security. But other patients of similar age never moved into the civil service and continued to work for lower wages in the old patient work program which proceeded the current PEP. So, there are generally three levels of retirement benefits—a minimum pension for older workers who retired from the patient work program, a medium pension for younger workers who retired from the patient work program, and a higher pension for younger workers who retired from a civil service position.

As of 2002, most of the mobile patients could be seen pretty frequently around the settlement. They spent a good part of their day in a round of going to church, to the hospital, the airport, the store and post office, and perhaps the bar or pool hall. They drove rather than walked, despite the small size of the settlement—probably because so many of them had foot problems due to the disease. A couple of those who didn't work drove around so much they seemed to be searching for something to do, while a couple others were reclusive and seldom to be seen. Only a few went fishing or did yard work. A few years ago many patients were involved in doing arts and crafts, but that had faded by the time our work began in 2001.[69] Some of the patients most involved had died and others had gotten less active.

We were surprised by how seldom patients seemed to visit each other at home, or to be visited by kokua friends. A patient explained it this way.

> *We seem to be individuals, I think that's why. We each have our own way of living our lives. One of the things, we like our privacy in our home. We no like nobody come and niele. We call that niele [to nose around in a rude way]. We no call that visitation. Because everybody come inside, "Oh, whose pizza that? Oh, where you get that table from? Oh, brand new TV." Nothing about you, no more even how are you. Me, when I get that kind visitors I tell them, "Get the hell out of here."*
>
> Henry Nalaielua (8/9/02 Int)

Figure 9. Two Patients Visiting

Many people we talked to—both patients and long time workers—said also that there is generally less visiting and less community activity than there was ten years ago, partly because the patients have gotten older and fewer in number, but also due to television. TV was first available by broadcast from Honolulu in the late 1950s, but the reception was quite poor.[illegible] Cable television was brought in about 1995, and that probably made a bigger difference. One patient complained that everyone is inside watching TV now; even if you go to visit, the TV is on and it is hard to talk.[illegible] Another patient we often visited is house bound and spent most of his day watching television. Several years earlier he had two close friends who came every afternoon to drink beer with him. When we knew him, they had died and he was hardly ever visited by other patients.

During community gatherings at McVeigh Hall, some patients and kokuas sit together, but it is usual that most of the patients sit at the table farthest from the front door, leaving the front rows of tables for the kokuas and outside visitors. There are perhaps a number of reasons for this separation. One patient told us that the reason is that most of the patients find it easier to come in the back door, which has a ramp, rather than up the front stairway, so they all end up at the back table.[illegible] We suspect that a number of patients also avoid sitting with kokuas in order to avoid embarrassment when they eat, due to their blindness or other disabilities. On the kokua side, most of the local kokuas are younger than the patients and not sitting with them is part of their normal behavior to respect elders. They greet them with a kiss or handshake when they come in, then go to sit at another table.

This division at parties is one of the ways the line between patient and kokua can be seen. Otherwise it is mainly heard in what people say. At our first meeting with patient Katherine Costales, who spent years outside Kalaupapa and then returned, she told us of her perception concerning the distinction between the two groups:

> *There's still a line between patient and kokua, an invisible line. I can see it. Those who stayed down here and went through the changes say there's no more line. But because I was outside and then came back, I see with a fresh eye. I don't agree with them, but I don't say anything. To me there's still a line.* (Douglas fieldnotes, Katherine Costales, 7-11-01)

She went on to elaborate on what she meant, that the kokuas still don't entirely treat the patients as normal people. They may eat and drink with you while they are down at Kalaupapa, but then avoid you when they see you outside.

One of the most perceptive of the nurses also spoke of the separation that remains between patient and kokua:

> *The physical barriers may have come down in 69, but there is still that separation. There's still, "you're the nurse and we're the patient. You're the kokua and we're the patient." And what a lot of them say from time to time is, "Well, you wouldn't be here if we weren't here." And it comes back to, well you wouldn't be here if we weren't here. So it's a symbiotic relationship, but they don't play it that way. They want the control. They will manipulate in those ways to keep their thumb on the kokuas.*
>
> Julie Sigler (2-4-02 Int)

What the patients say to the kokuas when they are angry at them is, "If no more us patients, you kokuas no more job." This is one manifestation of their refusal to accord the kokuas an equal place at Kalaupapa. They insist that Kalaupapa is their home, and not the home of the kokuas. There are other manifestations of this basic theme. Patients have told us that kokuas cannot own beach-houses, only patients can; that kokuas cannot own garages, only patients can. According to the state nurse Julie Sigler, there is an "unwritten rule" that a kokua cannot own more than one dog, but a patient can have as many as he or she wants. Probably all of this represents an attempt by the patients to assert some power, in a situation where the DOH administrator and NPS superintendent and their assistants have the formal authority. But it is not only that. One patient told of overhearing a kokua at the airport brag that he had a house up Topside and another house down here at Kalaupapa. She said it "hurt" her to hear that, because she had to go through being isolated here to be able to call Kalaupapa home and he did not. The patient sense of entitlement to Kalaupapa was eloquently expressed by one of the patients:

> *We paid for this land. The shame, the abandonment, the exile, we paid for this place. Blood, suffering, bones buried out there, down Papaloa.*
>
> (Makia Malo 9/26/01 Int)

The same reasons lie behind patient resentment concerning benefits which were once reserved for patients and then got extended to the workers. Until the 1990s only patients lived in individual houses. Workers lived in dormitories, except for the supervisors. When the houses started to fall empty as the patients became fewer, and the administrator offered them to workers, the patients objected.[illegible] Kalaupapa Store too is still a source of bad feeling. Although the store has been open to kokuas for more than ten years, there are still lingering feelings that it should be primarily for the patients. The store has a limited supply of many items. One patient told us repeatedly that the kokuas should not buy out an item at the store and leave the shelf empty so there would be nothing left for the patients. Another patient, Paul Harada, pointed out that the store was established for the patients. He said that the state brings in supplies to the store at taxpayer expense for the patients to buy tax-free, but that the non-patients should have to pay sales tax at the store just like they would outside Kalaupapa.[illegible]

Patients are especially resentful when workers appear to them to be favored over the patients. The DOH considers Kalaupapa a hardship post for its workers and one of the special benefits it provides them is to install appliances when a worker moves into a house. The patients complained that the DOH paid for appliances for the workers, but never paid for patients' appliances.[illegible] (In response to patient agitation, the DOH established a new policy in 2005 to buy appliances for the patients if they were lacking or needed replacement.) In several cases, patients have moved into the care home or moved to Hale Mohalu, but their houses at Kalaupapa have continued to be allocated to them. When the patient died, the house was then given to a kokua to live in. We have heard patients complain in those cases, that the house was allowed to get run down so long as the patient held it, but as soon as it went to a kokua the DOH fixed it up.

At the same time that patients try to limit the place of the kokuas at Kalaupapa, they also want them to be sociable and to play a supportive role in the community and they complain if they do not. About one-third of the kokuas have their families and homes on Topside Moloka'i, so they leave Kalaupapa most weekends. A few go home nearly every night. We were told by the spouse of a patient that, "The patients don't like when the kokuas don't live down here." We also heard complaints from patients themselves about workers who leave every night, because it means these workers don't participate in the community. Once a patient inquired of Linnekin what workers he was interviewing. When given the name of one of the NPS workers, she commented, "We never see him. Most of the kokuas we never see." This implied the criticism that many of the kokuas keep to themselves. The remainder of her conversation, however, showed that it might not be easy for kokuas to get close to patients. "They seldom come [to our house] unless we invite them. And we're choosey." The legacy of segregation at Kalaupapa is that workers seldom visit patients at home. In the past it was against the rules and today many workers are unsure they would be welcome. Conversely, many patients feel their home is a sanctuary and they rarely invite non-patients there. Even their own callers don't usually stay with them, but are instead are housed at the Visitors' Quarters or at one of the patient-owned beach houses.

Kokuas

In 2002 there were sixty non-patient workers, forty state DOH workers, one state Department of Transportation worker, and 19 NPS workers. The workers are analyzed by ethnic group and place of origin in Table 3, below. The ethnic categories "Hawaiian," "local," and "haole" are used in the table (and elsewhere in this report) as they are used currently by local people at Kalaupapa, and all over Hawai'i. "Hawaiian" is used for persons with any proportion of Hawaiian descent. "Haole" is used for white persons (but not for Portuguese, who are classified separately in local terminology). "Local" is used for persons raised in Hawai'i — mainly Hawaiians, Chinese, Filipinos, Portuguese and Japanese — except for haoles. (However, Caucasians raised in Hawai'i are often called "local haoles" if they speak pidgin and behave in a local way.)

Table 3. Ethnic Group and Origin of Kalaupapa Workers in 2002

	State Nurses	Other State	Total State	NPS Maintenance	Other NPS	Total NPS	Total Workers
Hawn Topside		14	14	9	1	10	24
Hawn Other	1		1	2	1	3	4
Total Hawn	1	14	15	11	2	13	28
Local Topside	1	2	2				2
Local Other	3	8	12				12
Haole Mainland	4	4	8	1	5	6	14
Foreign	3	1	4				4
Total Workers	12	29	41	12	7	19	60

It will be noted that the 24 workers who are Hawaiians from Topside Moloka'i form the largest group. Most of them work in the DOH or NPS maintenance divisions. In general the jobs that require more formal education or training in both organizations draw workers from farther afield. Jobs that require less education or training draw more workers from Moloka'i, which has a relatively unskilled population. Within the group of state workers, nursing requires more education than the other jobs. Only one of the nurses comes from Topside Moloka'i; more than half of them come from the mainland U.S. or (originally) from a foreign country. By contrast more than half of the remaining DOH workers come from Topside Moloka'i and only a few come from the mainland or a foreign country. There has always been a big proportion of the DOH workers from Topside because jobs are so scarce on Moloka'i.

There are a number of overall differences between the park staff and the state workers. The DOH has a direct role in caring for the patients and for buildings and grounds that patients use within the settlement. The primary role of the NPS is outside that sphere, caring for buildings and grounds that the DOH has turned over to the NPS within the settlement, for the cemeteries and the rest of the peninsula outside the settlement. It is the case that the NPS staff has taken over the maintenance of utilities at Kalaupapa Settlement in recent years. It is still true, however, that the DOH workers generally have much more direct contact with the patients in the context of their work than do the NPS workers. State workers are also more likely to live full-time down at Kalaupapa than NPS workers and therefore more likely to have contact with the patients outside of work.

Because the State of Hawai'i considers Kalaupapa a hardship post, it affords state workers a number of special benefits for working at Kalaupapa that NPS workers do not receive. State workers (DOH and DOT) get free meals served at the state cafeteria, they get free appliances in the state housing provided them, and their water and electricity are paid for by the state. State workers who live off-island get one paid round-trip air flight to their home per month. Those who live Topside and walk up and down the trail get "trail pay" for their time walking. NPS workers get none of these benefits.

Interviews of workers as well as observation showed that workers seldom drop by patient houses in a casual way, just to visit. Outside of work, they usually meet patients in a "public context" – at church, at community events held at McVeigh Hall (such as Ladies Bingo Night or the SuperBowl Party) or at regular party locations like the bar or the pool hall. Most patients attend Sunday church services, but relatively few of the workers do (only about 11 in 2002). Secular community events are put on by individuals or by two community organizations, the Kalaupapa Lions Club and the Activities Club. A few workers play a big role in helping to put on community events. Others attend such community events regularly, but do not usually help with the event. A third set of workers never shows up for community events, either because they leave the settlement every day after work and are not available, or because they dislike parties. The rest fall in between, coming sometimes and not other times.

Workers were also interviewed about whether they hug or kiss patients. One of the NPS workers told why usually he doesn't do that. He first came to Kalaupapa in 1986, when the line between patient and *kōkua* was still quite marked according to him. He said that he was taught not to touch the patients because it made them uncomfortable, that he doesn't even shake hands unless the patient initiates that. There is little doubt that patients felt uneasy about being touched by non-patients when segregation first ended, because they had for so long been taught not to have contact with non patients. Makia

Malo described his discomfort at being touched when he first left Kalaupapa as a released patient and was participating in a drama workshop in Honolulu in the 1970s.

> *Karen had the workshop out at the Kapahulu Library. Ten Fridays in a row we met at the Kapahulu Library for two, three hours, I think. And I had to – one thing I couldn't handle: people touching me. I was very self-conscious. So we did this kind of exercise, you know, standing in a line and then repeat after her. And then we turn to our right and then you touch the person from behind so we form a circle, yeah? You touch the person on the shoulder and you massage the person's shoulder. I couldn't do that. I couldn't touch anybody. And I didn't like people touching me. And she had a lot of those exercises, and I was getting pissed off. Because I couldn't handle that, you know. And so the second time or third time she told us to do that I said, "You know, Karen, I no can do this. I no can handle touching people, people touching me. You going do this all the time, I going quit."* Makia Malo (10/29/01 Int)

Nurse Charlotte LaCroix, who came to Kalaupapa in 1990, was one of several who broke through that barrier to touching.

> *There was that segregated feeling when I first came. I could feel it. There was us, we, and them – there was national park, state, and the patients. It wasn't really defined, but you could feel it. I didn't go to [mass at] church that much, cause we'd have mass at the hospital. But the people were not touchy. I noticed that with patients, you just kinda watch that [interpersonal] space. And – not saying I started it, but I got a touch where people hugged, this kinda thing, we did that. And so, we had mass in the hall [at the hospital], and we had the peace sign, so I just went over and clinch clinch [hugged someone]. And it got better. Gradually people started becoming a little more open to it, like it's okay. So I guess our idea broke that feeling for them. It was like shame-based for them. When I look back from then to now, they seem more empowered.*
>
> *There are some that you didn't, like some cultures, there's some Japanese that are really kind of still reserved about that. That gets to be a personal thing I think, how people are about space, and you have to respect that.* Charlotte LaCroix (2/14/02 Int)

By now many of the kokuas have followed Charlotte's lead. Gina Sasada, who came to Kalaupapa in 1984 described a similar experience with a patient who works with her at the store.

> *Aloha and I work in the store. Like, as far as I'm concerned, Aloha and I are friends. And I tell you a funny story about Aloha. Maybe I've been here a year, maybe not a year. Anyway, one day Aloha was standing next to me by the cash register and we were talking and laughing. And without even thinking about it, yeah, I put my arm around her and I could feel her*

> *freeze. You know, like, it's a kind of look like that. It must have been the first time I ever did it. I could feel her. You know. And I'm going, "Oh, God." And so I just continued talking, you know. And, Ilada never moved. And I just kept talking. But all of sudden in the corner of my eye I seen her look up at me like that. I said, does she really know she, does she realize she has her arm around me? And she just kind of, she just kept kind of looking at me for a little while and then all of a sudden she smiled. You know. And, you know, from then on I kiss her, I hug her, you know what I mean. It's okay.* Gina Sasada (10/31/02 Int)

Often, the attitude of kokua toward patient is more an attitude of respect and desire to serve than it is one of friendship or intimacy. Perhaps the best way to illustrate the commitment of many of the kokuas to serve the patients is to quote them directly. The first three indicated that they felt called in some way to come to Kalaupapa, and their statements reflect the passion of their commitment. The last two came to Kalaupapa because it was a chance for a good paying job.

Charlotte LaCroix, nurse (4/14/02 Int)
It was something about their [the patients'] spirituality, it just drew you to want to work with it. It's like you wanted to make a difference. You wanted to come here and make their lives better. I just felt called to come.

Shannon Cravalho, DOH cook (3/27/02 Int)
Main thing the patients. The patients is first.
We'll back these people up no matter what. They should be here till their last breath. This is their home. This is our kupuna (grandparents).
Sometimes we tend to forget that we here for the patients - no do 'em for the paycheck, you gotta do 'em from the heart.

Randall Watamaki, DOH maintenance supervisor (8/11/01 Int)
I want to be remembered as a kokua in Kalaupapa.
My intention was to come here and to help. And to work here. I just feel that God blessed me with the opportunity to come and to do something good to help a special group of people. And I just feel blessed to have the opportunity to do that.

DOH Worker 18 (Langlas Fieldnotes, 2/10/02)
It hurts when a patient passes away. We look at them as family - like aunty and uncle. We look to them for help and they look to us. We're like ohana [family], although we're not related. I'm proud to have worked down here. I feel lucky. Because we're the last who still work here. I look at it as a blessing to help the patients.

Blossom Kaeia, DOH business office clerk (7/9/01 Int)
I've learned that that - our job here, is to serve our [patients], serve them.
When I first came here, it was like I was fighting back. "No, you can't get this thing," you know? "It's just out of the world you asking me to." But I've learned. You just try to work something out that'll satisfy them. There's always an answer.

Lucy Whiting, NPS Administrative Technician (3/24/02 Int)
I feel kind of proud when I'm up on the top [of the pali] there and hear people talking about it [Kalaupapa]. I feel very proud and privileged that I am living here. And to listen to their discussions of "who could do that?" and of course they're all serving on the patients side. They don't think about the others that are here to work, and who are working to keep the settlement going and the patients, to contribute to their lives too

A surprising number of the state workers interviewed came to Kalaupapa in order to serve the patients. At least four local workers had a parent or grandparent who was a patient at Kalaupapa and that gives them a reason to be extra mindful of the patients. Even among those who came primarily because they needed a decent job, the idea has taken root that they are here to serve the patients and make their lives comfortable. Some people said they came because they felt a call to serve, or because they were looking for spiritual or psychological healing. Several nurses gave a similar reason, that they had found their previous nursing work unfulfilling and wanted to do more holistic nursing. All of these responses might be lumped roughly under the heading of "feeling a call." Others said that they came because they were looking for a good job and were having a hard time finding one elsewhere. Most of these are people who were living Topside, with its high unemployment rate. The difference between DOH and NPS workers when asked why they came is striking. Nine out of thirteen of the DOH workers felt some sort of call, while none of the seven NPS workers did. The attitude of serving the patients would not seem to apply so much to the NPS workers because they do not have as much role in caring directly for the patients as part of their work. However, they may serve the patients through some kind of community service outside of work, particularly if they stay down at Kalaupapa. All of the long-term NPS workers surveyed showed that they had developed a desire to serve the patients after they came to Kalaupapa

Settlement Politics and Patient Concerns

Power relations at Kalaupapa are complex, and the situation is quite different from the usual national park where the park superintendent is definitely in control. There are many players, some with formal decision-making power and others with informal power to influence decisions. For the most part formal power is shared by the DOH Kalaupapa Settlement Administrator (currently Mike McCarthy) and the superintendent of Kalaupapa National Historical Park (Tom Workman during the period of our fieldwork). Although each has superiors that he answers to and other political forces to deal with, each has considerable effective power. Broadly speaking, the DOH and the NPS control different aspects of Kalaupapa, although in some areas they share control. The two entities share control over the settlement. Each has jurisdiction over certain buildings and grounds, which it manages. Each provides employment for workers and volunteers at Kalaupapa, and each provides services to the patients. The DOH regulates visiting by outsiders to Kalaupapa Settlement and establishes the rules governing the behavior of visitors and workers there.

Up until 2004, when the state legislature held a hearing on the administration of Kalaupapa, the current DOH Settlement Administrator had a pretty free hand at Kalaupapa. His superiors in the DOH Hansen's Disease Branch seldom came to Kalaupapa and they exercised only limited administrative oversight. However, the administrator is constrained in dealing with the DOH staff and resources at Kalaupapa in other ways. He is limited by the authority of the settlement doctor (Dr. Jones in 2001-2003, Dr. Brady in 2004-2008) and the nursing supervisor who both work directly under the Honolulu office, rather than under him. They make the decisions in matters related to patient medical issues and supervision of the nursing staff and sometimes come into conflict with the administrator. The settlement doctor can also affect the allocation of resources by the administrator. Sometimes a patient obtains a desired housing improvement because the doctor declares it to be medically necessary. The administrator and his staff managers are also constrained in dealing with the DOH workers at Kalaupapa by the union which represents worker interests. Interviews with DOH and NPS workers showed that both groups felt that the DOH workers had an advantage in dealing with their supervisors because they have a union which represents them, whereas the NPS workers do not. For example, the union rules make it complicated to discipline a worker for avoiding work by unjustifiably claiming sickness.

The NPS, under the park superintendent, manages natural and cultural resources at Kalaupapa. That includes the Congregational and Catholic churches within the settlement and at Kalawao, used by patients and kokuas and visited by tourists. The churches are owned by their respective denominations, but maintained under cooperative agreements with the park. Under the agreements, the NPS helps with maintenance and ensures that the historic integrity of each structure is maintained. Outside the settlement, the NPS is largely in control, but even there the NPS is considerably constrained by the fact that nearly all the land of the park is owned by the state of Hawai'i rather than the federal government (except for the 23 acre site of the Moloka'i Light Station, the old lighthouse, which was always federal land and has recently been transferred to the NPS). All of the eastern portion of the park is under the jurisdiction of the state Department of Land and Natural Resources (DLNR) and is used by the NPS under a cooperative agreement. The airport is under the jurisdiction of the state Department of Transportation (DOT). The western third of the peninsula, which includes the settlement itself, is held by the state Department of Hawaiian Homelands (DHHL), which manages its land for the benefit of Native Hawaiians. That land is leased to the NPS and the DHHL must agree to changes in land use there. When the NPS proposed a new landfill site on its land, the DHHL initially refused to allow it, although it has since approved the construction of a solid waste composting facility on its land.

Both the settlement administrator and the park superintendent are affected by players with informal power, especially the patients. The patients are organized into several groups to provide input to the administrators. They have long elected the Kalaupapa Patient Advisory Council (KPAC). Recently the non-profit corporation called Ka Ohana o Kalaupapa was formed by a group of patients, together with family members and friends (including some of the kokuas) to support patient interests. When the park was established in 1980, a commission of 11 members, the Kalaupapa National Historical

Park Advisory Commission, was formed, in accordance with the enabling legislation for the park, to advise the Secretary of the Interior (effectively the park superintendent) on operation of the park and visitation policy. Seven of the eleven members were patients elected by the patients at Kalaupapa, so the patients should have an important influence on park management through the commission. However, the commission was inactive during the 1990s and only revived again in 2003.[illegible] By the end of 2007, few of the patient members were left at Kalaupapa (some had passed on and others were at Hale Mohalu because of long-term illness) and the commission had become ineffective again.

If the patients are unhappy with the actions of the administrator or park superintendent and find that their complaints fall upon deaf ears, they often make attempts to bring pressure on them from outside – by writing and talking to their administrative superiors in the DOH or the NPS, by enlisting the help of sympathetic news media reporters, and even by lobbying their state and federal legislators. Indeed, the park was established largely because the patients were unhappy with the state's management of Kalaupapa and worked with Congresswoman Patsy Mink who fought for the park's creation.[illegible] However, patient lobbying with legislators is usually ineffective unless the patients unite, and then they can have a real impact.

Trouble Issues for Patients

DOH authority at Kalaupapa is based on state law (HRS 324, Hansen's disease) and administrative rules (Title 11, Chapters 168 and 170). Chapter 168 empowers the DOH to control visitation at Kalaupapa in order to maintain it as a closed community on behalf of the patient residents.[illegible] In addition to the formal administrative rules, "informal settlement rules" not given a public hearing are established by the DOH under the current settlement administrator to govern the conduct of guests at Kalaupapa.[illegible] These include the printed rules given to visitors when they arrive.

Patients often express grievances with the DOH Settlement Administrator and staff, both privately to each other and directly to the administrator or his assistants. One important area of patient grievances concerns benefits given to state workers that seem to the patients to unduly favor the workers, as described earlier – their being supplied with appliances in their Kalaupapa living quarters that are not given to the patients and their use of the state store originally meant solely for the patients.

A second important area of grievances involves the arrangements for visitors. Under the rules established by the administrator, all "guests" must register at the DOH office and obtain a permit. That means guests (or callers) of both patients and workers, everyone except the state and park workers themselves. The family members of workers – their non-working spouses, children or parents – can come in only as guests. Rules established by the administrator, based on input from the patients, govern the length of guest visits and what guests may do at Kalaupapa. For example, guests are not permitted to pick opihi or to do any fishing besides pole-fishing; they are not permitted to travel outside the settlement unless accompanied by their patient or worker host as escort. Prior to 2005, children under the age of 16 were not permitted to visit, except for those related to patients, and they were restricted to staying in the beach house area. As of 2005, children related to patients (not those related to workers) were allowed to visit and stay in the settlement, but were to remain in the house or yard of the patient they were visiting.

These arrangements are a source of conflict among the patients themselves as well as a source of conflict between patients and the administrator. The rules are frequently altered as a result of patient pressure on the DOH administrator. To give an example concerning visits by children, several patients have been pushing since the 1980s to be able to have their relatives under age 16 visit them, while the majority have resisted that change. The rule against children visiting at Kalaupapa was originally established by the DOH during the period when patients were still contagious, and because medical opinion held that children were especially susceptible to the disease. A majority of patients polled by us in 2005 were still against letting children visit. They gave various reasons. Some feared that children would stare at patients physically affected by the disease and make them feel bad. Some feared that children would be disruptive. Some still feared that children might contract Hansen's disease at Kalaupapa (although the common medical opinion indicates that such fear is unwarranted).[50] Patients told us that the current administrator was inconsistent in applying the rules regarding visiting by children and this was a source of passionate resentment by them. Obviously it is not easy for the administrator to establish rules for visiting by the children of patients in a situation where the patients themselves disagree on what should be done. However, the main complaint was that he allowed the children of workers to visit and even stay in the settlement in violation of the rule[51] and this was not an issue on which the patients disagreed.[52]

NPS jurisdiction at Kalaupapa is based on the federal enabling legislation for Kalaupapa National Historical Park (Public Law 96-565, given in its entirety in Appendix D). Section 102 of that legislation is given below.

The Congress declares the following to constitute the principal purposes of the park:

- (1) to preserve and interpret the Kalaupapa settlement for the education and inspiration of present and future generations.
- (2) to provide a well-maintained community in which the Kalaupapa leprosy patients are guaranteed that they may remain at Kalaupapa as long as they wish, to protect the current lifestyle of these patients and their individual privacy, to research, preserve, and maintain the present character of the community, to research, preserve, and maintain important historic structures, traditional Hawaiian sites, cultural values, and natural features, and to provide for limited visitation by the general public.
- (3) to provide that the preservation and interpretation of the settlement be managed and performed by patients and Native Hawaiians to the extent practical, and that training opportunities be provided such persons in management and interpretation of the settlement's cultural, historical, educational, and scenic resources.

Because the NPS is mandated to protect the current lifestyle of the patients, it supports the DOH visitor policy and resists pressure to increase the number of tourist visitors to the park, even though increased park attendance is generally used to measure park success within the NPS. In addition to those purposes specific to Kalaupapa National Historical Park, the NPS also carries out its mandate relative to all national parks, including the preservation and maintenance of the natural and archaeological resources of the park.

During the period of our fieldwork, some patients did express grievances directly to the NPS managers at Kalaupapa, but for the most part they expressed them privately to each other or to kokuas. Some patients did express their grievances directly, but complained that they were not listened to. Some of the patients still have difficulty in confronting authority. That can be traced to their experience during the days of segregation, when they were taught to do what they were told by the authorities at Kalaupapa. Most importantly, the community lacked an established process for patients to express their concerns directly to park managers until the institution of regular community meetings in 2004.

One area of patient grievances has been the park's management of natural and cultural resources. For example, patients complained that plants valued by them have been cut down, sometimes removed deliberately by the resources management division in an attempt to control alien plants, sometimes mown off accidentally by the maintenance division in the course of maintaining the roadways. For the most part, such grievances have been the result of too little consultation by park staff with the patients to understand what resources they value.[13]

A second area of patient grievances concerns the park's attempts to bring additional people into Kalaupapa, either as nonworking spouses of NPS workers or as volunteers. It is easy to understand why park management wants these changes. The fact that workers cannot have their spouse live with them at Kalaupapa imposes a considerable hardship on the workers and makes it difficult to recruit them. In 2001 an interim superintendent held a public meeting to propose a change in policy that park workers be allowed to bring their spouses to live at Kalaupapa, whether or not the spouse works there. Patients opposed the change at the meeting. They continue to be concerned that the park might act unilaterally to change its policy (although that would seem to be inconsistent with current DOH rules concerning the settlement).

> *We, the patients, figure that if spouses were allowed, yeah, this place would be overwhelmed with kokuas. Now you talk about, oh, it's not fair to the worker. Yes, it's not fair to the worker – but then again what can we do about it? I mean, you have to think like the workers here, you know. And I have to think like the patients here. So eventually we're going to be overwhelmed, because we're overwhelmed with workers already.*
>
> Paul Harada (8/8/02 Int)

The sorest point for the patients in their relationship with the park during the period of our research was the park's volunteer program. We often heard complaints about the volunteers in the settlement and it was the issue most often raised with park administrators at community meetings held in 2004-2005. From the standpoint of the park management, the volunteer program is very important because they lack sufficient staff to carry out all the tasks that need to be done to properly care for the park's cultural and natural resources. But the patients do not see it that way. A common complaint is that they cannot identify the volunteers and don't know what they are doing at Kalaupapa. Sometimes patients also say that there are too many, that they don't think they are all needed and some are perhaps only here "on vacation."

> *Today I see one face, tomorrow I see one different face, you don't know who the hell is this guys. That bothers me. Yeah. So I questions them. "Hey, whatta you guys doing here?" "Oh we come for the national park."*

> *That's all they gotta mention, eh? Nobody gonna question it. But you wonder what they really doing over here, if they stay over here only for hang out.* Boogie Kahilihiwa (6-23-05 Int)

Two attitudes underlie these complaints. One is the suspicion of unknown outsiders common to the patients. The other is the patients' feeling that non-patients are not entitled to be at Kalaupapa unless they have some purpose which benefits the patients or contributes to preserving Kalaupapa for the future. Their response to the volunteers reflects their insistence on their own primacy at Kalaupapa. They are also concerned about the status of the NPS volunteers, whether they should have the privileges of the kokuas at Kalaupapa to move outside the settlement unescorted and fish, or whether they are to be treated like guests who cannot do that.

More recently, the park has moved to deal with these issues. In 2005, park staff held a community meeting with the patients to discuss the volunteer program and elicit patient concerns. One main concern expressed was that people don't know who the volunteers are. Two actions have since been taken to deal with this issue. The park began displaying posters which describe new volunteers and their work at Kalaupapa. In addition, T-shirts were printed for the volunteers to wear when they are in the community. A second concern, about how volunteers should act and what privileges they should have at Kalaupapa, was addressed in guidelines, drafted in consultation with patients and the DOH, for a manual specifying proper volunteer behavior at Kalaupapa.[24] The guidelines distinguish between short-term volunteer groups and individual volunteers, who are treated like visitors, and long-term full-time volunteers, who are treated like park employees. The new rules allow only the long-term volunteers to move outside the settlement on their own, go fishing and sponsor other visitors.

Political Processes

The processes by which grievances are expressed and settled at Kalaupapa range from gossip to formal meetings to bringing outside publicity and political pressure to bear on administrators. Our impression is that there is a lot of gossip going around at Kalaupapa. One worker generalized that, "Rumors can go around the settlement real fast, cause the place is so small. And the story changes by the time you get it second or third hand." Gossip, of course, generates public opinion and creates social pressure to conform. Thus, some kokuas told us they felt they needed to come to community parties and "show face" for a half hour so that patients wouldn't talk about them failing to attend.

Of the two formal institutions that act to promote the interests of the patients, the Kalaupapa Patient Advisory Council is long established, while Ka Ohana o Kalaupapa has only been formed recently. The patient council was formed at the instigation of the state, and officially it has only an advisory role to the DOH.[25] It was already established in the 1950s, according to patient Henry Nalaielua and long-time state worker Joe Mollena. The patients elect six council members, including the chairperson (currently Gloria Marks). In the 1970s, the patient council was under the leadership of long-time Chairman Bernard Punikaia, and at that time it was very vocal in pushing for what the patients wanted. Joe Mollena described the situation in the late 1970s, when Jack Halstead was the DOH Administrator:

> *During that time, the council had Bernard Punikaia. Oh, every time they hold meeting down in Paschoal Hall about him [Halstead], he gotta come inside, eh? Ohh, he catch hell, you know. They go for him until his face turn red. He like come out, but he say, "We not finished with you yet." He cannot go out.* Joe Mollena (6/23/03 Int)

More recently, people say the council has been relatively ineffective. Patients and kokuas alike commented in 2002 that the patients and the council "don't fight like they did before." In large part that is due to the increasing age and infirmity of the patients. The once active Bernard Punikaia, for example, has suffered a stroke that impaired his memory. Of those on the council during the period of our research, only the Chair Gloria Marks seemed to really play a strong role.

The patient council was established to advise the DOH administrator and it has no official role vis-à-vis the park. DOH Settlement Administrator McCarten confirmed to Langlas in 2001 that he and the park superintendent both use the council as a vehicle to obtain patient opinion, that they solicit council support for their decisions, but are not required to follow council advice. The amount of actual influence of the patient council, or of the patients in general, depends mostly on the influence the settlement administrator and park superintendent choose to give them. The previous settlement administrator, Mary Beth Maul (1985-93), often had public meetings with the patients to discuss issues and she sought their input to establish written policies (for example, the 1991 agreement on visitation by minor relatives of patients). The current settlement administrator Mike McCarten (who started in 1993) acted differently up to 2003. He seldom met with the patients in public meetings[30] and patients often complained during 2002-2003 that he did not enforce the rules consistently.[31]

By 2003, patient grievances against the current administrator had built up to a high point. They signed a nearly unanimous petition to the state legislature asking for an audit of state funding at Kalaupapa and lobbied their legislators. As a result, the House of Representatives asked for an audit and the Hawai'i State Auditor's Office started an investigation in July 2003, which included taking testimony from many patients. The audit resulted in a report in December 2003 which was highly critical of the administrator, as well as his DOH superiors, citing a lack of response to patient concerns. As a result of the report, the DOH agreed to hold monthly meetings to discuss issues of concern to the patients and the administrator's DOH superiors have exercised greater oversight over him. The meetings began in January 2004. Following the critical report, a joint state senate-house committee hearing was held in January 2004 which further examined the administrator's management of Kalaupapa.[32] Dr. Linda Rosen, Deputy Director, stated that the DOH was trying to improve communication with the patients. She suggested that the park superintendent should also attend the monthly meetings, in response to one legislator's comment that he had heard patients complain about poor communication with the park administration as well as the DOH. At the hearing, many patients called for McCarten to be replaced as administrator, but that did not happen. We see here the power of the patients when they lobby the legislature, but we also see here the limits of their power since they were unable to obtain his removal.

In August 2003, around the same time as the petition and audit, a group of patients, together with friends and family members met to form Ka Ohana o Kalaupapa (hereafter referred to as the Ohana). A patient central to the formation of the group, Ku'ulei Bell, said that it was formed so that as the patients continue to age and their ability to defend their interests declines, the organization can do that for them. According to the group's mission and vision statements, its overall purposes are to promote patient welfare at Kalaupapa, ensuring that they can live out their lives in the settlement, and to help preserve the legacy of Kalaupapa and educate the public. Initially the group decided to work on two pressing concerns, the need for a return of dialysis services for patients at Kalaupapa and the need for better communication between patients on the one hand and the DOH and NPS on the other.[illegible] The Ohana was successful in its first goal of changing the DOH decision that patients who need dialysis would be treated only at Hale Mohalu in Honolulu and in getting a dialysis machine set up at Kalaupapa care home with a technician to run it. The patients argued for this so that those who need dialysis could stay at Kalaupapa. Several outside groups and agencies were tapped to provide help with the program, including the Office of Hawaiian Affairs, which provided funding for the new dialysis program.

Due to the impact of the auditor's report and the legislative hearing, the Ohana was also successful in its second goal of establishing better communication with the administrator and superintendent through monthly community meetings. It set up the first community meeting in January 2004, chaired by Ku'ulei Bell. Subsequent community meetings were organized by the settlement administrator rather than the Ohana. The Ohana is also concerned with a number of other issues, including that of setting up a monument in memory of all the patients brought to Kalaupapa. That issue concerns the NPS, since the monument will affect the historical integrity of Kalaupapa and the NPS would like to have some say about the nature and placement of the monument.

Since 2004, there has been a marked improvement in communication between the patients and the DOH and NPS managers.[illegible] Besides the DOH Administrator who chairs the monthly meetings, his superiors from Honolulu have come to about half the meetings. They present DOH initiatives, listen to patient concerns and monitor the actions of the administrator. Park managers have also attended the meetings, including the superintendent and the chief of cultural resources management. They announce upcoming NPS actions at Kalaupapa and respond to questions. The park managers have also held their own meetings with patients, to consult with them on proposed NPS actions and to talk about the park's volunteer program.

This improvement in patient communication with the authorities at Kalaupapa is especially important at this time when things seem to be changing fast at Kalaupapa. The Congregational minister, who came in 1994, assessed the changes in 2002 this way:

> *There's a lot of transition going on right now, this year, probably more than I've seen in the last year and a half, and probably more than I've seen since we've been here. A lot of changes going on.*
>
> Don Rycraft (3-15-02 Int)

There has been further change since 2002. The park has taken over much of the maintenance from the state and its staff has grown while the state staff has shrunk. At the same time, the number of patients at Kalaupapa has further decreased. Perhaps more significantly, there are few patients left who are active in the community. The patients have a sense of being overwhelmed in numbers by the new NPS workers and volunteers, of being less central to what goes on at Kalaupapa. At the same time they wonder how long the state will continue to support them at Kalaupapa.

The patients could see the influx of new people as a plus. They could welcome visits by children and be happy to have children come into their lives. They could welcome the spouses of workers as people who would contribute to the community which they can no longer easily maintain. A few of them do see things this way, but most do not. As Anwei Law noted long before, the patients often resist change, because they fear it will mean losing their place at Kalaupapa — their importance within the settlement and even their ability to remain there.[91]

CHAPTER 4. KALAUPAPA CULTURE

To some extent every social group, every community develops its own unique subculture — its own set of shared traditions, values and meanings. At Kalaupapa a "patient culture" developed in the nineteenth and twentieth centuries based on the common experience of the patients and on their isolation, and it persists today. The patients are no longer the largest group at Kalaupapa, however, and the question arises as to how far the non-patients who live at Kalaupapa share the same subculture which developed among the patients. To some extent, there is a larger Kalaupapa subculture that is shared by the kokuas as well as the patients.

As indicated earlier, the patients at Kalaupapa have come from a variety of ethnic groups, but Hawaiians have always predominated. There are some characteristics of Kalaupapa culture that seem to derive from Hawaiian culture, and that have been adopted by patients from other ethnic groups as well. Two minor examples are seen in the fact that the Japanese patients at Kalaupapa learned to eat poi as well as rice, and that Japanese patient Paul Harada uses Hawaiian *la'au lapa'au* (medicinal plants).

A number of features of patient culture have been described earlier, the categorization of the people who live at Kalaupapa as either patients or kokuas, the patients' distrust of authority, their sense that only they are entitled to live at Kalaupapa and that they should take priority over the kokuas and their related concern to maintain the rules of the settlement. The focus in this chapter is to describe a further set of themes that we see as important in patient culture. Two of these themes, the importance of helping the community and the recognition of the presence of spirits, seem to derive from Hawaiian culture and from the broader local culture shared by the ethnic groups of Hawai'i.[77] Three other themes seem to derive more directly from the patient experience at Kalaupapa, namely, the importance of pets, the importance of religion, and the perception of Kalaupapa as a refuge. Pets became especially important to patients, perhaps because they were separated from their children. Religion became especially important to them prior to the introduction of the sulphone drugs, because it promised life after death when death seemed imminent. And finally, because of their years of segregation, the outside world came to seem difficult and unfriendly and Kalaupapa came to seem like a refuge from the outside. Chapter 5 following will describe another aspect of patient culture, the inscription of cultural meaning on the landscape of Kalaupapa.

These cultural characteristics are shared to some extent by the kokuas, especially those who grew up in Hawai'i and those who have lived at Kalaupapa for a long time. Kokuas who grew up in Hawai'i bring with them the same attitudes toward spirits and toward helping the community that the patients brought to Kalaupapa. Kokuas who have lived for a long time at Kalaupapa have absorbed many elements of the patient culture. Many kokuas have come to adopt the patients' idea that patients have a privileged place at Kalaupapa. Those who fish use place names for the coast that they have learned from the patients. To some extent they may have adopted patient attitudes toward pets. However, the kokuas, even those who have lived at Kalaupapa for a long time, do not generally seem to share the patient emphasis on religion or the patient attitude toward the outside world.

Helping the Community

An important value within Kalaupapa culture is the importance of helping the community by participating in putting on a community event of some sort. Most of those events are parties of some sort, with food, drink and entertainment. There have also been other kinds of activities in the past—an annual community walk (the Walk-a-Fun), an annual fishing tournament, Christmas caroling and craft competitions—but many of these did not take place in the last couple years because many of the patients have gotten too old to participate.

Figure 10. Christmas Caroling (Patients and Kokuas), 2004

Twenty years ago the patients did most of the work for the community events, and they all pitched in, as described by Edwin Lelepali for putting on the Mother's Day Party (see p. 64).[93] This kind of attitude—that everyone who is a member of the group should help whole-heartedly—comes out of traditional Hawaiian and local culture in general. Today at Kalaupapa there are not enough patients who are still vigorous enough to do the work, such as decorating, catching fish, cooking, and cleaning up after community parties. The community depends on help from the kokuas as well as the few remaining patients who are younger and relatively active. Some of the kokuas are not easily available to help because they do not regularly stay in the settlement outside work hours. Some kokuas who do stay down at Kalaupapa get involved regularly in helping out at community functions, but others do not. In general those who "felt a call" to come to Kalaupapa to serve the patients are more likely to help, but others help because they developed a similar outlook of service after they came.

There are a couple Kalaupapa clubs that put on community events. The Lions Club was formed by male patients in 1948 with the encouragement of the Kalaupapa

Settlement Administrator Lawrence Judd. It puts on its Charter Day in August, and invites the members of Lions Clubs from other islands in Hawai'i. The club also puts on a Christmas party for the Kalaupapa settlement. In 1965 the club built Ocean View Pavilion on the road from the settlement out to the airport, a venue used for Charter Day and for many other Kalaupapa parties. The Kalaupapa Lions Club was once open only to men, but it was opened to women in 1990.[94] Its active members today include about equal numbers of patients and kokuas. The Activities Club was formed by a group of recently arrived kokuas and some younger patients about 1991 in order to get additional activities going, like the Walk-a-Fun.[95]

Figure 11. New Year's Party at McVeigh Hall, 2006

Although it is not organized as a club, the craft shop has long been a center for art and craft activities at Kalaupapa. Many patients and kokuas have gotten involved in painting, weaving, lei-making and other crafts over the years, beginning in the 1940s when an occupational therapist was brought in to start a craft program.[96] The craft program was once centered at the old hospital and then moved to the present craft shop after the hospital burned down. Before 2005, items created by patients and kokuas were sold in the craft shop. In connection with the shop, there have been lei day contests on May 1 and Christmas craft fairs, both providing an impetus for people to be creative, especially by using materials that can be found locally. Ellen Storm, wife of the Congregational minister, took the main responsibility for managing the craft shop and organizing the competitions in recent years until her departure. The primary function of the craft shop might be seen as encouragement of individual creativity, but the contests are important community events. People participate in a competitive spirit, and also to make something exciting happen at Kalaupapa. In 2005 Ellen left Kalaupapa and the craft shop was closed as a venue for the sale of Kalaupapa craft products. However, the Christmas craft competition, called the Festival of Trees, has been continued, due to the leadership of patient Cathrine Puahala and the participation of several kokuas. At Christmastime too, a lavish seasonal display is still created to decorate the craft shop window.

Figure 12. Entries for the Festival of Trees, McVeigh Hall, 2005

Besides the club and craft shop activities, there are other manifestations of the desire to help the community, and provide a range of activities for those who live there, especially the patients. Patient Edwin Lelepali has for years taken the initiative to sponsor community parties, including the Bingo Nights, an annual Superbowl Party, and an annual Mother's Day to honor the mothers of Kalaupapa. He contributes much of the food and does much of the cooking, helped out by others. Similarly, Shannon Crivello, one of the cooks, put on a luau during several years prior to our research project. The whole community was invited but he says he did it for the patients.[97] Shannon comes from Topside and used his connections there to bring Hawaiian cultural groups into Kalaupapa. One year he arranged for the Hawaiian voyaging canoe Hōkūle'a to sail in to Kalaupapa. Nurse Julie Sigler leads a group around the settlement caroling every Christmas. Another nurse formed a hula *hālau* (school) to teach patients and kokuas and the group has performed at several community events.

The help that the two NPS workers Lucy and Albert gave patient Elaine Remigio in running her bar (called Elaine's Place) in 2001-2003 was also a community service. Lucy began helping the previous owner of the bar years ago and her role became more important after Elaine became the owner and particularly after Elaine's health began to fail. She viewed her work at the bar as important to the community.

> *I think Elaine's Place is a very important place in the community because it's not only a place where you can go and get alcohol beverages, that's not the main point. I have always seen it as a place for the community to gather. You don't need to get into alcohol, you may go there to get ice*

> *cream, or soda pop, or what have you, whenever you feel like having, but it's the spirit of coming together and to sit and talk among yourselves, again to discuss who came and went from the airport or as people are coming in for the weekend or for a length of stay. I think that's an important place because this is where you get a lot of that information. I have always felt that it is a very important place in the community to have because without it, you would not have a place for people to gather, because people still do gather there.*
>
> *I open for her, more to help. Actually, I've come to realize I don't do it just for Elaine; I do it for the community. Because if we didn't open it—and that has happened on a few occasions, it had to be closed down for a few days because we had conflicting schedules. And I have found that, my goodness, it's like the end of the world. And so, by keeping the bar open, people still come; there's a place for them to come and sit and talk. And I sometimes think, if we didn't open it, they'd have nowhere to go.* Lucy Whiting (3/24/02 Int)

Customs regarding distribution of fish could be looked at in the same way, as designed to help the community, particularly the patients. When a school of akule appears at Kalaupapa in the summer and the workers go out to catch it with a lay-net, the catch is supposed to be distributed around the settlement. Most of the workers are Topside Hawaiians and the custom, according to an elder Topside Hawaiian worker, is "Hawaiian style, okay let's all get out there. Let's go out and catch this fish because we want to share with everybody, especially the patients." It doesn't always work out that way. Often the state workers go separately from the NPS workers, and sometimes they don't share with all the patients. But often enough, the fish does get distributed out to the patients. An older kokua explained that to her and her husband the patients should have priority.

> *Like when my husband was living. If they [patients] 'ono for fish or opihi he used to go pick up for them and we always share. Like when he used to own a boat and he go out and pick up Kona crab. Everybody, his first catch is for the whole settlement. He was always like that. The patients were always first in his eyes. The kokuas, which is us, are last. Which is the way I look at it too, because this is their place, you know. He catching fish for all of us—the kokuas and the patients—but his number one in his eyes is the patients first. Yeah.*
>
> DOH worker 18 (2/16/02 Int)

People say it is inappropriate to sell fish at Kalaupapa. One of the long-term local kokuas explained this to me, as follows:

> *One guy, when I first got the boat, this commercial fisherman up in Molokai asked me, "Hoh, you're in the perfect place 'cause there's a lotta fish in that area, outside around Kalaupapa." And I go yeah, so he says, "But how you gonna get rid of it all?" 'Cause he thought I was gonna try*

> *and make some money. And I says, "I'll give it away." Which is what I do with all my fish, well the ones that I don't keep for myself. That's how it is over here. You cannot sell fish in Kalaupapa. You know, you'd be banned.*
>
> Randall Watanuki (8/11/03 Int)

The idea that you shouldn't sell within the community is common to small Hawaiian communities.[16] Undoubtedly the Hawaiian patients who came to Kalaupapa brought that idea with them. A couple of the Hawaiian patients mentioned to me the related Hawaiian concept that when you share your catch, you get more fish the next time.[17] Cathrine Puahala said that her Hawaiian husband never sold the fish he caught in the 1960s.

> *We were against that. My husband was with the Hawaiian boys and he never sold fish. He told me that people came and asked to buy fish. It made him feel funny kind. He just say, "Take what you need." He always gave his fish away; he never sold. Everybody got his share.*
> *There was a lot of fish here—but only as long as you don't sell. If you sell it, then you'll lose the gift of the fish coming back.*
>
> Cathrine Puahala (Langlas fieldnotes, 6/03)

Both ideas about distribution of fish—that it should be shared out to the community and that it is wrong to sell fish within the community—obviously are tied to the maintenance of equality by sharing the wealth. Maintaining equality by avoidance of disparity is another social trait common to Hawaiian and local communities.[18] Sharing the wealth is a concept also seen in the generosity of the patient entrepreneur Richard Marks who runs Damien Tours. Richard said that his business has only really become profitable in the last couple years. In consequence, Richard has begun giving an annual $100 Christmas gift to each patient in the settlement.

Back in the 1950s-1960s some people did sell fish at Kalaupapa. Paul Harada, for one, said that he caught fish and sold them to other patients to make enough money to pay into the social security system.[19] He said that some of the patients got mad at him for selling fish instead of giving it away (though not the ones who bought from him). This seems to represent a difference between the cultural ideology of Hawaiians and that of other ethnic groups, who would feel it alright to sell fish within the community. Paul was not the only patient who sold fish, although no one else did it regularly, according to those we talked with. A Japanese patient crew who used to catch akule in the 1960s sometimes sold their fish too, although they usually gave it away.[20]

It is also the case that it is inappropriate to sell fish caught at Kalaupapa outside the settlement. This too is related to concern for the community, because people see that at Kalaupapa, as elsewhere in Hawai'i, there is less fish than before. Commercial fishing is seen as a major cause of that reduction in fish stocks, particularly in the case of opihi, the greatly desired and widely-sold Hawaiian limpet. Over the years, the patient council has pushed the settlement administrator to establish rules which prohibit kokuas from selling fish commercially outside the settlement and which radically limit the fishing privileges of those who come to visit patients or kokuas. Visitors can fish with a pole, but not with a throw-net. They are not allowed to collect opihi. These rules were put in place after it was discovered that visitors were taking out coolers filled with fish and opihi, and after the Honolulu markets verified that they were selling opihi from Kalaupapa.

Spirits of the Dead

Anyone who moves to Kalaupapa soon becomes aware of the large number of graves there of patients who have died. Kalaupapa people, both patients and kokuas, are pretty matter of fact about the presence of the spirits of patients that have passed on. For example, when we first moved into the house provided by the NPS for us to stay at Kalaupapa there was a hospital bed in the front room. Some months later when we returned for another visit the bed was gone. When we asked the NPS administrative assistant about the missing bed, she said casually that they'd had to take the bed out because people were seeing spirits in that corner of the room. Another kokua, Harry Arce, told us stories about people who saw spirits when they stayed at the Visitor's Quarters.

> *Harry: They get scared. Just like everybody else man. Gotta take their lumps. Because some people they not right for this place, eh? so, you not right then 'll let you know you not right.*
> *Langlas: Oh yeah? Because some people say, "Oh, I never saw anything."*
> *Harry: Well, some people are ignorant, that's why. Because they saw something, but they just kind of dismissed it, uh?*
> Harry Arce (2/05/02 Int)

His attitude is, we think, typical of modern Hawaiians. But not only the Hawaiians at Kalaupapa have experience with spirits, so too do workers who come from the mainland.

The kind of experience people have with spirits varies. Sometimes people have a bad experience with an unknown spirit and get scared. For example, a part-Hawaiian kokua kept seeing spirits in his house. Eventually he went to the Congregational minister for help in getting them to leave him alone. In another case some years back, a patient moved out of her house for a few weeks after she saw the lady who used to live in her house and got frightened. Other times people see or feel the spirit of a loved one and welcome the contact. A patient whose husband has been dead for several years says that he still comes back to visit her. She is nearly blind, but she hears her wind-chimes sound or hears his slippers in the other room and she knows he's there. A particularly beloved nun who worked for years at the Kalaupapa care home died recently. Shortly after her death, two patients saw her spirit. Patient "Randolph" reported that he saw her come to his door. He invited her in, but then she disappeared.

Some patients expect that their spirit will stay at Kalaupapa after they are buried at Papaloa graveyard. Thus, a Hawaiian patient, in the course of recounting her argument with the temporary park superintendent during 2001 over whether the park would allow its workers to bring their spouses with them, told us she had given him a warning. She told him, "As long as I'm here I'm going to be watching out and looking out for our rights. Even after I die and I'm in Papaloa [graveyard] I'm gonna be watching you."

Love for Pets and Wild Animals

Early in our fieldwork several people told us that the patients are especially devoted to their pets. Nurse Julie Sigler explained their attitude.

> *There's one [grave] where there is the husband and wife and dog that's buried at the spot, because their dogs were their children. Their animals were their children.*
>
> *I know that there are several patients who, they've told me that the children don't want to have anything to do with them, or are very angry at them, because they weren't raised by them. And of course that was beyond their [the patients'] control. Some of them are close with their children. [But] I see more of an estrangement.*
>
> Julie Sigler 12-4-02 Int

Of course, pets could never truly replace the children who were taken away from the patients at birth, but there seems little question that this argument is true in broad outline — that patients have lavished love and given attention to their pets because they were unable to give it to their children. One patient is known for writing the song "Baby Pakalana," which is just like many songs written by Hawaiians to express their love for a child. Outsiders think the song was written for her daughter, but actually it was written for her cat. This patient attitude toward pets goes back at least to the 1940s. A patient who came in 1940 told me that the "old folks" had pets when he came, "because no children, that's why." Since segregation was ended in the 1960s, some of the patients have been able to create a relationship with their grown children, but almost all of them missed out on raising those children. For those patients who remained childless as well, pets fill a gap. This is particularly the case for men, because there were always more men than women at Kalaupapa and many men were unable to marry.

The patients' special attitude toward pets is most noticeable when it comes to their dogs. As one patient said about the dogs at Kalaupapa,

> *Hard to find dogs like that [past] any place. People come from any other island they surprised the way dogs live here. Almost like human being.*
>
> Henry Nalaielua 2-18-02 Int

Many patients cook special food for their dogs, take them riding every day and bury them in their yards when they die or in the graveyard next to where they expect to be buried themselves.[10] We asked a patient who has had many dogs how a dog should be treated, and she said they should be "treated nice, like a human being." She said also that she believes that dog spirits go to a dog heaven. Of course there is some variation in how solicitous patients are of their dogs. One deceased patient is said to have given his dog a special bedroom and bed in the house, while another wouldn't even let the dog in the house. Several times patients complained about how a person was treating his dog, leaving the dog tied up all the time and never paying it any attention.

Given patients' love for dogs, it seems paradoxical that so few have a dog today. Of twenty-nine patients who could conceivably have a pet dog at Kalaupapa, only eight of them do (and two of these are a married couple). The explanation for this is that most patients don't feel able to give a dog the care they think it deserves. Several told us they aren't able to take proper care anymore because they need to go out to Honolulu periodically for extended medical treatment, and it's hard to find anyone to take over while they are out.

Figure 13 a & b. Left, Patient Boogie Kahilihiwa with dog. Right, Grave of Naia's dog Zorro

Many patients have cats as pets in addition to dogs. One patient now has thirty cats. After she had a slight stroke, she refused to go out for medical treatment because she was so concerned her cats would not be taken care of, until a kokua assured her she would come every day to feed them.[104] Another patient told me that she and her neighbor used to have fifty cats each. Patients are exceptionally soft-hearted toward animals in general. Many patients feed half-wild cats outside their house, or at a certain location out in the settlement. One who feeds cats described her daily routine as follows.

> *I feed the mongoose when I feed my cats, so that they don't bite the cat's tail or bite the eye so they get blind. I take all this dried foods. So I gotta make extra food-plate for the mongoose to come.*
>
> *The mongoose respect the cats when they come and eat. Before that, they were wild, and the cats chase them all the time. They all chase, but the mongoose learns how to come in, how to take, and how to eat. But they learn, and when's there's enough food there, they all go. Then I bring my dog in to finish up. She's the cleaner--the vacuum cleaner. She cleans all—she eats, see—and that's enough for her. And that's part of my life. And when I see them, it gives me joy and I feel that life is wonderful—if you know how to live that kind of life. It brings joy to me,*

> *and I go inside and sit on my chair and think. I'm thanking God that all my animals are all being fed. From the hospital, go all the way up—I make my rounds until I get home. And if I don't do it, I feel something is wrong.*
> Katherine Costales (8/20/04 Int)

Figure 14. Katherine Costales Feeding Feral Cats

Figure 15. Feral Pigs at the Dump

The patients' soft-hearted attitude is extended even to animals that most outsiders would consider to be pests. Many patients feed the feral pigs at the dump. At one time the settlement was overrun by deer, to the point that the deer ate up the decorative plants and fruit trees. When the NPS staff carried out a deer eradication program, many patients felt bad about it. Some even said they would rather have let the deer eat their plants than have them killed.[105] The mongoose are a problem in the settlement too, but nobody wants to kill them.[106]

Such soft-heartedness toward animals is not unknown outside Kalaupapa. Among much of the population of mainland America, attitudes toward pets are not dissimilar to those of the Kalaupapa patients. However, our impression is that rural, local people in Hawai'i are usually not as caring of animals as the patients. The broader local culture of Hawai'i that the patients came out of is one where many people hunt wild pigs and goats for food and often do not treat their pets particularly well. For example, many local men on the Big Island keep dogs for hunting chained in their yards. We cannot say so much about kokua attitudes to pets, how far they have generally adopted the exceptionally caring attitude of the patients. We did not survey the kokuas on this topic and can only speak from our observations. Several long-term kokuas have attitudes that seem to parallel those of the patients. One local worker has several cats of her own that she takes elaborate care of and she also feeds wild cats. Another local worker (married to a patient) has four dogs that he takes out riding every day. A retired local worker volunteer has a dog that he takes out riding twice every day. A haole couple originally from the mainland has four dogs that stay inside the house and that they take out riding regularly. But these kokuas probably represent the caring extreme. Two other local kokuas who have dogs leave them tied up outside the front door, generally 24 hours a day. They are an object of criticism by the patients, who wonder why they have a dog if they're going to treat it like that.

Parents Without Children

As argued earlier, the development of patient love for animals as a cultural trait can be related to the devastation that patients felt because their children were taken from them. One patient described her feelings of loss when her daughter was taken from her as soon as she was born.

> *They brought her to me. They said, "Don't kiss her." I cried, you know. I wanted to hold her. They said "No, you don't touch her." I couldn't touch her, so I was just crying.*
>
> *First [visit], [when my daughter was] growing up, that was 1949. I saw her when she was a little baby. My husband and I went to Maui. His father and mother were there cause they took care of her. Then my in-laws gave me pictures of her—my baby, our baby. And when we got on the plane, ready to fly, then I start crying then, after looking at her picture. Oh, I just cried all the way to Kalaupapa. Cause I felt so bad, have to leave my baby back. It's sad. People don't know what we go through being separated from our children, our babies.*
>
> Catherine Puahala (2-5-06 Int)

In the past, some patients completely lost touch with their children. The children might have been taken to raise by a grandparent, uncle, or aunt and then never told who their mother was or that she was at Kalaupapa, because they considered it shameful to have a family member with Hansen's disease. However, it would be an exaggeration to say that most of the patients alive today are estranged from their children. Many of them were able to establish relations with their children in the 1950s and 60s, especially after their Hansen's disease became inactive and they were allowed to go out on "temporary release." The data we have indicates that of 18 patients who now have children alive, most of them have a relatively close relationship with at least one child. Still, it needs to be remembered that only two of these 18 patients had an opportunity to spend much time with any of their children when the children were young. One patient brought her children in the 1960s to live at the lighthouse, which is physically part of Kalaupapa Peninsula but, was said not to have been under the control of the DOH and the Kalaupapa Settlement rules.[17] Another patient left the settlement about 1970 to raise her foster-daughter outside and then returned to the settlement later.

Other patients who have children may have created a relatively close relationship with their child through occasional visits, but it is not the same as the bond created when a parent raises a child. This is clearly expressed by the patient who raised her foster-daughter outside during the 1970s, and who also had two older children that she couldn't raise because she was at Kalaupapa during the segregation days.

> *After when I came here, I would see them [my first two children] only on the times when I had to go doctor in Honolulu to Hale Mohalu, and that was about, oh, sometimes about three to four times a year. And, you know, by seeing them and then hearing them say, "We love you." Today I find out its not so. Because the child, when its eyes open, the first face it sees is its mother. And then I used to say, "Oh, my son loves me." But it's not so. They have a love, but it's a different type of a love, not as a mother and a child. Because, like when I took K—, you know, and I have her from just two days old, she sleep with me until she was 11 years old. And I know now for myself because a child would love the face it sees in the morning. And when they are sick, that's the face that will always be there for them. So I didn't have the chance to raise my son.*
>
> Katherine Costales (in ASL 1984-85, 18A: 7-8)

One elderly patient has only recently met her two middle-aged daughters. They were *hānai* (adopted Hawaiian style) by different sets of foster-parents and she had lost track of both of them. She discovered the whereabouts of first one and then the other and invited them to Kalaupapa to visit. In a way it is a success story, but a bond created so late in life is unlikely to be that close. Seven patients are estranged from one or more of their children. Five women have talked about that estrangement. Usually what they said shows that they don't feel the child loves them, and perhaps that the child is mostly interested in getting something out of them. One patient refuses to see either of her two children, although they have made requests to visit her. A second says she has disowned all but one of her four daughters, because when they call, "All they want is money." She said that she didn't actually want to have all those children:

> *After I had my first baby, they took em away on the plane after a few hours. After that, I never wanted more babies. For what? I felt I was going through all that just for nothing. But the church says cannot be sterilized.*
>
> Gertrude Kaauwai (Langlas fieldnotes 8/04)

The background to her statement is that during this woman's child-bearing years, the Territorial Board of Health, which was in charge of Kalaupapa Settlement, pushed women patients to agree to be sterilized so as not to have more children. Many of the patients agreed to the procedure.[10] A third patient keeps all three of her children at a distance. In talking about them, she does not clearly explain why, but a feeling of hurt is implied. Particularly in speaking of her third child, she says that the daughter only cares for the *hānai* mother, not for her. A fourth patient located her adult son in the Philippines where the father had taken him. She paid his way to Hawai'i, but when she found that he didn't want to get a job here to support himself, she cut him off. A fifth says that she is not very close to her son, who was raised by her mother. The patient said that when her son had children she was kept away by the son's wife, who seemed afraid to let her have contact with the children for fear of Hansen's disease.

A number of patients without children, and even some of those who have their own children, have established relationships with a favorite niece or nephew. Those relationships seem to be just as close as the relationships patients have established with their own children later in life when those children were already adolescents. Such relationships may even be easier because the expectations are less on both sides than the expectations are likely to be between parents and their own children.

Mother's Day at Kalaupapa

The second Sunday in May is celebrated across America in honor of mothers. But at Kalaupapa the celebration is a bittersweet reminder for those mothers who were forced to give up their children at birth because of segregation and Hansen's disease. At Kalaupapa there are no children to honor their mothers and their absence is notable.

In the 1940s, then Settlement Administrator Lawrence Judd honored all the Kalaupapa mothers by giving them carnation lei at a party held for them, with entertainment flown in for the special occasion. After Judd left, the tradition was carried on for years by the Kalaupapa Lions Club. On Mother's Day they would deliver flowers and candy to each woman's home, this time including all the women, whether they had children or not, even the nuns in Bishop Home. With a smile on her face, Gloria Marks wistfully remembered receiving a long stem single red or white carnation along with a box of chocolates. But eventually the tradition lapsed.

Sometime in the early 1980s, Edwin Lelepali decided to revive the Mother's Day party celebrations at Kalaupapa to honor all the mothers. His inspiration came from old timer, Alice Kamaka, who was then living in the Kalaupapa Hospital. One day Edwin overheard her say, "You know, nobody thinks about Mother's Day. What about all the mothers? Nobody remembers us." Her remark stuck in his head. Just before Mother's Day a year later, he thought about what Alice had said. So he "hustled up the boys" and held a meeting to ask what could be done. "How will we pay for it?" they asked. Edwin suggested they go house to house and ask the men to donate money for the party. No one else wanted to ask for money, so it was Edwin who went door to door and asked the man of each house to make a donation. Everyone gave and there was enough money for the party. Edwin planned the menu and enlisted the help of all the men in the community to prepare the food, to decorate and set up the hall, and play music. The whole community was invited. It was a time for everyone to get together and enjoy each others company. After the meal, there was usually entertainment, bingo or some kind of give-away with prizes. The main idea was that "everyone, especially the mothers, enjoyed themselves."

In the beginning there was lots of help. But Edwin admits that it gets more difficult as each year passes. Many of the old-timers are gone now and many of the kokuas go out on weekends and are not around to help. Edwin has been sponsoring the Mother's Day celebrations for some years now and he plans to continue as long as he is able. He no longer goes house to house to ask for donations. He will be eighty years old this year and wonders how much longer he will be able to continue the tradition. For Edwin, Mother's Day celebrates the memory of two special mothers: his beloved wife, Rose, who died in 1986 and his own mother who died at childbirth – the mother he never met, the mother who sacrificed her life to give birth to her newborn son.

Hansen's Disease, Death, and Relationship to God

Patient Richard Marks, 1985 (in ASL 1985-87, 2:8):
These people only had two things – their religion and their music, nothing else.[10]

Mormon Patient Ka'alei Bell, 8/11/02 Int.:
All the patients here, the religion is the most important part of their life. If you think about it, the Protestant church members [the thing they had] to survive was their religion. They turn to God. Us, we turn to our religion, the Mormon. We believe that we can get better. And the Catholic church believe that same thing. So the main thing in all of our life here is the church.

Catholic Patient Paul Harada, 12/01 and 7/10/04 Ints.:
We were in Kalihi, and we wanted to get well, and there was absolutely no cure for leprosy. Oh, we read passages in the Bible. And then we come to the part where Jesus cured the ten lepers and all that. So we figured that – well, maybe the whole idea was I tried to be cured spiritually.

I think the backbone of all the different entities [at Kalaupapa], that is the church, because it's always there for you, yeah? To me, that's life for me.

[What is really important] in this settlement, I guess religion already, because we're down to the last end already. I don't know, maybe getting ready for the next world I guess.

It is easy to see that religion plays a big part in the lives of most of the patients today, and that is probably true for patients at Kalaupapa back as far as the nineteenth century. Apparently many patients turned to religion for comfort in the days when there was no cure for Hansen's disease, when they saw so many other patients dying and felt their own death was imminent. Indeed, some of them even hoped to be cured through prayer, as Jesus cured the sick in the Bible. Today, they still turn to the church for comfort in the face of death. Their Hansen's disease may be in check, but they are all nearing the end of their lives.

The majority of the patients attend church regularly on Sundays. Of the thirty-five patients usually at Kalaupapa as of 2002, twenty-three regularly went to Catholic mass on Sunday, five regularly went to the Congregational church on Sunday, and three to the Mormon Church. Only four patients did not attend Sunday services on a regular basis. That means nearly 90% of the patients attend church regularly, compared to 40% of the general U.S. population aged 65 and older.[11] Two of those who didn't attend services regularly are nevertheless members of one of the churches. We were told that one is a member of the church just so that she will have a place for her funeral service to be held.

Figure 16. Part of the Roman Catholic Congregation in the church yard (with Researcher Charles Langlas in the back row)

Generally the patients are old-style Christians, who by and large keep their faith to themselves. They welcome you to church services, but they don't pressure you to convert, nor do they pepper their conversation with talk about God. One of the Mormon patients makes the importance of her faith clear, because she often mentions praying before making a big decision in her life. One of the Congregational patients told us of her turn to God in the last few years and how it has altered her life for the better. Of the Catholic patients, there was in 2002 a core group of eight[111] who attended mass at St. Francis every morning. Many of them even came before mass began to meditate for a half-hour or so. There was another group of five Catholic patients who were confined to the hospital and went to a Sunday mass there. They were not be able to attend the daily morning masses through the week The Catholic patients have also developed a surprising participation in charismatic services. Once a year, a group visits Kalaupapa from St. Anthony's Catholic Church in Kailua, O'ahu and holds a service in which a priest lays hands on individuals, so that they receive the spirit of God. Nearly all the Catholic patients go up to the front of the church to receive the spirit, at which they fall back, assisted by two "catchers," who let them down to the floor.

All the churches provide a connection between the patients and religious folk from outside Kalaupapa. Both the St. Anthony's group and the St. Vianney's choir mentioned previously visit the Catholic congregation every year. On average, four service groups are hosted every year by the Congregational church. Every few months a group of Mormons come down from Topside to maintain the Mormon Church and grounds. Many of the church-going people who come have long-standing friendships with the patients and their visits are enjoyed. Other religious folk occasionally arrange to visit through the Congregational minister or the Catholic priest in order to attend services at Kalaupapa. These visitors often seem to regard their visit as a pilgrimage, and speak of what a privilege it is to worship with the patients. The patient perspective on this is somewhat different. Patient Paul Harada, for example, said that he didn't really understand what such people are thinking when they say such things. The visitors see the patients as being akin to saints and he does not share that view.

Figure 17. Edwin Lelepali, Katherine Costales, and Barney Kaauwai, Singing at Kana'ana Hou Congregational Church.

Clearly the patients have seen a lot of deaths in their time at Kalaupapa. Many of them never expected to live this long and perhaps they accept their impending death more easily than most Americans do. Most of what we initially heard about patient attitudes to death came from those who assist them during their passing—the nurses and the Congregational minister—rather than from the patients themselves. The minister came down to Kalaupapa after working with the dying in the Hilo hospice.[112] He thought that he would be able to use his former experience of helping the dying elsewhere when he came to Kalaupapa, that he would help patients to overcome their denial of impending death and their anger at what was happening to them. But he found that the patients have different feelings about death than those he was used to helping outside. In his words,

> *These people have dealt with a lot of death and they have sort of, [what would be] for other people a macabre or cynical look on it that other people don't know how to deal with.* (Lori Rycraft, 3 15 02 Int)

Because the patients have watched so many friends die at Kalaupapa, they take those deaths as a matter of course. Many of them came to Kalaupapa during the years before the sulfone treatment and they expected to die within a few years, so their gratitude for their long life outweighs their concern for their death.

Some patients have seemed even to welcome death as a release from their life of suffering from Hansen's disease. The then nursing supervisor told us a story of how her own attitude to death at Kalaupapa has been altered by talking to a dying patient.

> *I kept saying, I said gee L. I'm really going to miss you. She said, "Oh don't. Don't worry about us." So I was crying when I was giving her a bath. And she said, "Don't cry," she said, "because now I'll be beautiful again." And she smiled and "Don't worry," she said, "Don't cry." So then I said, "Okay, can you tell everybody?" So I named all the [deceased] patients that I knew, and I said, "Can you tell them that we miss them? I said they can come and visit us." She said okay, then she smiled, you know. It makes, it makes it more easier that way to say goodbye. And then she smiled. She said, "Oh yeah, I'm going to tell them that, to say hello." I have done so many death in my career but they're different. They're just so special, you know. And maybe it's because of their lifetime here in Kalaupapa that makes it very special.*
>
> Fe Austria-Schwind (2 5 02 Int)

The same nursing supervisor said that at Kalaupapa funerals it is the workers who cry, not the patients. She said that the patients see it as a relief, because now the patient is free of pain. Another nurse observed that the patients generally don't go through a long grieving process.

Although most of the nurses interviewed spoke of the patients dying peacefully, accepting their death, that view was not universal. Another nurse gave a more nuanced view, saying that some of the patients are ready to die and some fight death, that it is an individual thing.[31] Her own feeling was not that the patients accept death as a release from suffering, but rather that they are emotionally numbed by the number of deaths they have witnessed at Kalaupapa. She concluded this from her own reaction during a year when six patients died and she became emotionally numb. After we had been working at Kalaupapa for two years, we realized that this whole question of how patients feel about the approaching end of their lives was one that we needed to explore more fully with the patients themselves, that we were holding back from asking them about death as well as about their belief in God. That was primarily because of our own reluctance to bring up those topics. Like most Americans outside Kalaupapa, we find it awkward to talk with a person about his impending death.

Among the patients we subsequently interviewed, Paul Harada was perhaps the most clear about his acceptance of impending death and the importance of religion to him.

Paul Harada, at age 78, came to Kalaupapa in 1945
In 45 when I came over here, by that time I was covered with sores. I was beginning to become an advanced patient. I couldn't breathe through my nose, and I had ulcers on my face, my hands, my feet. So in 45 I figured, if the disease continued the way how it had continued from 41, in 1950—give or take one or two years—I'd be dead. I mean, everybody else was that way, yeah? (12/01 Int)

They take me to McVeigh Home. I kinda remember that in the first week, oh, every day I could hear the bell toll. So, every day somebody was dying. And that's only the Catholic Church, because the Protestant Church and the Mormon Church, I think the bell wasn't loud enough to be heard at McVeigh. But already I had figured, I knew more or less that I was gonna die anyway. I kinda accepted the fact that this is my life, and sooner or later I would be joining those people. I accepted that. I didn't fight that, because that's the reality of life in Kalaupapa.

The fact that I became a convert to Catholicism, I figure that's the most important thing that ever happened to me. Because prior to that I was just a pagan, yeah? I didn't believe in Buddhism, I didn't believe in God. Really. I [only] heard about all these things. So if I was living, if I didn't have the disease, I got married, got my family, I would just be a father if I had children. But no religion, no nothing.

So that, to me, was the most important thing in my life. So I've never been that bitter about being afflicted with the disease. You know, it's good to have money, good to have health, good to have everything, but without religion... I figure religion has been the best of all the good things. (7/10/04 Int)

In the quotation from Paul that begins this section, he speaks of how the patients are getting to the end of their lives and are getting ready for the next world. Several times Paul made remarks that showed he was thinking about the end of his life and ready for it to end (Langlas fieldnotes, various dates). Once he said he wanted to try all the different kinds of fishing for the last time, another time that he only wants to live two or three more years. After a recent heart operation he said, "I'm ready to go. The quality of life is not there any more, my legs going."

We asked six other patients if they were thinking about their death and how they felt about it. Their answers have been given below in full, because they seem so significant. They are arranged in order of their arrival at Kalaupapa.

"George," at age 79, came to Kalaupapa in 1940
Langlas: "George," are you ready for your death?
G: Yeah, Chuckie, I'm ready. I'm ready to meet the man upstairs. (6/22/03 Int)

Henry Nalaielua, at age 77, came to Kalaupapa in 1940

Kind of hard when you know somebody and you see them die. Sometimes. It's not easy to see a friend die, eh? Ah, but this is one of those things and one of the places where those things going happen, so you got to accept, and not always easy to accept death. But you know already from what you see, it's going to come, so. All the old timers here they all have the same. They look at me. Clean. No more sores. No more nothing. I get two good feet, two good hands. They look at you, they tell you straight in your face. "You know boy, you take care of yourself, maybe you can live seven years, maybe eight years." Sometimes we get cocky, we tell them we going live more than that. "Oh, yeah? No act sassy. No act sassy. You don't know boy. You don't know this place."

McGuire: Are there things that people do to prepare for dying? You know for old age and dying like.
HN: Most people I don't think. I really don't know the answer to that, but I don't think they prepare themselves for death. I don't think anybody here does. Very few people, if any, ever prepare their life, you know, and are ready to face death if it should come. But most people here, even though they look [at] grave, most people are afraid of dying. You know. I have no idea, but that's the impression I get. (8/6/02 Int)

Edwin Lelepali, at age 74, came to Kalaupapa in 1942
I know get few more years to live, you know. So, eh! What the heck, man. I take em as how I feel. I no want live like, you know. I no like live that kind life this guys live on the [wheel] chair. As not for me. You know, I believe that there are people out that's kind of proud, you know. And I think I'm one of them, you know. I don't want to end up like that. I want to go. They tell me go, I go. I cannot see people clean me. Oh! I hate that. (9/26/01 Int)

Katherine Costales, at age 74, came to Kalaupapa in 1948
I want my future, you know, like being in Kalaupapa, yeah? For me there's so much meaning here. When I was outside for 18 years, you never see what you're supposed to see because you get wrapped up in a whole lot of things. And yet nothing makes sense--for me, nothing makes sense. But when I came back here, yeah, life for me made sense. Why I'm living it, yeah? And when I think of dying at one time or another, it was horrible. It was not supposed to be said, but then when you serve the Lord, it is just another step to going home. But I know that when I came here it was for a reason and if I had done something that was right in the sight of God, then I know that when I go home I feel alright and I know I'm not afraid of death anymore like I was afraid before.

The fear gone away only about five years ago, because then I talked to my daughter and she said, "Oh mommy, mommy! Not now. Not now." Because she said, "Let me die before you." And I say, "No. No, you have children, yeah, and if you died before me, I cannot go. I could not go take care of your kids. I'd be too old." And I say, "If I die, you let me die." Because they scared of death--she scared. So I say, "When I die, all I ask is that you there with me. You see me and give me the blessing." And I say, "No go down in the graveyard and go talk story. I not going get up and talk story with you. Talk now with me--tell me now. (8/20/04 Int)

Clarence Naia, at age 77, came to Kalaupapa in 1954
Langlas: Do you think about your own death?
CN: No, I not thinking about my own death. I only think about my knee and my back. I not that sick yet. God takes you when he's ready, that's all I can say. If you live to one hundred, that's God's love. Even if you live to ninety. (6/20/03 Int)

Ivy Kahilihiwa, at age 68, came to Kalaupapa in 1956
Langlas: Ivy, I know you're young yet, but have you thought about your own death?
IK: No, I'm an old woman. I'm 68.
Langlas: Are you ready for death?
IK: Yes. God's gonna tell there's a place for you, plenty of room. Well, it's his decision if you go to heaven or whatever. We already prepared. But, you cannot think about it all the time. I still enjoy life, but I'm getting on. (7/8/04 Int)

Obviously, there is variation among the patients. Some of them are much readier for their own death than others. Those like Paul Harada, who came before 1946, would have seen Kalaupapa at a more hopeless time, when many were dying and there was no cure for the disease. On the whole they seem readier for death than some of those who came later, but that does not account for all the variation.

The Kalaupapa way of death is different in several ways from the traditional American way, where even medical personnel have difficulty talking honestly with the dying about what it happening to them and where the dead are taken to funeral homes to be embalmed by specialist morticians. Former nurse's aide Frances Padeken told us that the nurses make a "make bag" (death bag) for the patients who are in the hospital, which has the clothes and personal items they want to be buried in. Clearly the implication is that nurses and patient have talked together about the impending death and at least to that extent have accepted it. The patients we asked did not all recognize the term "make bag," but did recognize the custom. For example, Katherine Costales said she had worked before at the Kalaupapa care home laying out the dead, and that when a patient was near death they would ask them what they wanted to be buried in and hang it up in the room.[114]

When a patient dies, the funeral must be carried out fast, because there is no way to embalm or otherwise preserve the body at Kalaupapa. Often a patient who dies in the morning is buried that afternoon. The nurses prepare the body for burial. They dress the body in the clothes that have been agreed upon earlier, and in the case of a woman, apply make-up. They put salt in the body orifices in place of embalming. If the patient is Hawaiian, they make sure to make a *lei* for the patient to wear when buried.[115] Today, most of the community, both patients and kokuas, turns out for the wake and funeral service. As part of the service, those who are there share their memories of the dead person, saying whatever they like.[116] In this way, everyone has a chance to say goodbye. Those who don't want to speak in front of the group may just talk to the people who sit beside them. Older patients give a different picture about funerals in the days when there were more patients and many were dying. They say that they seldom attended funerals then, only if it were someone they were especially close to.[117]

Langlas attended the funeral of a patient who had been at the hospital for some years. It was obvious on that occasion that the nurses were the most affected of the kokuas. Some were crying and several of them stood to say something about the deceased. A group of maintenance workers (both state and NPS) stood at the back of the church or out on the portico, taking a very peripheral position. Many of them probably had never known the deceased, since he had lived for years in the care home hospital, and had only come out of respect, an act which is now customary at Kalaupapa. After the service, most of the patients and workers usually go on to the grave for interment and sing a favorite song of the deceased, as they did that day. Usually there is a gathering after the interment, where food is served (just as at most funerals in the islands). At this particular funeral gathering, the mood was fairly upbeat and Hawaiian music was being played on a CD player.

In the past, some patients wanted to be buried outside Kalaupapa, because they knew their family feared the stigma of having a relative buried at Kalaupapa.[118] But that sentiment seems to be disappearing and most of the patients now want to be buried at Kalaupapa. If they are at Hale Mohalu in Honolulu and feel they have come to their terminal illness they usually want to come back to Kalaupapa to die.[119] A nurse said that of thirty patient deaths she has seen in her time at Kalaupapa, only six burials were at Honolulu and that was because the death was sudden.[120] For a seriously ill patient, the decision about whether to go to Honolulu for medical treatment or to stay at Kalaupapa is difficult. If patients die in Honolulu, they may end up being buried there. We have recently witnessed the passing of three patient friends at Honolulu near death, who were desperate to return and die at Kalaupapa. All three were only able to get back a day before dying. Some patients insist on staying at Kalaupapa to avoid dying in Honolulu, even if that decision might shorten their life.

In the area of their relationship to God, the kokuas are generally less involved in church worship than the patients. Whereas 90% of the patients attend church services regularly, only 38% of the kokuas do—the same percentage as for Americans in general. That overall percentage of 38% masks some big differences among the kokuas, however. Two subgroups attend church at much higher rates, the nurses (70%) and the spouses of patients (58%). In the case of the nurses, two reasons may be suggested for why so many are involved in religious worship. First, they often came to Kalaupapa because they felt a call to minister to the patients, meaning that the nurses who came were likely to be religiously inspired before they came (two of the group are nuns). Second, the nurses are intimately involved with the deaths of patients and perhaps turn to religion to help them deal with those deaths.

Most of the kokuas are much younger than the patients and they never had the patient experience with frequent death, so one would not necessarily expect them to have thought as much about their own death to come. Some of them, however, have clearly been affected by living at Kalaupapa. The Congregational minister believes that living at Kalaupapa affects most people who stay there, by bringing them into contact with death and putting them in touch with the spiritual dimension in some way.

> *They have to deal with their mortality, and when you deal with mortality, you get connected to deeper layers of substance. I think it has to do with getting in touch with your part in the bigger picture – which then I'd see the bigger picture as creation or something, without putting it in language of the church. I think there's a lot of people here who participate in the church; and there's a lot of people that don't. And you can't be here if you don't have that kind of a connection, because you have to deal with death when you're down here.*
>
> Lon Rycraft (3/15/02)

A former nurse's aide, no longer at Kalaupapa, was asked about her experience with death during the time she worked there and how it affected her. She spoke of the first death of a patient that she witnessed and how fast the funeral took place.

> *To me, it made me see death as something very easy, if you're prepared. The people here, I don't know what it is. They don't go through a long grieving process. It's more like they've accepted it from the day they came here. And for myself, I've said what better way to die. Just go and put away [the dead]. [But] you'll always remember them, even now, when we talk about certain ones.*
>
> *One experience that I know I would never have had if I didn't work here was burying the dead. I got to prepare their bodies after they die and prepare them for burial. To me, it was quite an experience, that most people don't have.* Frances Pastaken (9/24/01 Int)

Aside from the nursing staff, we only interviewed two kokuas specifically about their attitude toward death or their spirituality, while three others made spontaneous remarks during an interview on another topic. None of this group of five attends church at Kalaupapa.[121] Three of them said they are more aware of death since they came to Kalaupapa, but it has not made them more spiritual. One these said he said feels differently about death now.

> *...but it's hard to say how. Before, I never thought much about sickness and dying, but now I do. You are out in the world, with many things going on, and you don't think about it. But I'm taking care of patients. I see them*

> *sick and dying all the time. I'm scared of dying sometimes, even though I'm in good shape. I try not to think about all those who've passed, but sometimes I do in the evening. Sometimes I tell my wife, when we leave here, after the patients are gone, we need to go travel or something before we die. We might die anytime.* DOH worker 8 (2/02 Int)

Two others had a seemingly deeper reaction to living at Kalaupapa. They didn't simply think more about death, they came to a deeper understanding of it.

> *It helps me understand how to deal with death.*
> DOH worker 23 (8/10/02 Int)

> *I learned faith from the patients.* [But the faith he learned is not specifically Christian.] *There are other religions besides Christianity.*
> DOH worker 27 (3/27/02 Int)

Although this sample of kokuas is limited, the material collected does coincide with the opinion of the Congregational minister that people who work at Kalaupapa get more in touch with their own mortality through the experience they have with death at the settlement. That was true for all five of the kokuas who discussed the topic. Their experience at Kalaupapa does not seem to necessarily bring them into a deeper connection with the spiritual, since only two of them indicated that. As you might expect, what happens seems to depend on the individual and the perspective he or she brings to Kalaupapa.

Relationship to the Outside World

Earlier we described how the patients' sense of Kalaupapa has been transformed from a prison that they cannot leave to a sanctuary from the outside world. Among the patients that we interviewed, relatively few still carried a sense of Kalaupapa as a prison. A few of them were taken directly from their homes to Kalaupapa, but most were taken initially to a facility on O'ahu – to Kalihi Receiving Station up to 1949, to Hale Mohalu after that. Many of those who went to Kalihi in the 1930s or early 1940s and were subsequently transferred to Kalaupapa were frightened when they first came to Kalaupapa by the sight of so many patients in an advanced stage of the disease. They saw skin covered with nodules and altered facial features. Some who came as adolescent girls had been frightened by stories about how older men were going to grab them as soon as they got off the boat. However, most of them soon came to like living at Kalaupapa better than at Kalihi, as illustrated by the following quotation:

> *You know, all in all, Kalaupapa has been a wonderful place for me. When I first came to Kalaupapa, I never like come. I wanted to be with my family. But they said no you gotta go Kalaupapa. Oh, I never like. I cried. After two months, end of the three months, even my father couldn't get me out of Kalaupapa. No way I would leave Kalaupapa. No way! I just love it*

> *here. I can go hunting, I can go fishing. I can go swimming. Honolulu, I cannot do that in town. I wouldn't give up this for that.*
>
> Edwin Lelepali (9/26/01 Int)

Some never became reconciled to their isolation at Kalaupapa. For example, Patient Makia Malo spoke of his frustration and anger at being trapped in the settlement. After 1950, patients had a choice whether to come to Kalaupapa or to stay at Hale Mohalu. Those that came to Kalaupapa after that time came because they had requested it, often because they saw that life was freer at Kalaupapa than at Hale Mohalu. That group never experienced Kalaupapa as a prison.

When the state ended its isolation policy in 1969, a number of the patients then at Kalaupapa left and established residence outside, but most stayed. As of 2005, there were twenty-nine patients living full time at Kalaupapa outside the hospital. Two of them had spent many years living and working outside before they returned to Kalaupapa to live. There were three others who were living primarily on the outside, but who were still on the Kalaupapa Registry as residents, with houses at Kalaupapa to which they returned periodically in order to see friends and spend time at Kalaupapa. Those five have learned how to be comfortable outside, but most of the others seem not to be entirely comfortable there.

All of the patients we have interviewed had a desire to get out and see something of the outside world after the isolation law was repealed. Some of them have traveled widely, to IDEA (International Association for Integration, Dignity and Economic Advancement) conferences on the U.S. mainland or in other countries to work for the advancement and dignity of people who have Hansen's disease. A number have traveled to Europe for the beatification services for Father Damien and Mother Marianne. At least eight patients regularly take trips to Las Vegas to gamble, to Honolulu to shop, and sometimes take vacation cruises. Another five patients visit their children or siblings regularly. At the same time, they find it a relief to get back to Kalaupapa where life is quieter and easier (see the quotation from Pauline Chow on p. 11). Some who once left Kalaupapa frequently to go to Honolulu or Maui have pretty much stopped doing so except for flying to Honolulu for medical purposes – since they have gotten older, and in many cases less ambulatory.

There are a couple reasons for patients to limit their trips outside and to want to come home. One reason is fear that outsiders will avoid them or react with horror if they find out that they have had Hansen's disease. A nurse described the reaction she saw when she traveled to the Big Island with a group of patients. They stopped at a store and the clerk asked where they were from.

> *Before the patients could speak I said, "Oh, we're from Kalaupapa." And the woman behind the counter took a step backward. And there it was. I finally saw why they don't say that. That stigma is still there.*
>
> Julie Sigler 12/4/02 Int)

For this reason, many of those who moved out permanently hid the fact that they were patients at Kalaupapa in order to avoid such a reaction.[22] Some still hide today. Those whose appearance has been visibly affected by the disease are afraid of being stared at and only a few of them have moved out of Kalaupapa. Two patients who have stayed at Kalaupapa describe their feelings about going out below. Neither of them has been very obviously altered physically by the disease, and both of them say they feel free. But both still betray some self-consciousness about being outside.

> *When I go out, if they look at me, I look back and say, "I owe you money or something?"*
> *No, I feel free. I don't care about telling people I'm from Kalaupapa. It's up to them to take it or leave it. [But] when I visit friends, and their friends that know them come around, I get the feeling they looking at me, but they don't ask. That, I don't like. I'd be happy to talk to them.*
> *My grandson invites me to come visit, but I don't know his family. I don't want they sit down, they look at me. When I'm out, people do that.*
> Clarence Naia (8 5 02 Int)

> *Paul: I guess there's no place like home, and this is home. I enjoy going [to see] my family and people and friends, but it's always coming home that [is] the biggest thing. Like you feel safe.*
> *Paul's wife Winnie: He gets very uptight before he leaves the settlement. He grumbles a lot.*
> *Langlas: How do you feel when you travel outside?*
> *Paul: Oh, I don't feel anything. I mean I go, I eat with people around. We come to the same table and then talk about it. I tell em, hey, I'm from here. If they don't like the idea, well that's their tough luck, not mine.*
> Paul and Winnie Harada (7 10 04 Int)

> *Those who've moved out have an attitude towards us. They feel we don't have the guts to go out. My handicap makes me kind of back off [from people]. I'm not ashamed of it, but...*
> Paul Harada (1 02 05 Int)

Another reason for patients' discomfort outside is the difference in life-style between Kalaupapa and the outside world. In Kalaupapa living is slow-paced. It is easier and less stressful as far as the patients are concerned.

> *I'm used to it, you know. I like the quiet life. Of course, I do go out and visit my family, and my children, my grandchildren, my great grandchildren, but I always like to come back home. Come back home, I can relax.* Gloria Marks (8 5 02 Int)

At Kalaupapa nearly everything is provided for the patients by the government. Outside they have to fend for themselves in a more complex social world. A patient who moved out of Kalaupapa in the 1960s and returned later described the difficulty she had living outside.

> *And then to go to the store... like in Kalaupapa here at that time you had the best of everything, the best. And I went out the best, it just gobbles up the money. The thing you gotta go for is the second best and go look for sales. Gotta look for a better things that won't cost too much. But staying in Kalaupapa for 20 years or over, for 21 years, it was a hard thing for me to live [outside], because of the fact when we go outside we live foolishly.*
>
> *There's no more grabbing in here. There's no more hassles in here. And you're always a step ahead of people on the outside [you need to be], but here is not so.*
>
> Katherine Costales (in ASL 1985-87, 16A:3-4)

Although she found the adjustment to living outside difficult, she persisted because she wanted to be free, to get away from the restrictions of Kalaupapa where she was always told what to do.

We gathered only limited evidence about kokua attitudes toward Kalaupapa, to what degree they see it as a refuge from the outside world, but they have less reason to seek a refuge. The kokuas have never been stigmatized as a result of having Hansen's disease — they are not stared at outside, they have always had the freedom of the outside world and the necessity to cope with it — so they certainly have less to fear from the outside. Most of them travel outside regularly, at least one weekend a month. Nevertheless, we have heard a number of kokuas speak of how happy they are to leave the noise and bustle of the outside world and get back to Kalaupapa after a trip outside. A few of the kokuas seldom leave Kalaupapa and it seems they have grown less comfortable with the outside. One kokua interviewed said that he didn't want to leave any more, that as soon as he goes out he wants to come back. Another kokua said that he didn't want to go back to the "rat race" of working and living outside Kalaupapa, but subsequently he did leave. A third kokua interviewed was a retired worker who had been at Kalaupapa for forty years, and who was allowed to stay as a volunteer worker for the state. At that time in his life, he was just as tied to Kalaupapa as the patients are, closer to people down at Kalaupapa than to people outside.[11] He said he planned to stay until he couldn't work any longer and had to leave. (In 2006 this worker also left.) The group of kokuas that is uncomfortable outside is surely a minority. There is another group of kokuas who are very attached to Kalaupapa, but more because of their attachment to the patients than because of their discomfort with the outside. Three that we interviewed said that they plan to stay at Kalaupapa "until it closes," that is, for as long as the patients are there.

CHAPTER 5. THE LANDSCAPE OF KALAUPAPA

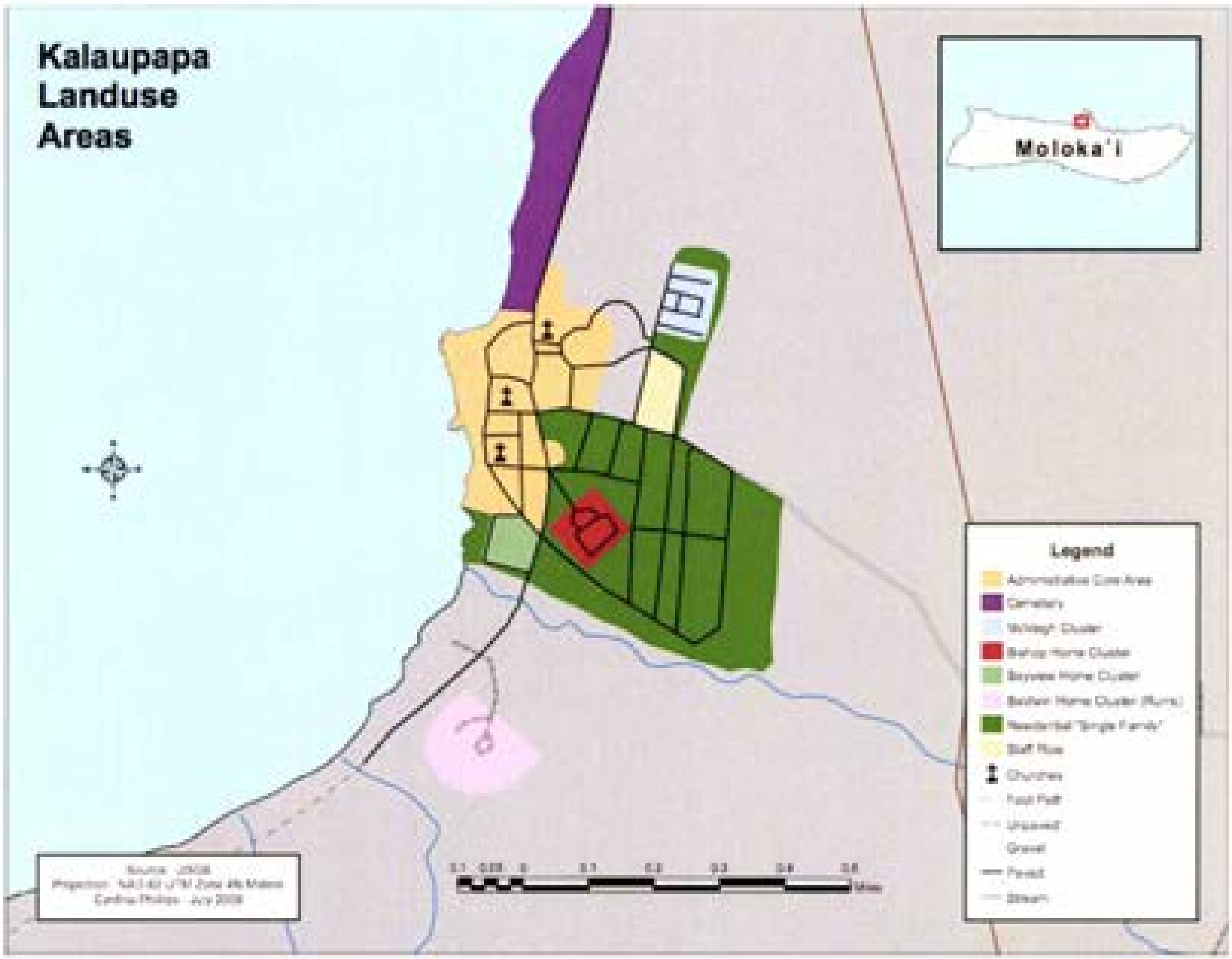
Kalaupapa as a Cultural Landscape

The Kalaupapa landscape is the most important monument to the History of Hansen's disease in Hawai'i, and perhaps one of the best known in the world. The tragic story of this exile community has been repeatedly portrayed in literature, film and stage dramatizations. The history of the area is also "written" on the land in structures (residential and governmental buildings, cemeteries and informal burial grounds, stone walls, and sacred *heiau*), pathways (trails, streets, and pipelines); resource areas (fishing spots, hunting grounds, flowers, foliage and salt collecting places), domesticated plants and animals; and other artifacts that attest to human occupancy of the area.[125] What is not explicit on the physical landscape however, is the symbolism and meaning that these same elements hold for the individuals who now live at Kalaupapa, particularly those patients who remain today, survivors of the last wave of exiles to the peninsula who came between 1941 and 1969. Likewise, the DOH and NPS workers who live at Kalaupapa carry their own mental images of the land that has bounded all of their lives

This section of report focuses on some of the visible elements of the landscape that were singled out by patients and workers. Their mental images and personal accounts of the ways in which they interacted with landscape elements form an invaluable record of how the area has been used, viewed and valued. Their perceptions and accounts have persisted and become transmitted over time and space. By focusing on what we heard from them, we have tried to uncover a deeper meaning of Kalaupapa than can be gleaned from the vantage point of a casual observer.

The Settlement

The spatial layout within Kalaupapa "village" today reveals the extent to which the community can be said to reflect an institutional design; as well, the presence or absence of certain activities may suggest dependency on external forces that constrain growth and autonomy within the community. Map 2 illustrates the spatial design of the settlement proper. The layout of the settlement generally conforms to the typical pattern in small port towns. Clustered into an administrative "core area" of sorts fronting on the deep water harbor are the administrative, industrial, and service buildings, including the hospital, the DOH Administration Office, the Federal Post Office, the NPS Headquarters and Ranger station, the Kalaupapa Store (which carries mainly food items) and Kalaupapa Warehouse, and the DOH and NPS shops. Saint Francis Roman Catholic Church (built in 1899; rebuilt in 1908) and Kana'ana Hou Congregational Church (built in 1915) lie generally within this cluster. The Mormon Church of Jesus Christ of Latter Day Saints (the existing structure built after the 1946 tsunami) is only a short distance away at the northern edge of the core area. (In addition to these, there is the small Saint



Map 2. Generalized Landuse Areas within Kalaupapa Settlement.

Figure 18. St. Francis Catholic Church complex showing rectory, garage, community hall and chapel.

Figure 19. Church of Jesus Christ of Latter Day Saints (Mormon)

Figure 20. Kana'ana Hou Congregational Church

Elizabeth Chapel, located next the convent at Bishop Home, but it has always been used primarily by the nuns who cared for patients.)

Evidence of social hierarchy and spatial separation persists in the present organization of residential land use within the settlement. All except one of the houses now reserved for administrators and staff are located at the back (eastern boundary) of the settlement, farthest from the shoreline in an area appropriately named "Staff Row." Staff

Row came into existence before 1910, prior to the relocation of patients from Kalawao to Kalaupapa. At that time, the location of Staff Row was designed to maximize distance between the administrative workers who lived at Kalaupapa and the patients who lived in Kalawao. Later on, the houses of the patients were built at Kalaupapa, but away from Staff Row. The expected capture of prime shoreline location by the community elite (i.e. the government administrators and professionals) is largely absent at Kalaupapa. The present location of Staff Row relative to the shoreline is not the result of altruism, however; rather it is the product of earlier attempts to maximize distance between patients on the one hand, and their medical caregivers and other governmental staff on the other. This general departure from a laissez faire residential land use pattern is one of the many effects of Hansen's disease evident on the landscape. The single exception is the DOH Settlement Administrator's residence, which occupies a fenced-off shoreline parcel situated between Visitors Quarters and Bay View Home. Formerly this building was reserved for the supervisor of Bay View Home, and has now been assumed by the current DOH Settlement Administrator.

Figure 21. Staff Row

Figure 22. Bay View Home complex viewed from near the shoreline.
The building to the left was the main kitchen-dining room. It currently houses the NPS Resources Management Division. The remaining buildings are dormitories and a kitchen-dining room once used for blind and disabled patients and now used by the NPS for visiting researchers and volunteers

Currently most of the patients, as well as the workers who serve them live in individual houses. Prior to 1960, however, most of the patients lived in one of four group homes built in the settlement—Bay View Home, Bishop Home, New Baldwin Home or McVeigh Home. Each group home had one or more dormitory buildings, a kitchen and community dining room. McVeigh Home included a cluster of cottages as well. Bay View Home was used to house patients who were blind or disabled. Bishop Home was built to house unmarried girls and women, but by the 1940s it was mainly used for girls. It was run by nuns of the St. Francis order. New Baldwin Home was established to house men and boys and was run by lay brothers of the Sacred Heart order. (The original Baldwin Home was located at Kalawao.) McVeigh Home was established for Caucasians, although it housed patients of various ethnic groups by the 1940s, including many married couples. Each group home was a little community to itself, with its own kitchen and communal dining room. The homes had their own baseball and volleyball teams that played other teams. As the number of patients diminished, the group homes lost their function as residences. Most patients moved out into individual houses. The group home dining rooms were closed in the late 1960s.[125] Starting about 1990, as the number of patients dwindled further and individual houses fell vacant, houses were given to state and NPS workers to live in.

Two other places are currently in use for community gatherings, McVeigh Hall and Ocean View Pavilion. However, the most important gathering place in the minds of patients is Paschoal Hall, despite the fact that it has been out of use now for more than ten years. Situated near the middle of the settlement, Paschoal Hall is perhaps the most highly valued building on the landscape. It is an imposing structure, in the context of the community setting, that represents one the finest examples of period public architecture in Hawai'i. Outside the building is an open field that buffers it from Staff Row to the east. At the north side is a tennis court and to the west is a panoramic landscape that encompasses both pali and ocean views. Patients and longtime residents maintain a treasury of memories about the social activities held in Paschoal Hall.

Paschoal Hall symbolizes happiness in the midst of pain. The hall is an enduring reminder that, even while smitten with the "sick," patients could still have fun and partake in normal social relationships. Nowadays the partially renovated structure stands as a metaphor for the loss of centrality of the patient in the affairs of the park. The NPS began restoration work on the structure in 1998, but ran out of funds and work on the structure was still unfinished in 2008.[126] Patients long for more continuity with the past when attention to their needs was the reason for the work performed by all non-patients. It would be wonderful if they could once again experience being entertained in Paschoal Hall because,

> *Lotsa things happened in that hall, nice things happened in that hall.*
>
> Ku'ulei Bell (7/16/02 Int)

Figure 23. Paschoal Hall freshly painted in 2004, west elevation.

Movies, movie stars, community plays, dances, fairs, romances and more were staged at the Hall, and are recalled with pleasure, humor, nostalgia and a touch of melancholy. Patients feel an intense sense of loss regarding Paschoal Hall, resulting from a longing for the social activities of bygone times as well as their loss of access to the facility. There is a desire to know how the space will be used in the future, and a need to reclaim ownership — if only in a limited way.

Patient Gertrude Kaauwai described the complex significance that Paschoal Hall holds for her, as someone who came to Kalaupapa as a child in the 1940s. It is obvious that for her Paschoal Hall is at once the symbol of the community's culture and a witness to their history. The intensity of her sense of loss is obvious from the number of times she uses the word "sad" to describe her emotions and her desire to bring the Hall back to the life she once knew.

> *As I can remember, even how young I was, that Paschoal Hall—there was lot of things that we used to do in there. First of all Paschoal*[17] *really helped to rebuild the whole place of the Hall. And so we had lot of dancing in the Hall and we even had bingo in the Hall. We used to get those Christmas plays that we'd go and act in there. Sister Wilma, she used to get us to act in the Hall. The Hall had a lot of people in there that would come and enjoy whatever entertainment we had in there. And then in that Hall had actors and actresses come over and entertain us.*[18] *And then on Fridays, as I remember, we had movies.*
>
> *Today, to me as I look now at the hall [silence]. The woman that took care of the yard—the place was so beautiful. You could get all flowers, plants around the hall. So beautiful, when you look. Today it's different. Today it's sad knowing Paschoal Hall. I am not used to see that place as empty and it's kinda sad because there was so many things we did in there, so many.*
>
> *So today, when I look at the Hall, the memory is sad. It's sad because I still say if they fix up the place and clean the place up and open up the place, where we can have those entertainments in there and you know I think that would be beautiful. The memory can come back of how beautiful it was. So, today as I look at it, not like before.*
>
> *Sometimes when I pass by, I stop in front of the hall and I will [crying] sometimes tears come because you can picture everything what was going on. It was beautiful memory of enjoyments in the hall. 'Cause had all the dancing and all, it's all so different, so different. So, today the hall is not a happy memory, it's not.* Gertrude Kaauwai (16.10.05 Int)

Her sadness that Paschoal Hall can no longer be used by the community is echoed by many other patients.

> *…like Paschoal Hall… I don't know. It's sad to see that like that. You see, because that one, that Paschoal Hall is really something. Better than up McVeagh [McVeigh Hall, where community functions are now held]. But we had, at that time they had so much of old programs at Paschoal Hall.*
> Ivy Kahilihiwa (8.8.02 Int)

While some structures of sentimental value may be temporarily or permanently off limits to patients, those who are able take advantage of the network of formal roadways and informal tracks that provide a high degree of connectivity within the peninsula. With the exception of the road to Kalawao, the existing formal network of graded and mostly paved roads does not have an organic quality—meaning that it does not exhibit the free form typical of access ways that emerge out of the every day travel patterns of the people. Rather, the existing grid-like street pattern is an orthogonal one--a stamp of administrative control typical of an institutional arrangement in which efficiency and control is sought by a regulatory system. Contrasting with this formal network is a set of informal tracks (unpaved and ungraded) throughout the area that evokes a more vernacular stamp on the landscape. For example, an ungraded track creates a short-cut from McVeigh Hall across a field to Papaloa graveyard.

What is missing from the current settlement layout is much more revealing that what is present. No physical evidence of schools remains in the settlement, although there were schools started in 1943 when children were relocated to Kalaupapa from Kalihi Hospital at the beginning of WW II after the Pearl Harbor attack. (There is a small library, built recently and named for Mother Marianne.) Neither is there significant private commercial activity, other the bar (for several years known as Elaine's Place and since June 2003 under new proprietorship as Fuesaina's Bar), which sells beer, wine, soft drinks and snacks on a part-time schedule. The absence of a range of entrepreneurial activities attests to the fact that Kalaupapa is no ordinary community—realistically it is a community that continues to dwindle. What is missing makes clear the bounded nature of a lived world in which the individuals are dependent upon the state, not truly autonomous. This is especially evident with respect to one of the most fundamental of human urges, to share life with children and ensure continuity of culture and place beyond the individual lifetime.

Beauty of Plants

The vegetative landscape found in the settlement today is in part the cumulative result of what was planted by generations of patients, and kokuas as well. As individuals, they planted fruit trees and flowering trees and bushes in their house yards. As patient workers, they planted and tended decorative hedges throughout the settlement and along the edge of Papaloa Cemetery, as well as individual plants in public areas. Among the long-lived fruiting trees planted are mango, mountain apple, lemon, avocado (pear), *'ulu* (breadfruit), tamarind, and coconut. In particular, there are many mango trees that bear in the summer. Patients and long term workers know the locations of all the mango trees and keep track of when they are ripe for picking. The many flowering trees include poinciana, crown flower, plumeria, be-still trees, and shower trees. They are particularly vibrant in May-June, following the Spring rainy season. There is also a year round display of *huapala*, an orange-flowered vine, on the rock walls near to the bar and of bougainvillea shrubs throughout the settlement.

Figure 24 a & b. Poinciana tree (left), Plumeria tree (right)

What we see in the settlement today is only a vestige of the beautiful fruiting and flowering landscape that patients remember from the 1940s to the 1960s. A long-time resident of Bay View Home described the yard there when he was young in the 1940s. "Once upon a time it was nice here. We had all kind plants and trees." He described a network of hedges that decorated the compound: a red hibiscus hedge bordered the home on the ocean side, tall croton hedges stood next to the buildings, and low hedges with pink-and-yellow foliage lined the sidewalks. Today, he says the compound is bare and it looks ugly to him. A patient who came to Kalaupapa as a 14 year old in 1942 vividly recalls the beauty of the Kalaupapa landscape of her youth.

> *When we first came to Kalaupapa, all you saw was flowers. All you saw was flowers growing along side of the road and the trees is just full with blossoms, lots of plants, lots of greenery, all trees, ironwood trees. And night-blooming cereus—they were all on the stonewall blooming beautiful. Lot of shower trees, yellow shower, pink shower, just full bloom, so beautiful Kalaupapa. And then later on, they started to dig it out. Because they said was too much work. People had to go around and clip the tree to shape it, and they thought it was too much work. So, they dug the plants out and threw it away. So it's just plain grass now and it looks terrible—shabby.*
>
> *We used to have a nursery here, and there used to be a man brought here. His name was Murakami. He was the nursery keeper. He was the man that made all potted plants, big ones, and they were taken to the hospital, to the store, to the social hall where they have entertainment. And this was his job—planting all this plants along the side of the road to make it look nice. But when he left, everything started to die off. They used to have a group go out water all the plants in the settlement. They never let them die. They were beautiful. It's too bad they never had any video at that time taken of the settlement, different areas. Otherwise we have that to show. They had a lot of nice—you see up the hall from the main intersection, by the library—all that went all the way up, purple*

> *bougainvillea. It went up alongside of the road. It went all the way up and when it was in bloom, it was so pretty, so beautiful.*
> Cathrine Puahala (7/12/2002 Int)

The beautiful landscape of plants that patients describe at an earlier time took a lot of work to maintain—watering the plants, trimming the hedges, digging out the trees which grew in them.[129] As the patient workers aged, they were replaced by a smaller force of state maintenance workers. By 1980, the settlement was no longer well maintained and many areas were overgrown by weed trees, mainly haole koa and Java plum.[130] When the park was first established in the 1980s, both the DOH and the NPS maintenance crews worked hard to clear out the haole koa from the graveyards at Papaloa and Kahaloko, as well as from the settlement itself. Unfortunately, it seems that the attempt to "clean up" the settlement and outlying areas sometimes resulted in the removal of trees valued by patients along with the weed trees. An investigation of the plants valued by the patients has recently been carried out by Jennifer Cerny (2004).

Only a handful of the patients are still able to maintain their house yards today. Among them, Paul Harada clearly stands out. Not only does he maintain the bright flowering borders in his house yard; he has turned the entire next door lot into a vegetable and flower garden. When Paul realized that there were very few sources of flowers to adorn his church (the St. Francis Roman Catholic Church) throughout the year, he became a gardener for God as it were—tending a variety of flowering plants and colorful foliage to provide year a round supply for the enjoyment of patients and visitors and no doubt to celebrate his unshakable faith. He grows red poinsettias in pots to fill the church at advent season, and pink panthus flowers for year round.

> *I started planting these things, panthus ... then [W] went working and then [N] took over. So when [N] took over, she didn't even have to go look for flowers 'cause I was the one responsible for the flowers, 'cause I planted. It's a hard job arranging the flowers right? You have things to do, that's your job to arrange them every week. ... I mean that's the reason why I did it.* Paul Harada (6/23/03 Int)

Figure 25. Paul's yard

Figure 26. Paul's garden, with panthus flower to the right side

Graves

Patients who came to Kalaupapa in the 1940s remember when there were two or three deaths each day in the population of less than a thousand souls. Patient "George" recalled how in the days before the sulfone drugs, grave diggers and the crematorium were busy daily, especially since the corpses had to be disposed of as soon as possible because there was no embalming in the settlement. Coming to Kalaupapa, patients anticipated a life expectancy of only a few years according to him. The cemeteries of Kalaupapa Peninsula stand in mute testimony to this experience.

Figure 27. View of Papaloa graveyard from the north, looking toward the settlement

The burial ground at Papaloa, shown in the photo above, is vast in scale and enormous in its impact on the visitor. The placement of graves and the style of grave markers exhibit a random organic quality that befits the history and character of Kalaupapa. This graveyard (consisting of several named cemeteries) is the first significant structural cultural imprint on the land that confronts a visitor en route to the settlement from the Kalaupapa Airport, located at the northern tip of the peninsula. About nine tenths of a mile from the airport, a relatively small cluster of graves pops up out of the shrubbery on the ocean side. This cemetery scenery is briefly interrupted by a break in the sand dunes but it soon reappears, broadening, pushing relentlessly along the coast. The huge burial ground contains well over 1,300 graves[131] and stretches almost a mile and a third amidst the coastal sand dunes on the seaward side of the airport road. The large scale of the burial ground, together with its location on the way in from the airport, imposes upon the newcomer the enormous burden of death that has been borne by the Kalaupapa community and that shaped the lives of those exiled in the settlement, considering the 8000 some individuals estimated to have died at Kalaupapa since 1866.[117] The human toll from Hansen's disease is even more sorrowful for those who dare to reflect on the lost lives concealed within the dunes. A longtime worker reminds us that in Kalaupapa it is important to look beyond surface appearances.

> *The way I feel about the cemeteries is that they represent such a small portion of people that were here, because many of the headstones were washed away when the tsunami came, April 1, 1946, to Kalaupapa.*
>
> BJ Reed (7/10/02 Int)

A longtime nurse gave her insight into the more personal feeling that patients have about Papaloa Cemetery

> *I was riding with this patient HY, and I used to take the patients for a ride. We were riding one day, we were going past [Papaloa] – just down from the cattle guard, and he goes, "You know, I used to play baseball with that fellow [in] that graveyard, and that was a girlfriend of mine, and that was my neighbor, and that was a fellow I used to eat with at McVeigh. Now I know maybe twenty or twenty-five of them, that's how many people have died since I've been here, maybe thirty." But each one of those meant [something] – that was a person to them who was special to them—maybe they didn't like them, or they had arguments with [them], but each one of them was an individual.*
>
> Julie Sapler (7/14/02 Int)

The large formal burial place referred to above as Papaloa[118] is but one among several Kalaupapa burial sites associated with deaths from Hansen's disease. On the road to Kalawao lies Kahaloko Cemetery. At present, Kahaloko Cemetery is well demarcated and neatly presented. But patients remember when it was completely overgrown, before the NPS workers cleaned out the vegetation in the 1980s, following the establishment of Kalaupapa as a National Historical Park. As one patient told us,

> *We never knew they [the graves] were in there but we heard stories, spooky stories, but not knowing that this was a cemetery.*
>
> Ivy Kahilihiwa (8/2/02 Int)

Less than a mile further east along Damien Road are the two nineteenth century churches: the Siloama Congregational Church (Church of the Healing Spring) and St. Philomena Catholic Church. There are graves in both churchyards. Notably, Blessed Damien, who died after 16 years devoted to the service of sufferers of Hansen's disease was buried at St. Philomena's. Another large cemetery for Hansen's disease victims lies to the east of St. Philomena's churchyard. This third and oldest cemetery is different in appearance from the Papaloa or Kahaloko cemeteries; patients say that there are many burials here, but nothing visible is visible save a great number of depressions at the surface of the ground which seem to be graves, suggesting that the bodies may have been hastily buried. Cast against the relatively elaborate tombs in the adjoining churchyard these burials seem cold and impersonal. They not only imply the absence of family caretakers but they also reflect the grim state of affairs in the community at the time.

Elsewhere on the peninsula there are small clusters of graves. One such cluster is situated about mid elevation along the road leading up to Kauhako crater from the south. The graves are on the right (eastern) side of the road leading to the crater rim. About twenty feet off the roadway, there are four elaborate crypts surrounded by a rock wall. One of the crypts has a distinctive wooden door leading to the remains of William K. Notley.[11] Nineteen other graves are located nearby. Several of them have inscriptions written in Hawaiian. Another small cluster of tombs is situated near to the rim of the crater. The impressive site atop the hill, together with the large size of each tomb, suggests that they are graves of individuals who were of considerable social status. Patients say that the absence of markers and the overgrowth of vegetation obscure other graves in the area of Kauhakō Crater. In particular we were told that Mormon graves are located in the area just south of the crater, but a brief search on one occasion did not uncover any evidence. Patients tell of other locations around the settlement where there are graves, for instance there are supposed to be three graves near the dump at the back of the settlement (between the Waihānau stream bed to the south and the residential area). The open pasture immediately west of Kahaloko Cemetery was a cattle grazing area up till 1988, but "lots of graves are beneath the surface (Lionel Kaawaloa, 8-4-02)."

Cemeteries are the most fundamental structural element on the Kalaupapa landscape, not only because of their size in relation to the dwindling population there, but because they are the landscape element most symbolic of the modern history of the area as well as the metaphor for Hawai'i's experience with Hansen's disease. The centrality of this landscape element implies that every effort should be made to preserve them. Perhaps this physical reminder will help those who come to reflect on our past inhumanity as a society, and our potential to overcome that inhumanity. Katherine Costales (3-8-06) echoes the sentiments of all residents, saying that, "The entire peninsula is a burial ground. Leave it as it is."

The Sea

Like the pali in the days before segregation was ended and the patients were "paroled," the ocean served as a vast and formidable boundary, sealing them off from contact with friends and family outside. Nevertheless, having been raised as islanders, the patients were comfortable in the ocean; for them it was and remains their playground, and a rich source of marine resources. The sea also provides residents with shells for crafts and with salt in the summer. There are many stories about the abundance of fish, opihi, limu (seaweed), and lobster caught by patients, workers, and folks from Topside. There are stories about the Fishing Nun (Sister Richard Marie), of a cave whose walls were papered pink with crawling lobsters. There are stories of swimming at the pier and surfing with home-made surfboards. There are stories of people who died fishing and places named after them on the dangerous north shore of the peninsula, where the waves come in from the deep ocean. Needless to say, the ocean also presents a changing palette of beauty, as her colors range from pink at dawn through the rich aquamarines, azures and deep blues of sunny days, grays of overcast and stormy days, and violets of sunset.

When the patients were younger, fishing was not just for food, but for fun. When Paul Harada grew up at Baldwin Home, the boys were taken out fishing in the afternoon as a reward for good behavior.

> *That was the only recreation we had, when you think about it. What can you do in Kalaupapa? You know, you see all the high school kids [today], they're all doing different things, yeah? But we can hardly play sports, and we cannot go out. There's nothing to do except fish. No TV.*
>
> Paul Harada (12/20/01 Int)

The women patients loved fishing too.

> *Oh, I used to love to go to the beach. You see I had the same instincts like my auntie. My auntie was a beach-goer. Oh, she loved to fish, she loved to make opihi. And then, over here get āhole. Oh, everybody go crazy. Nellie [another woman patient] used to be one of them. Āhole run, oh, she's up there Kalawao. With pole. Put em down and pull em up. So much.*
>
> Cathrine Puahala (3/23/02 Int)

Only a couple of patients, Paul Harada and Boogie Kahilihiwa, still do a lot of fishing, but a larger number of them collect salt in the summer. The northern coastline of Kalaupapa Peninsula is flat, windswept and rocky. High surf brings water inland and leave sea water pools in the depressions in the flat rock, especially during winter storms.

Figure 29. Paul Harada Picking Salt

Figure 28. Drying Salt

When this seawater evaporates, thin crusty layers of salt are left behind. The glistening white salt crusts on black lava are an attractive sight, and patients look forward to the late summer months (July to September) when weather conditions are ideal for salt formation. Patients turn salt "picking" excursions into picnics that can last for hours. Those who are still able to trek across the lava, indicate that they pick salt whether or not they have an existing supply. As Pauline Chow says,

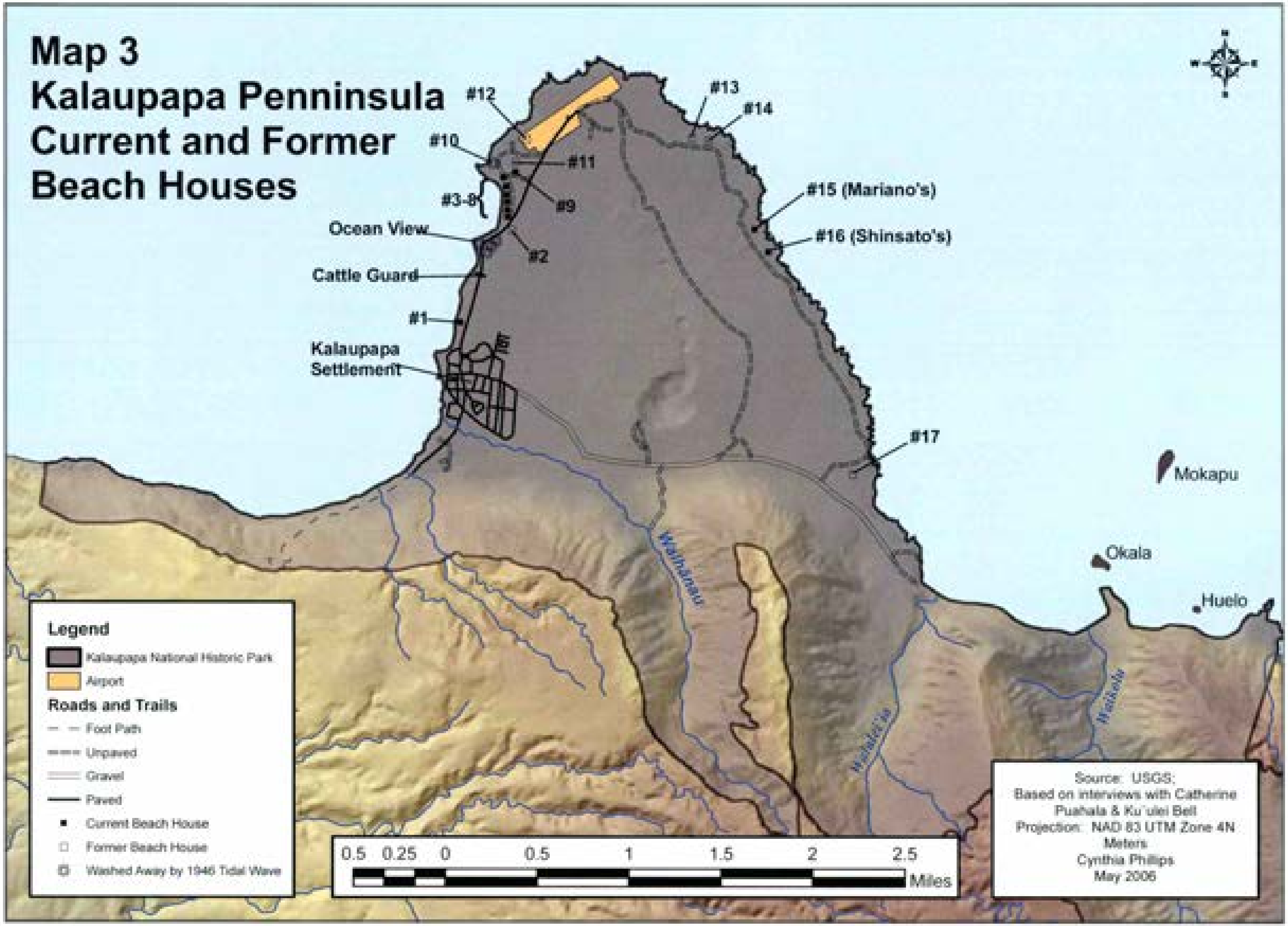
> *I just like to go do it. To me it is relaxing: you're sitting there and just picking the salt.* (8/19/04 Int)

Beach Houses, a Testament to Patient Independence

Between the airport and the settlement there lies a set of beach houses built by the patients. All of the houses in the settlement proper were built and owned by the state (earlier the territory), but the beach houses represent a sphere of independent action by the patients. They acted for themselves in building them and they were located outside the settlement, where it was easier to avoid control by the administrative authorities. Access to building materials in the settlement has always been limited, since everything must be shipped in by barge, so many beach houses are constructed with salvaged materials found within the settlement. Although the patients do not own the land, they own the beach houses. Ownership is transferred to other patients by gift, sale or inheritance. At one time, the beach houses were distributed farther along the coast, all the way to Kalawao. (See Map 3 following.) Today, only one beach house remains on the east (windward) side of the coast.

Figure 30 a & b. Two Beach Houses.

In recent years the beach houses have been less used by the patients. As they have gotten older, some owners have allowed their beach houses to fall into disrepair. In the last couple decades, the main use of the beach houses has been to put up relatives or



Map 3
Kalaupapa Penninsula
Current and Former
Beach Houses

Source: USGS;
Based on interviews with Catherine
Puahala & Ku`ulei Bell
Projection: NAD 83 UTM Zone 4N
Meters
Cynthia Phillips
May 2006

friends who come to visit patients. Before the end of patient segregation, however, the beach houses seem to have had a very different function. They provided a break from the routine and social control of life in the settlement. Several patients said that the beach houses were often the venue for wild parties. One house was reportedly bought by a Filipino patient in order to run gambling parties. Inside the settlement gambling parties might be raided by the settlement police, and it was probably easier to avoid the police outside the settlement. A patient who came as a teenager to Kalaupapa in 1959 remembered that he and several other young men used to rent out that beach house about 1960.

> *We used to go down there, six of us. We each would get one month rations and go out there and stay for the month.*
>
> Boogie Kahilihiwa (2-14-03 Int)

Another patient spoke of going with her husband to stay at a friend's beach house for a change of scene, and of going fishing out there.

> *We used to stay down the beach house. Cause my friend loan us the beach house. So we took care of the place. It's so good to go stay down the beach. Early in the morning you can hear the water coming in, going out. Nighttime you can hear the water rising, coming inside.*
>
> Catherine Puahala (2-16-03 Int)

Although the beach houses are little used today by the patients themselves, they are an important element of the landscape to preserve, because they represent patient initiative, independence, and zest for life.

Kalawao --the Old Settlement and Judd Park

As the place to which the first Hansen's disease patients were sent, Kalawao is where the worst episodes of Hawai'i's Hansen's disease saga were played out from the mid-1860s to the 1890s. Kalawao instantly became a purgatory and then a final resting place for thousands of men, women and children (perhaps over 5000) whose lives were truncated because an effective antibiotic treatment of the bacterial disease was decades away. Obviously, patients alive today were not so unfortunate to have lived in Kalawao, but that does not mean they are lacking strong emotional connection to that place. All of the patients are inextricably linked to Kalawao by "the sick" and in some cases by ancestry; and they all can tell stories that form the invaluable oral tradition of Kalaupapa. It is not surprising that Kalawao is one of the first elements mentioned by patients when asked to identify their own special places in Kalaupapa because for historical reasons, Kalawao and Kalaupapa are intertwined.

> *I guess because of the history, and Father Damien being up there, you know with the settlement being there. So, I guess it's more the history of*

> *the first patients being out there ... I guess there has to be, you know, with the history and with the suffering and the people being there. But then again it affects different people different ways.*
>
> Pauline Chow (8.12.02 Int)

Although Kalawao is only about two miles east of Kalaupapa Settlement, there is a real and perceived spatial separation and discontinuity between the abandoned leprosarium there and the newer settlement at Kalaupapa. Kalawao bears strong witness of the past (important churches, cemeteries, graves of Blessed Damien and Brother Dutton, and abandoned residential areas). At present the elderly patients mostly go to Kalawao for special events, like the monthly services at Siloama and Saint Philomena churches, or they take visitors (family and friends) on sightseeing excursions, fishing or an occasional picnic outing at Judd park farther to the east.

For the most part, though well maintained today, Kalawao conveys for many an unshakeable presence of grief and loneliness. This is partly because of the physical site characteristics: being on the most windward side of the peninsula, the area experiences high cloud cover and can appear gloomy much of every day, especially during the winter rainy season. The relatively high cloud cover and low sunlight intensity is compounded by the shadowing effect of the forest of tall trees and towering cliffs on this side of the peninsula.

> *...on that side of the island gets cold about three o'clock. The sun hides behind those parts sticking out, and that's what made them happy down Kalaupapa, 'cause it was warm out here. And the sun stayed longer. When the sun goes down [at Kalawao], it gets cold.*
>
> Cathrine Puahala (7.12.02 Int)

While many visitors come from the United States mainland and overseas to Kalawao (and Kalaupapa) these days to venerate or simply to behold the place where heroic figures like Father Damien, Mother Marianne, and Brother Dutton lived and worked and died in service, Kalawao is above all, a monumental graveyard for thousands of patient-martyrs. Their sacrifice was "imprisonment," the action that was then believed to be necessary to prevent the contagion spreading to others within their home communities. Therefore, importantly, the sense of place in Kalawao is that of suffering and death and that imagery is apparent in the following comment.

> *And you know that place next to Father Damien's grave, there's a little place where they used to put cattle, and then a big ground where you come down to ... all on the left, there's thousands of graves over there. And there's no markers. And there's thousands of patients buried there. All the patients that live in Kalawao, how many of them died and that was the graveside where they buried them ... nowhere else but over there. They buried them all over there. That whole area when we came, they had fence around ... almost like, don't go in there.*
>
> Cathrine Puahala (7.112.02 Int)

Patient Richard Marks (12/30/04) had four choice words to describe Kalawao: "It is sacred ground." In the same vein a long-time worker said:

> *Kalawao is a very, very special place and there's a lot of heavy, the Hawaiians call it mana [spiritual power], there's a lot of heavy mana there and you can feel it. I've taken many people back there and they reacted in many different ways. But there's kind of a great sadness back there and most everyone feels that when they go back there. I've taken many people back there and they've just broken down, just sobbing, just sobbing.* BJ Reed (7/10/02 Int)

The heavy atmosphere often associated with the old settlement at Kalawao contrasts with descriptions of its beauty, and with the memories of good times at Judd Park.

> *Kalawao is a beautiful spot. You know when you stay at the Old Baldwin Home and you look out to the two islands? It is just perfect. I don't think there's any other place as beautiful as Kalawao.*
> Cathrine Puahala (7/12/02 Int)

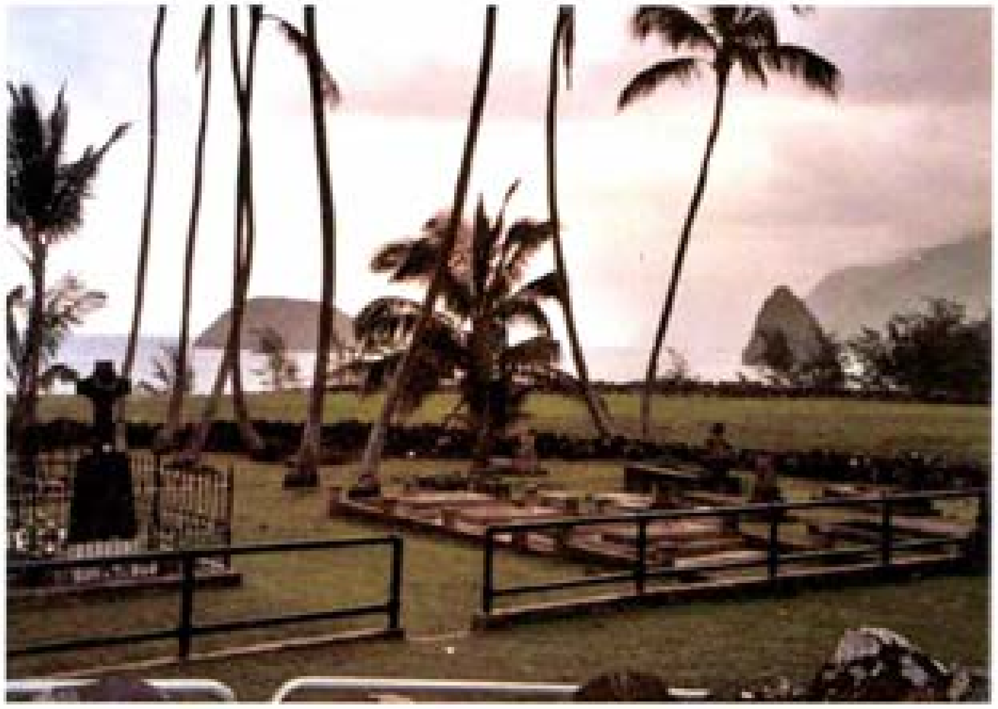


Figure 31. Mōkapu and ʻŌkala Islands from Kalawao,
Father Damien's Grave on the Left

Many patients told of going out to Judd Park for community picnics in the old days,[135] or of riding out there for a break.

> *Kalawao that's the best place! We would ride horses to Kalawao and I used to go—me and some of the other girls—used to go hiking, you know go walking from here all the way Kalawao. We used to go around the island walking, going down the beach, there were lot of things we used to do.* Gertrude Kaauwai (6/10/05 Int)

> *I used to go riding just every other day before, but not now. We do have mass at Kalawao again. It's about the only time I go now, you know, like for Father Damien's feast day or we have visitors. Father has visitors, visiting priests, and he almost always wants to say mass up there. Then we go up there and have mass. But a lot of people go to just go take ride and some will go out back and check the fishing grounds out there. Way back, when I first got here [1962], every Labor Day we'd have picnic for the community up there and we'd spend the day up there.*
> Pauline Chow (8/12/02 Int)

Figure 32. Judd Park at Kalawao

Patient Clarence Naia (6/21/03), nostalgically traveled back in time: "Those were the good old days", he said, when if the weather was good he and his friends would go camping out at Kalawao on the weekend. "No tents." They would just sleep in their cars, or put mattresses in the pavilion at Judd Park. The men would dive for fish. Then the women clean the fish and cook, and the men would drink up. They'd eat lots of food and have "good fun." With laughter he says, "Sometimes you had to tell the couples, 'No make noise!" Our research team was able to feel the happiness it still brings to patients to picnic at Judd Park in 2003 when our team was invited by KB and her best friend to share food and song there.

The Pali—Isolation and Connection

Standing 2,000 feet in vertical towering magnificence, the cliffs (or pali) that form the southern boundary of Kalaupapa Peninsula have been profoundly important in molding the experiences and shaping the collective consciousness of Kalaupapa residents and visitors alike. Over the past half century the pali itself has transformed from goat denuded barren crags, as seen in old photographs, into verdant mountainside. This physical change mirrors the gradual acceptance of the sentry-like mountain mass, once seen as *prison wall* and now seen more as a protector. Catherine Puahala speaks about the pali, recalling what she observed through her teenage eyes in 1942, and then describing how it has changed.

> *All I know is when we first come up on the boat, we just look at the mountain. It's just a long, long mountain because it starts from way down the other end, yeah. From the ground, then it starts to go up, up, up—and all we saw was dirt and kind of blue rocks, gray rocks. It didn't look nice at all—it was just barren. But today you look at it, it's green. It's green and it has trees. You know all the pine trees from the park up there? They're coming down to Kalaupapa. They're all on the side of the cliffs coming down. It's from the seed that grows. And soon some day they will be down to Kalaupapa alongside of the cliffs. The mountain is very beautiful. It was always beautiful, but there wasn't enough vegetation to make it look pretty and now there's lots of things growing.*
>
> Catherine Puahala (7/12/03 Int)

Pauline Chow was one of the last patients to take up residence in Kalaupapa in 1962. To her the pali was never a threat, and now she sees it as providing security against intrusion from the outside.

> *Well, when I first got here [1962], I thought it was a beautiful sight, but I'm pretty sure it wasn't for everybody. And back then, I guess it was more like a—maybe like a jail, I guess—in the sense, you know, it was inaccessible to the rest of the island. But I've come to admire that pali. I think it's beautiful. It's different so—and in a way it could prove to be a haven.* Pauline Chow (8/12/07 Int)

Historically, the pali made Kalaupapa a place of isolation for the patients, but it also was the means to connect Kalaupapa with the rest of Moloka'i, known to the residents of Kalaupapa as Topside. Three known trails became established up the pali.[14] Perhaps the most well known of these in early times was the 'Ili'ōlika'a trail, also referred to as Damien trail, that traverses the western ridge of Waihānau Valley to the towns above. Today this trail has been overgrown and is difficult to follow. The currently used trail which leads from the southeastern corner of Kalaupapa Peninsula is commonly called the Kalaupapa Trail today. The trail was built by 1889, although it likely follows the route of an even older trail. A third trail went up through Waikolu Valley.

Many of those who work at Kalaupapa live on Topside Moloka'i and climb up and down the pali trail regularly between home and work. Their relationship with the mountain is quite different from that of the patients who stay at Kalaupapa. Climbing for three miles around twenty-six switchbacks can be an arduous and deeply personal journey. Marco is a young Hawaiian worker who says that for him the pali trail is the most significant aspect of the Kalaupapa landscape. He implies that just as the trail is exacting physically, so too is the responsibility weighty that he accepts to be a worthy intermediary, and a guardian for the knowledge shared by Kalaupapa *kupuna*.

> *For a lot of people, as you come down the trail you seem to enter a different time. It provides a transition between two worlds that you have to live in. Traveling the trail at times is hard, strenuous and trying. On the trail you are reminded that you have relationships in two worlds. You play different roles in each place--one of the communities is slow, the other is faster in pace. Living in these two worlds is tough on families. They do it as a sacrifice to work. But the reward is having fellowship with people in Kalaupapa. The experience helps one adjust to different environments and people Topside look to you as a source of information and as a guide. You can't treat that responsibility lightly since it is important that you represent Kalaupapa as a kokua.*
>
> Marco Jordan (6/8/05 Int)

Figure 33. Pali trail with mule train.

Patients were forbidden to take the trail to Topside during the days of segregation, but they nevertheless have many stories of "sneaking out" for a day or two during that period. Some even took a plane to another island. Frequently their escape was noted and when they returned they were punished by being put in the Kalaupapa jail for a while. The following story was written down from Clarence Nara (quotations are in italics).

> Nara said he once sneaked out Topside from Friday to Sunday. *My 'brother' was a released patient. He told me to come with him. That time I was clean, that's why.* He wore boots and long pants to cover his foot [where the disease showed]. They stayed with A.D., because he was related to him. On Sunday his cousin G.M. called a Filipino taxi driver to drive him to the trail. The driver got scared when he told him to drop him at the trailhead down to Kalaupapa, but the cousin lied and said Nara was in the Coast Guard, working at the lighthouse. Then he met another patient coming up as he was walking down.
> "*Where you came from?*" the other patient asked.
> "*Oh, my family just left [I walked them up the trail],*" said Nara.
> "*You bullshit.*"
> *[But] his own self was going up too.*"
>
> They locked you up if they caught you sneaking out. Then they would set a court date. The punishment was you couldn't leave on temporary release. *The workers from down here, if you met them Topside, they'd pretend they don't know you, they won't tell on you.*
>
> (2.08.02 hc)

For a long time, many Topside people have had connections to Kalaupapa. Many work there now or worked there before, or someone in their family worked there. (In 2002, 26 out of 60 workers at Kalaupapa were from Topside. See Table 5.) Others have a relative who lives at Kalaupapa or one who lived and died there. At the same time, many people who grew up Topside have told us that they weren't told much about Kalaupapa. Even the knowledge that a relative lived down at Kalaupapa might be hidden, as in this story told by a long time DOH worker.

> *I first came down here 1945 to visit my grandmother. I didn't know I had grandmother down here before that. I wondered why my mother always came down here, and I asked her and asked her. Finally she told me. It wasn't right to hide that. She was shame to tell me. Why? I was living down near Halawa. I took off and walked down the trail to Kalaupapa, without telling my family anything. I was 14 then, but I had a man's body already. So I was underage to visit Kalaupapa, but they didn't ask my age. I went to the hospital and asked where she lived. I went up to the house. She was shocked to see me. She looked bad – her arms all covered with sores – but I didn't care. I wasn't afraid of the sickness. She asked me to come eat with her. I ate out of the same bowl with her – poi and salmon, sardines. Then she gave me a burlap bag full of big cans to take back with me. I carried it up the trail – tied the mouth closed and hung it around my neck like a pair of saddlebags. I gave it to my father when I got back – he was happy – but I didn't tell where I got it from. They thought I must have stolen it. But*

> *my hānai mother suspected something 'cause that big kind can only comes from down here those days. Up here we only had the small kind can. She told me, "Boy, did you go down Kalaupapa?" I asked, "If I tell you the truth you going beat me?" "No, but I will if you lie." (I could take away her whip and handle her already then, but I'd be shame to do that.) So I told her. Then they feast up on the canned goods. They were happy.*
>
> (Douglas fieldnotes, Barney Kaauwai, 8/10/02)

Some Kalaupapa patients feel that there are still people who live Topside who fear contagion from Hansen's Disease and they still feel stigmatized there. The cost of this alienation is reflected in the following text:

> *But you know when we go Topside, they give us the eye. They give us the eye like to say, "Who are you? You don't belong up here." They're scared of us yet. Only the guys who come down here constantly are not afraid of us. Like the kokua boys, they not scared of us.*
>
> *Yeah. And then we go to the restaurant, we get the cold shoulder by everybody. They just look at us like they like telling us, "How come you folks look like that? You folks shouldn't be up here." But we have rights now. So if they don't like us to go in the restaurant, we can charge them. We just go the lawyer and charge them. We have rights. Doctor said we can go around, we can go around.*
>
> *Some of them work in the kitchen before. When we go up the store, we see them and say, "Hi." They give me one good look. They are like the people know that they know us and yet they work down here. Oh, I feel so cheap. And I talk to my other friends and I say, "You see that. I guess they scared."*
>
> *And if they see you coming up the road, they duck in some place so they don't have to say hello to you. They don't want people to see that they know us. They scared.* (Catherine Puahala 17/12/02 Int)

Overcoming the feeling of alienation from the place and people Topside is not easy; yet many are ready to demand acceptance from Topside, as stated by a patient who lived for many years Topside and then returned to Kalaupapa:

> *I feel free now. People have to accept me for what I am. When I went up to [H.'s] funeral, I stood up for her and talked. And I said, "I am from Kalaupapa. And I know [H.] because I worked with her." I feel free to say I'm from Kalaupapa now, and if people don't like it, that's their problem.* Katherine Costales (8/30/04 Int)

Chapter 6. Conclusion: Kalaupapa and Its Future

The life of Kalaupapa Settlement has changed over the years since its founding around 1890 when the people were moved there from Kalawao. Prior to the 1940s patients were sent to Kalaupapa to wait for death. By the late 1960s, however, the disease had been brought under control by the sulfone drugs and the community, consisting mostly of patients, had a thriving social life. From the 1980s on, the kokuas — who now included the NPS workers in addition to the DOH workers — came to play an increasingly important role in maintaining the social life of the community as the patients aged. That is the Kalaupapa community that we observed, one where patients and kokuas interacted freely. The motivations of the kokuas for working at Kalaupapa vary, but many of them dedicate themselves in their own way to serving the patients. Some work as nurses or housekeepers, some help put together community parties, others share fish that they catch or play music for the parties.

To the extent that Kalaupapa has a unique culture, it inheres in the patient culture formed as a result of the conditions under which patients lived prior to the introduction of the sulfone drugs in the late 1940s. Living with the misery of Hansen's disease and with the expectation of death in a few years led the patients to a high degree of religious commitment, one still observed among them today. Some prayed that God might heal them, others for life after death when death seemed inevitably near. The humiliation that patients experienced from the staff during those years and the operation of the segregation rules created a bond of solidarity among them and differentiated them from the workers, resulting in the social categories patient and kokua which remain important to this day. The stigmatization that patients experienced at Kalaupapa and when they first went outside in the 1970s, as well as their long isolation at Kalaupapa, led them to feel uncomfortable outside. These experiences led them to decide to stay at Kalaupapa even after they were allowed to leave. All of these cultural characteristics are shared by the patients, but generally not by the kokuas. The isolation of the patients from their children, who were taken from them at birth, is probably the reason for the extraordinary care that patients lavish on their pets and even on wild animals. This characteristic is shared by a number of the kokuas.

With the end of patient isolation as the sulfone antibiotics rendered their disease inactive, the patients began to assert the right to participate in decisions that affect them. Part of this new patient activism was that they came to realize a sense of entitlement to Kalaupapa, to feel that they were owed for having been incarcerated there. Makia Malo spoke for all the patients when he said, "We paid for this land. The shame, the abandonment, the exile: we paid for this place." This sentiment led to the patients' sense of priority over the kokuas, to their refusal to accord them an equal place at Kalaupapa and to their anger when they feel disadvantaged relative to the kokuas. In turn many of the kokuas have absorbed the feeling that the patients should be privileged.

Other cultural characteristics of Kalaupapa are shared by the patients and by many kokuas, because they are common to those who grew up in Hawai'i. The value placed on helping the community at Kalaupapa — by putting on community events and by sharing fish — was brought to Kalaupapa by both patients and kokuas who grew up in local communities in Hawai'i. Likewise, both patients and local kokuas brought with them an awareness of the world of spirits. Stories of encounters with spirits of deceased patients are often told. These characteristics often get absorbed too by kokuas from outside Hawai'i after they live at Kalaupapa.

The patients' identities are intimately tied to Kalaupapa. As they become older and their numbers diminish, they are concerned about losing the community they have helped to shape. One of their concerns is that they are more and more outnumbered by non-patients at Kalaupapa. In 2002, Paul Harada said, "We're overwhelmed with workers already." That is exacerbated by the fact that many of the patients are too old to be very active, so they play less of a role in what goes on at Kalaupapa. Of the 21 patients still at Kalaupapa, there are only five in the youngest cohort, aged 65-70. Only a few patients are still active in the work of the community or participate in community meetings. A related concern is the loss of important community activities outside of work. There are few people to keep up the round of parties and competitions that once made Kalaupapa a lively place for them. Some of the kokuas are dedicated to helping put on those community events, but not all the kokuas get involved. There are fewer events now and they are smaller affairs. The slowed pace of social life in the settlement led Catherine Puahala to remark in summer 2006, "This place is dead."

The declining number of patients creates an even more critical situation in regard to the three churches, since few of the kokuas attend church at Kalaupapa. At our last visit in December 2007, the Mormon congregation was not meeting at all because there were no patient members left in the settlement. The congregations of the Catholic and Congregational Churches were still meeting, but both were very small. The weekday mass at the Catholic Church drew only three patients and one non-patient, down from nine patients and one non-patient in 2002. At Christmas time, 2007 there were only three members to decorate the church, and they found it difficult. When Father Joseph Hendricks had to retire in 2006 due to ill health, the congregation feared they would be left without a permanent priest. Luckily, a new priest was eventually found. The Congregational Church has only three patient members left to attend Sunday service, although three kokuas also attend regularly. The church no longer has a minister and the members take turns leading the service.

Underlying the patient concern that they are dwindling in number is their fear that the state will end its support for keeping them at Kalaupapa when their number gets smaller still. What will happen when there are only ten patients left at Kalaupapa, or five or one? The patients feel that the state still owes them a debt to repay by maintaining them at Kalaupapa. The non-profit group Ka Ohana o Kalaupapa may play a crucial role in advocating for the patients as they become too few and too infirm to do that for themselves, ensuring that the State and the Park Service carry out their obligations to the patients to support them so long as there are any patients left at Kalaupapa. Equally important to the patients as they near the end of their lives is where they will die. All of those we talked to want to die and be buried at Kalaupapa. Usually they are taken to Hale Mohalu for medical care when they have a serious or terminal illness, and several have been brought back just before their death. It is important to the patients to be able to return to Kalaupapa early enough to die there with grace and dignity.

When the last patient is gone, the State Department of Health which now cares for them will depart, leaving the National Park Service as sole management authority.

That may bring new problems for the Park Service. Hawaiians from Topside Moloka'i have told us that they are biding their time until the last patient is gone, and then they will agitate to take Kalaupapa back for Hawaiians to use. It must be remembered that the western third of the peninsula belongs to the Department of Hawaiian Home Lands and its lease to the park will soon run out. The DHHL could give in to that pressure and establish a new management plan for their land at Kalaupapa instead of renegotiating the lease.

By and large, both patients and kokuas feel that the NPS should continue to care for Kalaupapa, and in a manner that acknowledges the suffering of the patients and honors their social life. Whatever entity manages Kalaupapa in the future, it will need to terms with the fact that much of the peninsula is a graveyard. Among the graves are those of Father Damien and Mother Marianne who may soon be beatified as saints. Kalaupapa is likely to become an increasing focus for religious pilgrimage once Father Damien and Mother Marianne are beatified, particularly the old settlement at Kalawao with the early churches and the grave of Father Damien and Bishop Home in Kalaupapa Settlement with the grave of Mother Marianne. The patients and their families, and those who come to Kalaupapa to venerate the saints, want assurance that the graves will be maintained as a lasting memory of their suffering. The whole of Kalaupapa needs to be maintained as a monument to Hawai'i's experience of Hansen's Disease. It is a place that offers healing for the families of patients. For some time to come there will still be family members of patients who come to Kalaupapa seeking to understand the life of parents and grandparents that they hardly knew.

Patients interviewed about what should happened at Kalaupapa when they are gone stated their concern that their story be told, emphasizing three themes. (1) the early settlement at Kalawao and Father Damien's role there. (2) how the patients suffered from Hansen's Disease and how the disease was treated with the sulfone drugs, and (3) patient life in the twentieth century Kalaupapa Settlement. The patients that we talked to revere Father Damien, and Mother Marianne as well. They did not know them personally, but this does not diminish their sense of gratitude to these "saints" who gave their lives to attend to the physical and spiritual needs of so many who were afflicted with Hansen's Disease. Many of the patients we spoke with want society to know how they suffered from Hansen's Disease. They suffered physically from the disease and psychologically from their social segregation. Although the patients thought that visitors "should remember the suffering and sadness that people had to bear" at Kalaupapa, they also felt the visitors should learn that not everything at Kalaupapa was filled with pain and suffering and that they should also feel the serenity of the place as it is today.

As we came to the end of our work, many patients told us of their concern to have their story told. Makia Malo mentioned several times in his interviews that he feels a responsibility to tell his stories on behalf of his younger brother and all the other patients who died young, before the sulfone drugs could save them. Gloria Marks (Chair of the Patient Advisory Committee) kept after us, asking when the report would be done. "Don't wait until all the patients are gone," she would say. Sometimes patients expressed concern about who will be at the park to tell their story and what their perspective will be.

> *So how do they get the mana [spirit]? How do they get the feeling? That's what they need. That to me is important.* Ku'ulei Bell (7-16-02)

> *'Cause we [patients] the one here, that makes Kalaupapa unique. The one I like, what most for me I feel, let's get the story. But why bring one mainlander come over here and tell the story, huh? I can't see that. That's stupid. I think we get enough of Captain Cooks already. I say that. I not against them, but you know, that's how I feel. The story, give em to the local people. I mean, you really have to stay here and feel the place, you know. And lot of these guys they come from different — everybody come from different ethnic groups, but, they not familiar with over here our way of living.* Boogie Kahilihiwa (6-25-03)

These statements represent patient concern about the story that will be told about them at Kalaupapa. The first expresses patient concern about the "feeling" of those who will tell their story, that they be able understand and express all the pain that the patients went through. The second argues that because the patients are local people from Hawai'i, those who tell their story need to understand the culture local to Hawai'i. They shouldn't be people who come from the outside without experience of living here. We believe that in the future, it will be crucial for park interpreters to "get the feeling" of the patients through their recorded words — their stories as documented in the oral history interviews done by Gugelyk and Bloombaum, by Anwei Skinsnes Law, and by us, the autobiographies written by patients Olivia Breitha and Henry Nalaielua, and a forthcoming documentary made by filmmaker Paul Cox.

The patients are concerned about the legacy they leave behind. One part of that legacy is the preservation of the structures where people lived and the graves where they are buried. Recently, the patients and Ka Ohana o Kalaupapa have worked to have a memorial created at Kalaupapa, a monument which would have the names of all the patients ever brought to Kalaupapa inscribed on it. During Spring 2006, the U.S. Congress authorized the installation of the monument. More revealing than this physical legacy, however, is the record of the lived experiences told by the patients and the kokuas who serve them. This report is a part of that story, part of the record of their life — the suffering of the patients in the early years, the care of the kokuas for them, and the creation by the patients of a unique culture adapted to their disease and to their isolation at Kalaupapa.

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Appendix 1: Public Law 96-565

An Act
Dec. 22, 1980
To establish the Kalaupapa National Historical Park in the State of Hawaii, and for other purposes.
[H.R. 7217]

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SEC. 101. In order to provide for the preservation of the unique nationally and internationally significant cultural, historic, educational, and scenic resources of the Kalaupapa settlement on the island of Molokai in the State of Hawaii, there is hereby established the Kalaupapa National Historical Park (hereinafter referred to as the "park").

SEC. 102. The Congress declares the following to constitute the principal purposes of the park:

(1) to preserve and interpret the Kalaupapa settlement for the education and inspiration of present and future generations.

(2) to provide a well-maintained community in which the Kalaupapa leprosy patients are guaranteed that they may remain at Kalaupapa as long as they wish; to protect the current lifestyle of these patients and their individual privacy; to research, preserve, and maintain the present character of the community; to research, preserve, and maintain important historic structures, traditional Hawaiian sites, cultural values, and natural features; and to provide for limited visitation by the general public; and

(3) to provide that the preservation and interpretation of the settlement be managed and performed by patients and Native Hawaiians to the extent practical, and that training opportunities be provided such persons in management and interpretation of the settlement's cultural, historical, educational, and scenic resources.

SEC. 103. The boundaries of the park shall include the lands, waters, and interests therein within the area generally depicted on the map entitled "Boundary Map, Kalaupapa National Historical Park", numbered P07-80021, and dated May 1980, which shall be on file and available for public inspection in the local and Washington, District of Columbia offices of the National Park Service, Department of the Interior. The Secretary of the Interior (hereinafter referred to as the "Secretary") may make minor revisions in the boundary of the park by publication of a revised boundary map or other description to that effect in the Federal Register.

SEC. 104. (a) Within the boundary of the park, the Secretary is authorized to acquire those lands owned by the State of Hawaii or any political subdivision thereof only by donation or exchange, and only with the consent of the owner. Any such exchange shall be accomplished in accordance with the provisions of sections 5(b) and (c) of the Act approved July 15, 1968 (82 Stat. 354). Any property conveyed to the State or a political subdivision thereof in exchange for property within the park which is held in trust for the benefit of Hawaiians (as defined in the Hawaiian Homes Commission Act of 1920) shall, as a matter of Federal law, be held by the grantee subject to an equitable estate of the same class and degree as encumbers the property within the preserve and "available lands" (defined in section 203 of the Hawaiian Homes Commission Act) may be exchanged in accordance with section 204 of said Act. The vesting of title in the United States to property within the park shall operate to extinguish any such equitable estate with respect to property acquired by exchange within the park.

(b) The Secretary is authorized to acquire privately owned lands within the boundary of the park by donation, purchase with donated or appropriated funds, or exchange.

(c) The Secretary is authorized to acquire by any of the foregoing methods except condemnation, lands, waters, and interests therein outside the boundary of the park and outside the boundaries of any other unit of the National Park System but within the State of Hawaii, and to convey the same to the Department of Hawaiian Home Lands in exchange for lands, waters, and interests therein within the park owned by that Department. Any such exchange shall be accomplished in accordance with the provisions defined in subsection (a) of this section.

SEC. 106. (a) The Secretary shall administer the park in accordance with the provisions of the Act of August 25, 1916 (39 Stat. 535), the Act of August 21, 1935 (49 Stat. 666), and the provisions of this Act.

(b)(1) With the approval of the owner thereof, the Secretary may undertake critical or emergency stabilization of utilities and historic structures, develop and occupy temporary office space, and conduct interim interpretive and visitor services on non-Federal property within the park.

(2) The Secretary shall seek and may enter into cooperative agreements with the owner or owners of property within the park pursuant to which the Secretary may preserve, protect, maintain, construct, reconstruct, develop, improve, and interpret sites, facilities, and resources of historic, natural, architectural, and cultural significance. Such agreements shall be of not less than twenty years duration, may be extended and amended by mutual agreement, and shall include, without limitation, provisions that the Secretary shall have the right of access at reasonable times to public portions of the property for interpretive and other purposes, and that no changes or alterations shall be made in the property except by mutual agreement. Each such agreement shall also provide that the owner shall be liable to the United States in an amount equal to the fair market value of any capital improvements made to or placed upon the property in the event the agreement is terminated prior to its natural expiration, or any extension thereof, by the owner, such value to be determined as of the date of such termination, or, at the election of the Secretary, that the Secretary be permitted to remove such capital improvements within a reasonable time of such termination. Upon the expiration of such agreement, the improvements thereon shall become the property of the owner, unless the United States desires to remove such capital improvements and restore the property to its natural state within a reasonable time for such expiration.

(3) Except for emergency, temporary, and interim activity as authorized in paragraph (1) of this subsection, no funds appropriated pursuant to this Act shall be expended on non-Federal property unless such expenditure is pursuant to a cooperative agreement with the owner.

(4) The Secretary may stabilize and rehabilitate structures and other properties used for religious or sectarian purposes only if such properties constitute a substantial and integral part of the historical fabric of the Kalaupapa settlement, and only to the extent necessary and appropriate to interpret adequately the nationally

significant historical features and events of the settlement for the benefit of the public.

SEC. 106. The following provisions are made with respect to the special needs of the leprosy patients residing in the Kalaupapa settlement:

(1) So long as the patients may direct, the Secretary shall not permit public visitation to the settlement in excess of one hundred persons in any one day.

(2) Health care for the patients shall continue to be provided by the State of Hawaii, with assistance from Federal programs other than those authorized herein.

(3) Notwithstanding any other provision of law, the Secretary shall provide patients a first right of refusal to provide revenue-producing visitor services, including such services as providing food, accommodations, transportation, tours, and guides.

(4) Patients shall continue to have the right to take and utilize fish and wildlife resources without regard to Federal fish and game laws and regulations.

(5) Patients shall continue to have the right to take and utilize plant and other natural resources for traditional purposes in accordance with applicable State and Federal laws.

SEC. 107. The following provisions are made with respect to additional needs of the leprosy patients and Native Hawaiians for employment and training. (The term "Native Hawaiian" as used in this title means a descendant of not less than one-half part of the blood of the races inhabiting the Hawaiian Islands previous to the year 1778.)

(1) Notwithstanding any other provision of law, the Secretary shall give first preference to qualified patients and Native Hawaiians in making appointments to positions established for the administration of the park, and the appointment of patients and Native Hawaiians shall be without regard to any provision of the Federal civil service laws giving an employment preference to any other class of applicant and without regard to any numerical limitation on personnel otherwise applicable.

(2) The Secretary shall provide training opportunities for patients and Native Hawaiians to develop skills necessary to qualify for the provision of visitor services and for appointment to positions referred to in paragraph (1).

SEC. 108. (a) There is hereby established the Kalaupapa National Historical Park Advisory Commission (hereinafter referred to as the "Commission") which shall consist of eleven members each appointed by the Secretary for a term of five years as follows:

(1) seven members who shall be present or former patients, elected by the patient community; and

(2) four members appointed from recommendations submitted by the Governor of Hawaii, at least one of whom shall be a Native Hawaiian.

(b) The Secretary shall designate one member to be Chairman. Any vacancy in the Commission shall be filled in the same manner in which the original appointment was made.

(c) A member of the Commission shall serve without compensation as such. The Secretary is authorized to pay the expenses reasonably incurred by the Commission in carrying out its responsibilities under this Act on vouchers signed by the Chairman.

(d) The Secretary shall consult with and seek the advice of the

Commission with respect to the development and operation of the park including training programs. The Commission shall, in addition, advise the Secretary concerning public visitation to the park, and such advice with respect to numbers of visitors shall be binding upon the Secretary if the Commission certifies to him that such advice is based on a referendum held under the auspices of the Commission of all patients on the official Kalaupapa Registry.

(g) The Commission shall expire twenty-five years from the date of enactment of this Act.

SEC. 110. At such time when there is no longer a resident patient community at Kalaupapa, the Secretary shall reevaluate the policies governing the management, administration, and public use of the park in order to identify any changes deemed to be appropriate.

SEC. 111. Effective October 1, 1981, there are hereby authorized to be appropriated such sums as may be necessary to carry out the purposes of this title but not to exceed $2,500,000 for acquisition of lands and interests in lands and $1,000,000 for development.

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[1] Cerny did ethnographic work at Kalaupapa prior to the beginning of the Kalaupapa Ethnographic Project (See Cerny 2001). At the time we began the project, she facilitated our initial orientation to community life and she intended to continue working with us in carrying out the project. She was unable to continue, however, as she was soon hired as cultural anthropologist at the Park, and subsequently as chief of cultural resources.

[2] As we were once told by Makia Malo (Douglas fieldnotes 3/22/05) the model for Kalaupapa was a penal system and the patients were prisoners. Running away was a crime and the patients were not allowed to have guns. See also the description of daily life as incarceration by Henry Nalaielua (2006:19). Many patients told us that when they were first allowed to leave on temporary release when the sulfone antibiotics had made their sickness inactive it was referred to as "parole."

[3] Initially Jason worked with Jennifer Cerny on the cultural landscape research.

[4] "Kalaupapa Settlement" is used in three different ways. Before the creation of Kalaupapa National Historic Park, the term was used by the state for the whole peninsula and the adjoining valleys to the southeast. To older patients the "Settlement" is the town area where the patients have their houses, not including the beach house area to the north (Douglas fieldnotes, Catherine Puahala). In this report we call this the "Settlement proper." In DOH regulations, the term "Settlement" covers a larger area including the town, the beach house area and the road to the airport as far as the cattle guard before the lighthouse.

[5] Kalaupapa National Historic Park also includes the offshore waters out to one quarter mile. These waters are not part of Kalawao County. As for Nihoa, it was never part of Kalawao County, but it was informally part of Kalaupapa in the sense that the patients used it for fishing prior to the establishment of the Park. It is only accessible from Kalaupapa, not from Topside Molokai.

[6] Internally, this stretch which seems to be a single graveyard is composed of 15 individual cemeteries holding roughly 1200 graves. Some of the cemeteries are specific to a particular ethnic group or religion.

[7] Law and Wisniewski (1988:11-20).

[8] Law and Wisniewski (1988:27, 44, 49).

[9] For details on Damien's ministry, see Daws (1973) and Law and Wisniewski (1988).

[10] Quoted in *Damien: Servant of God and Humanity* (1974:19).

[11] Hanley and Bushnell (1980:69-72).

[12] Greene (1985:[illegible]).

The modern understanding of Hansen's Disease (Britton and Lockwood 2004; de Vries and Ottenhoff 1994) seems to be this. The bacterium that causes the disease can be transmitted to some unknown percentage of the population who become infected but never show symptoms of the disease, because the bacteria themselves are "virtually nontoxic." Disease symptoms are not caused by the action of the bacteria, but rather by an "immunopathology" in which antibodies that develop as part of the immune system reaction to the bacteria cause harmful inflammation. Only about 5% of the world's population have an immune system that reacts by causing inflammation. The severity of the symptoms depends on the genetic constitution of the individual, which determines both how much the bacteria multiply in the body and how much the immune system reacts.

[14] A policy of "paroling" patients who showed "improvement" in their case of Hansen's disease had already been instituted in 1912 (Hasseltine 1973:12-15). The paroled patients were required to report to a physician periodically for examination to assure that the disease was inactive. Eventually they could apply for a complete release. Approximately 30% of those put into segregation during 1912 to 1921 were released. About one third of those released were later found to be active cases and they were segregated again. Probably those who were paroled and later found inactive had a self-limited form of Hansen's disease called "tuberculoid," as opposed to the progressive form called "lepromatous." The tuberculoid form is thought to occur in individuals with greater resistance to the disease and there is often spontaneous healing. See Gugelyk & Bloombaum (1979:6-7).

[15] Anwei Skinsnes Law (1984:88, 188-194).

[16] Gugelyk and Bloombaum (1979:3).

[17] Law & Wisniewski (1988:49).

[18] 1961 Board of Health Annual Report.

[19] The census for 1965 is shown on a photo of the Kalaupapa Settlement entrance sign. The photo is in the possession of one of the patients.

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[20] Figures are taken from the Annual Reports of the Hawaii State Department of Health, Statistical Supplement, except for 1940, 1946, 1965 and 2000. The 1940 figure of "about 400" was given by several patients who came in 1940 or 1942. The 1946 figure comes from Gugelyk and Bloombaum (1979:17). The 1965 figure is taken from a photo of the 1965 entrance to Kalaupapa sign, which gives the 1965 census. The 2000 figure comes from Dean Alexander, then the park superintendent (pers. comm., Dec 1999).

[21] Richard Marks in Anwei Skinsnes Law (1985-87, 7:34-6); Sister Richard Marie Toal in Anwei Skinsnes Law (1985-87, 2:32-36); Joe Mollena Interview 3; John Morley Interview 1:9; Boogie Kahilihiwa Interview 1:4

[22] Among the many sources for the segregation rules in effect at Kalaupapa from the 1930s to the 1960s, the most important are the interviews by Anwei Skinsnes Law (1985-87 2:3-6, 2:32-37, 28:53), Judd's autobiography (1971:264-65) and Interview 3 with Joe Mollena carried out for this project.

[23] Breitha (1988:25)

[24] Judd (1971:264)

[25] Robert Worth Interview, pp. 7-8, in Anwei Skinsnes Law (1988-89)

[26] Gloria Marks Interview 1:18

[27] Randall Watanuki Interview 1; Joe Mollena Interview 3:6; Catherine Puahala Interview 2:4

[28] "John Morley" Interview 2:4; Boogie Kahilihiwa Interview 1:4

[29] Randall Watanuki Interview 1

[30] Lucy Whiting Interview 1:3

[31] Randall Watanuki Interview 1; Joe Mollena Interview 1:44

[32] [illegible] 1991; Joe Mollena Interview 3:1

[33] Gugelyk and Bloombaum (1979:103)

[34] Breitha (1988:57)

[35] Gugelyk and Bloombaum (1979:109-120)

[36] Anwei Skinsnes Law (1984-85:12A-12)

[37] Anwei Skinsnes Law (1984-85:12A-17)

[38] Patsy Mink Interview, p. 2, in Anwei Skinsnes Law (1988-89)

[39] Anwei Skinsnes Law (1985-87, 6:15-16)

[40] Patsy Mink Interview, p. 5, in Anwei Skinsnes Law (1988-89)

[41] The Pacific Cooperative Studies Unit is a division of the Research Corporation of the University of Hawai'i. It administers contracts from the National Park Service to perform research activities at national parks in Hawai'i.

[42] Mike McCarten Interview, 8-7-01

[43] Based on interviews with long-term employees at Kalaupapa National Historical Park

[44] Anwei Skinsnes Law (1985-87, 6:17)

[45] Gugelyk and Bloombaum (1979:17)

[46] Sources for the nineteenth century indicate that there were more than one hundred kokuas at Kalaupapa in the 1870s and 1880s, out of a total population of about seven hundred (BOH Minutes for November, 1875; Mouritz 1916:141-155). A 1905 law relating to kokuas at Kalaupapa is reproduced in Mouritz (1916:403-15), making it clear that kokuas were still being allowed to go to the settlement at that time. It is not clear exactly when the policy was changed that allowed spouses to accompany patients to Kalaupapa, but certainly it had been changed by 1938, the time when the first patients we interviewed came to Kalaupapa. According to one of our patient interviewees, there was in 1960 still a woman living at Kalaupapa who had originally come to Kalawao with her patient husband during the nineteenth century.

[47] Grace Sasada Interview 1:6

[48] Gloria Marks Interview 1:28; Randall Watanuki, personal communication

[49] Anwei Skinsnes Law (1985-87, 2:12-13)

[50] Anwei Skinsnes Law (1985-87, 27:7-8)

[51] BJ Reed Interview 1:7-8; Langlas fieldnotes, 6/02

[52] BJ Reed Interview 1:7; Dean Alexander, personal communication, December 2000

[53] Boogie Kahilihiwa Interview 1:6

[54] Lucy Whiting Interview 1:1

[55] Lucy Whiting Interview 1:16

[56] Clarence Naia Interview 2:11; BJ Reed Interview 1:4

Randall Watanabe Interview 1

McGuire fieldnotes, June 2002

Interview with State worker [illegible]

One of the three individuals spends almost half of his time at Kalaupapa. The other two visit only briefly. Many other individuals who were once on the Kalaupapa Registry have left Kalaupapa to live outside. They voluntarily went off the registry and have no house at Kalaupapa. A patient told us that some of them regret having gone off the registry because the state provides for their health care at a lower level than it does those who are on the registry.

Bloombaum and Gugelyk (1970) 17 n.11

Gugelyk and Bloombaum (1979) 105

It is clear that Native Americans and Pacific Islanders experienced catastrophic population declines due to the introduction of Eurasian diseases which had much less effect in Europe and Asia where they had been known for centuries. One reason for the marked population decline among Native Americans and Pacific Islanders was that they had developed no immunities to contagious diseases such as measles and small pox. Epidemiologists have also argued that the greater genetic homogeneity of Native Americans and Pacific Islanders was a cause for the introduced diseases to be more virulent among them (Black 1992).

Letter from [illegible] to Yoshinaga, 1957

Board of Health Report for 1961

Julie Segler Interview 1: 13

Paul Harada Interview 3: 5

Anwei Skinsnes Law (1985-87: 30-4)

Ellen Storm Interview 1: 5

Paul Harada Interview 1: 1

Paul Harada Interview 1: 1

Katherine Costales Interview 3: 2

Nancy [illegible] Interview 1; Joe Mollena Interview 3: 4

Paul Harada, Interview 3: 5

"John Manley" Interview 2; Paul Harada Interview 3: 4

Kahuler Hell (personal communication, 7-2005) spoke of the inactivity of the commission as of 2001, stating that the commission had not met in years. She later spoke of the revival of the commission (Kahuler Hell, personal communication 1-3-2004), saying that the push to revive it came from U.S. Senator for Hawai'i Daniel Inouye. According to the enabling legislation which mandated the commission, the terms of the commission members should actually have expired by 2003, and the commission itself was to go out of existence in 2005.

Eva Judd Interview, pp 31-37; Robert Bond interview [illegible] in Anwei Skinsnes Law (1988-89).

Administrative rules are subject to public notification and hearing before they are promulgated.

Mike McCarren Interview 5: 7-10

We polled twenty-five of the patients in 2005. Fifteen patients were clearly against allowing children in the settlement. Seven were uncertain or contradictory in their opinion. Only three were definitely in favor of lifting the restrictions on visiting by children.

Randall Watanabe Interview 2: 5-7 (2001), Boogie Kahilihiwa Interview 1: 1 (2001)

In May 2005 there was a threatened legal challenge to the rule against children visiting and during Summer 2005 the policy on visitation by children of workers was unclear. A 1996 prohibition was re-instated in December 2005 (Kahuler Hell, personal communication 12-2-05).

See Greene (1985) for an in-depth exploration of this topic.

As of June 2005, draft guidelines had been given to the Patient Council for approval. The Council agreed that the NPS might use the draft guidelines for the present.

Letter from Acain to Lewin 1981

"John Manley" Interview 1: 11; Auditor's Report, p. 17

Randall Watanabe Interview 2: 5; Boogie Kahilihiwa Interview 1: 1; McGuire fieldnotes, 4-02; Auditor's Report p. 15

Joint Hearing of the Hawai'i State House and Senate Committees on Health, 1-27-04

Ohana Steering Committee letter, Jan. 2004

The characterization of the community meetings in this paragraph is based on the minutes of the meetings held between April 2004 and April 2005.

See Ms. Law's comments in Judd p.14; Worth p.11; Anwei Skinsnes Law 1985-89.

"Local culture" refers to the culture learned through growing up in Hawai'i, which derives both from Hawaiian culture and the common heritage shared by the ethnic groups who lived together in plantation camps. The most obvious marker of local culture is the ability to speak pidgin. To a considerable extent haoles in Hawai'i, both recent arrivals and long-resident families, have remained aloof from local culture. Often they do not speak pidgin, even if they grew up here.

See also ASL 1985-87, 21:14 for a statement about how everyone helped put on parties in 1985. Earlier the population was larger and many parties were not community-wide, so a smaller group might put on the party, but the same general ideal held that everyone in the group should help. Thus, Henry Nalaielua (2006:51-52) describes parties put on by Baldwin Home in which all the able-bodied residents of Baldwin Home pitched in to prepare the food.

Edwin Marks Interview 1:16; see also Mouser (1998)

Charlotte LaCross Interview 1:2

Anwei Skinsnes Law (1985-87, 31:15)

Shannon Crivello Interview 1:1

Linnekin (1985:8); Douglas (2000:80)

Catherine Puahala Interview 1:8; Boogie Kahilihiwa Interview 1:5

See Linnekin 1985:142-47)

Paul Harada Interview 1:2

Patient A Interview 1:11

Julie Sigler Interview 1:22; Clarence Naia Interview 1:1; Kuulei Bell Interview 5

Julie Sigler Interview 2:12

Clarence Naia Interview 1:3; Kuulei Bell Interview 5

Paul Harada Interview 3:17

Douglas Fieldnotes, Parent "George" 7 July 2004

See Gugelyk and Bloombaum 1979:38-41

Anwei Skinsnes Law (1985-87, 2:16)

Sussman (2003)

In the summer of 2003 there were eight. As of 2005, two have stopped coming to morning mass. One of them says she has become too disabled to make the trip every morning.

Ivan Rygaard Interview 1:13-14

Charlotte LaCross Interview 1:4

Katherine Costales Interviews 1:3 and 4:8

Fr. Austin Schwind Interview 2:6-7; Katherine Costales Interview 2:3

Charlotte LaCross Interview 1:4; Julie Sigler Interview 1:2

Henry Nalaielua Interview 2:15; Paul Harada Interview 2:20

Fr. Austin Schwind Interview 1:3

Fr. Austin Schwind Interview 1:2

Julie Sigler Interview 1:6

All of these interviews were done anonymously, so the names of the interviewees are not given here.

Makia Malo Interview 1 tape 2:6

Joe Molleda Interview 1:45, 3:4-7. He left Kalaupapa in 2006 to live with his grandchildren on Maui. It was difficult for him to make the decision to leave, but he knew that he was getting too old to keep working as a volunteer doing maintenance work for the state.

This cultural landscape imagery reflects sequential occupancy of the land and includes some elements from the pre-Hansen's disease settlement era, such as house lot and garden structures which date from prior to 1850. Such elements maintain their cultural significance to the Native Hawaiians who have numerically dominated the Hansen's Disease population at Kalaupapa up to today.

On the closure of the group home dining rooms, see Catherine Puahala Interview 2:5-4. Cooking for the patients in the homes had been centralized much earlier, when Lawrence Judd was the administrator (Anwei Skinsnes Law 1985-87, 27:17).

The NPS recognizes the value of Paschoal Hall to the Kalaupapa community. At the time this report was written, funding for the restoration of Paschoal Hall had been won, but the park management has

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submitted a funding proposal for the completion of the hall's interior, with a priority second only to repairs needed to the pier structure. The pier is essential for the annual barges to supply Kalaupapa (Jennifer Cerny, personal communication, March 2005).

Manuel Gomes Paschoal (1916-1956) was a Republican member of the Hawaii Territorial House of Representatives. He was House Speaker from 1945-1948 (Sharp and Sharp 2007:211). Paschoal Hall was named for him in 1953 because he championed the rights of the Kalaupapa patients in the territorial legislature (Greene 1985:591). See also Boogie Kahilihiwa Interview 3:55.

During the period when Lawrence Judd was the Kalaupapa Administrator from 1947-49, he arranged for famous entertainers to fly in to Kalaupapa and entertain at Paschoal Hall, including singer Dennis Day and actress Shirley Temple (Makia Malo Interview 2; tape 6:13-14).

Boogie Kahilihiwa Interview 3:5.

Randall Watanuki Interview 3:14; Albert Pu Interview 1.

Brown et al. (1997) indicate that a 1991 directory to the grave markers at Papaloa identified 1,327 graves. But bearing in mind that the April 1, 1946 tidal wave destroyed many headstones, this directory may grossly underestimate the number of burials in the area at the time. Since 1946 nearly all burials have taken place at Papaloa.

This figure of 8000 patient graves at Kalaupapa is an estimate based on the number of patients listed in the admission register, some 5000 before 1895 and some 3000 after (Personal communication from Anwei Law to Jennifer Cerny, 6/17/2005). The number is not precise since some patients were given more than one admission number. The number of graves would also be somewhat less than the number admitted since some patients were released and [illegible] died outside Kalaupapa even before 1969.

Only one of the many cemeteries between the airport and Kalaupapa Settlement is formally given the name Papaloa Cemetery.

William K. Notley worked at Kalaupapa as an assistant under the resident superintendent of Kalawao Settlement Ambrose Hutchinson (Personal communication from Anwei Law to Jennifer Cerny 6/17/2005). Hutchinson served as superintendent from 1884 to 1897. Notley was growing taro in Waikolu Valley at the end of the nineteenth century. His name was given to Notley Springs in the valley and later to Notley Dam, which was built there as part of the water system to supply Kalaupapa.

See Makia Malo's tape, *Tales of a Hawaiian Boyhood, Vol. 1: The Kalaupapa Years.* The last part of the tape has a story called "The Picnic" about a typical picnic at Judd Park. In the morning the old folks talk story and play cards, while the younger guys drink and play ukulele. Later the younger boys play volleyball, then they have a tug of war with 30-50 on each side. Then they have lunch. After lunch, the younger ones go swimming in "Mormon Pond," a tide pool below the pali.

Two trails, the currently used trail and the one which leads up the western edge of the Waihanau Valley, are shown on the 1906 map, "United States Geodesy Station Sites, traced from Govt. Survey Reg. Map No. 1725, by F.E. Newton." A third trail leading up through Waikolu Valley was described by [illegible] (Interview 1:8). See Curtis (1991) for the name [illegible] and for the 1889 date for the currently used Kalaupapa trail.

The prejudices that Catherine Puahala vividly remembers among those who live on Topside Molokai has probably been eliminated now by understanding of the fact that Hansen's disease is no longer transmitted by those who take the sulfone antibiotics. Her lingering perceptions reflect the indelible impact that negative encounters have had on the psyche of Hansen's disease patients.