

MA'I HO'OKA'AWALE

The Separating Sickness

Ted Gugelyk
Milton Bloombaum



Interviews with Exiled Leprosy Patients at
Kalaupapa, Hawaii
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by Ted Gugelyk and Milton Bloombaum

Excerpts from interviews with exiled leprosy patients at Kalaupapa Settlement, Molokai, Hawaii, as part of the Social Aspects of Leprosy Research Project, University of Hawaii—Milton Bloombaum, Principal Investigator; Ted M. Gugelyk, Co-Principal Investigator.

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the Department and will contribute to the enlightened administration of the leprosy treatment program in Hawaii.

As stated in one of our preliminary publications concerned with a health policy question our research has touched on (the closure of Hale Mohalu Hospital in Honolulu over the strong objections of almost 90 percent of the Kalaupapa patients), "when it comes to the consideration of the social as opposed to the medical and/or physical care aspects of patient life, there is no special reason to believe that any non-patient's views . . . deserve greater consideration than the views of the patients themselves." (The Star, Vol. 37, No. 5, May-June, 1978).

In this collection of retrospective personal narratives, then, various patient points of view are expressed. Together, they give us a feeling of what it is like to be a leprosy patient in the Hawaii of 1978.¹

A Note about Leprosy--the Disease

Although leprosy has been recognized for over two thousand years, it was not found to be caused by a microorganism until 1873, by Dr. Gerhard Armauer Hansen. Leprosy, sometimes called "Hansen's Disease," is caused by *Mycobacterium leprae*, a member of the same family of organisms in which is found the cause of tuberculosis. It is a chronic communicable disease, thought to be transmitted directly from person to person, but only a small proportion of those exposed to an infectious case actually come down with the disease.

Leprosy is a disease of the peripheral nerves, but it also affects the skin and other tissues, especially the mucosa of the upper respiratory tract, the eyes, muscles, bones and testes. The two major forms of leprosy are called "lepromatous" (a progressive form in people with little resistance to it) and "Tuberculoid" (a self-limited form in those with more resistance). It is the Lepromatous form which causes skin lesions containing large numbers of bacteria, thus facilitating transmission of the disease to others. If left untreated, Lepromatous leprosy grows steadily worse, infecting internal

organs and the respiratory tract. Gross physical disfigurement also may occur in the advanced stages. The Tuberculoid form is more localized and benign, primarily affecting the skin and nerves. Here bacteria are sparse and present very little hazard in transmission. Usually spontaneous healing occurs in the tuberculoid form, but often with some permanent nerve damage. At Kalaupapa, older patients originally mandatorily confined with the tuberculoid form have attested to the spontaneous healing phenomenon. Because of this, some patients feel an error was made in the original diagnosis leading to confinement.

Among populations with some resistance to the disease developed through many generations of experience among Europeans and Asians, the tuberculoid form is more common. But among populations with little resistance, as among the Hawaiians of the 1800s, the more severe lepromatous form was usually contracted. It is estimated that ninety percent of the world's population has a natural immunity to the disease, and persons working with leprosy patients rarely contract the disease. But the disease does have a three to fifteen year incubation period before the first signs of it appear, and many afflicted patients claim no previous contact with known leprosy patients. It is thought that children are more susceptible to the disease than adults. Transmission often occurs within families, probably because in most societies children are most likely to be touched by relatives.

Since the 1940s, leprosy has been readily treated using drugs of the sulfone family. The disease can be "arrested" and patients rendered noncommunicable, therefore for those reasons isolation and confinement of persons with the illness is no longer necessary. Those who now remain in isolated places, like the patients at Kalaupapa, remain there by choice. But the seriousness of the disease and its effects are not past history. The World Health Organization estimates there are about fifteen million cases of leprosy worldwide, and less than twenty percent receive regular treatment.

Today, leprosy is found mainly in underdeveloped countries in Africa, Asia, Central and South America. In the United States, there are approximately three thousand known

cases, primarily in Texas, Louisiana, Florida, California and Hawaii. In the United States approximately 350 persons are treated at the U.S. Public Health Service Leprosarium at Carville, Louisiana. Carville is the only continental U.S. institution devoted exclusively to the treatment and research of leprosy. It was there that sulfone drugs were successfully introduced in 1941. In Hawaii, there are approximately 440 registered patients receiving treatment. Of these, about 128 of them are older patients at Kalaupapa, institutionalized before 1969, when the decision was made to do away with long confinement of treated lepromatous cases. The other 310 are tuberculoid patients, or new lepromatous ones, treated on an outpatient basis or in community hospitals. There are approximately thirty new cases of leprosy diagnosed in Hawaii each year, over 90 percent of whom are immigrants from Asia, Southeast Asia, and Pacific. The number of new cases found among Hawaii-born people is approaching zero.

Kalaupapa—The Community²

The residents remaining at Kalaupapa are vestiges of an international public health policy which physically and socially isolated people thought to be carrying the disease of leprosy (sometimes called Hansen's Disease--after Dr. G. Armauer Hansen, a Norwegian who discovered and isolated the mycobacterium leprae in 1873). Although Kalaupapa was established in Hawaii in 1866, other total institutions or leprosariums like Kalaupapa were established throughout the world. Compulsory segregation legislation was passed in Norway in 1885; in New South Wales in 1890; in Cape Colony, South Africa in 1892; in Japan in 1900; in Ceylon in 1901; and in Canada in 1906. In addition, two of the most famous leprosy colonies are Culion, in the Philippines, established in 1901; and Carville, established by the United States Public Health Service in Louisiana in 1894. Kalaupapa, then, may have been a kind of international public health model for the isolation and containment of the disease, and for those who carried it.

For thousands of years, however, victims of leprosy have been treated differently than those suffering from other

diseases. Historically and traditionally, isolation of leprosy persons was the norm. Some societies even killed leprosy victims, but most cast them off to some isolated mountain or island. Before the innovation of sulfone drug therapy in the 1940s, public health practices for dealing with the disease were not too different than those of centuries past. But in the 1800s the means for dealing with the disease became more formal. In Hawaii, and elsewhere, laws were established legally enforcing isolation of leprosy victims. "Laws touched upon marriage and divorce, estate and income taxation, claims against estates, absentee balloting, employment rights and State pensions of patients, fishing rights in waters off Kalawao, separation of infants from mothers, penalty for concealing persons with leprosy, rights and duties of kokuas (helpers), the oath of loyalty, the practice of medicine, the sentence of convicts . . . clearly, the legal, social and medical history of leprosy in Hawaii is an integral part of the historical fabric of the Islands."³

There is evidence early Hawaiians feared the Board of Health and mandatory isolation at Kalaupapa more than the actual affects of the disease of leprosy. Often, friends and family readily hid infected persons within households, rather than surrender them to a life of banishment at Kalaupapa. Yet, between the sixteenth and seventeenth centuries, a period of European exploration and colonization, Western governments were faced with the biomedical uncertainties of the etiology and epidemiology of a disease primarily endemic to non-Western people. Leprosy was envisioned as a foreign "non-white" disease--as strange and exotic as the newly contacted cultures. The early establishment of colonies like Kalaupapa may reflect an early social conception of the illness that is uniquely Western, and with instrumental functions as a defensive response. Governments feared a pandemic spread of leprosy throughout western territories and possessions. So, many "total institutions" like Kalaupapa were established.

Western attitudes toward the disease were affected by the biomedical uncertainties of its origin, spread, and cure. Perhaps leprosy was considered a disease of inferior people, and therefore associated with low standards of living. In

addition, biblical references to leprosy helped create a public conception of it with uncleanness and defilement. This taint of uncleanness and "moral impurity" gave a stigma to those unfortunates afflicted with leprosy and to the colonies to which they were sent.

There is evidence of cross-cultural differences regarding the degree of stigma associated with the disease. It was observed that "native Hawaiians possessed an absolute fearlessness and absence of any disgust for the disease in its worst form."⁴ Thus, the Hawaiian people feared the compulsory banishment and rough treatment by European and Hawaiian public health agents more than the disease itself. In fact, there was a high rate of intermarriage between the Hawaiians and the Chinese, who had given them the "Mai Pake" or the Chinese sickness. Also, "in countries where leprosy is highly endemic, stigma is not necessarily pronounced, whereas among Western nations where the prevalence of leprosy is low and historically debatable, a presumption of extreme stigma has emerged."⁵

The establishment of early Western attitudes, such as hopelessness of cure and revulsion to the disease, was reinforced by Christian missionaries such as the martyr, Father Damien, who worked for sixteen years among leprosy patients and died of leprosy at Kalaupapa in 1889. Believing that leprosy was incurable, Western clinical medicine abandoned leprosy patients and left them to the grace and mercy of dedicated Christian fieldworkers. Acting in the "extraordinary service" of Christ, Western missionaries began a worldwide service to leprosy colonies in 1874. To this day, working with Leprosy Patients is a field still dominated by Christian (church) agencies.

Leprosy was thought to be a "totally maximal illness," thus the negative social and emotional responses to the disease. Dr. Olaf Skinsnes' (1964) hypothetical disease model expressing the ultimate in physical disablement and social revulsion might apply to leprosy. Thus, a totally maximal illness would: (1) be externally manifest; (2) be progressively crippling and deforming; (3) be non-fatal and chronic, running an unusually long course; (4) have an insidious onset; (5) have

a fairly high endemicity, but not be epidemic; (6) be associated with low standards of living; (7) appear to be incurable, and (8) have a long incubation period" (Gussow and Tracy, 1970).

After 1946, the innovation of prophylactic treatment by drugs of the sulfone family, along with Penicillin and Mycin, made leprosy cease to resemble a maximal illness. The psychological effects of the disease could be arrested. Similarly, physical deformity resulting from the disease could in some cases be corrected by plastic surgery. However, although the *Mycobacterium leprae* could be controlled physiologically, the negative social-psychological concept of the disease may not lend itself to rapid abatement. In time, the Hawaiians, too, grew to fear the disease. According to the World Health Organization, perhaps no other disease causes such a reaction in the community and so much distress and unhappiness to patients and their families. This anxiety may follow leprosy patients and relatives throughout their lives and cast a shadow over their families and professional and social activities. Fortunately, the situation is gradually changing. Nevertheless, prejudice still persists to a degree that is not found with any other disease."⁶

It has been over thirty years since the introduction of sulfone therapy, but there has been a continuous resident population at Kalaupapa and other communities like it; but there has been a dramatic shift in the character of confinement. Prior to 1946, virtually all residents of the Molokai colony were legally quarantined as bacteriologically active patients. In 1866 there were 141 involuntarily confined residents; in the 1890s about 700; and in the early 1900s over 1,000. By 1966, twenty years after therapeutic relief became available, the community had 162 patients. However, out of this number only thirty-one were classified as active. In December 1968, the population consisted of 141 individuals of which 20 were active. In February 1975, there were 149 residents of which a similarly small percentage were active. By August 1978, there were 128 patients voluntarily in residence at Kalaupapa.

Therefore, a significant number of "cured" patients elected to remain in the total institutional setting, for most

it had become a community, and most of all, it had become a home. Even when they were eligible to return to the general community; they voluntarily confined and isolated themselves from the society to which they might have returned. Today, their median age is close to sixty, having resided half a lifetime or more in confinement, and most are partly deformed and scarred. There are also lesser numbers of Chinese, Japanese, Filipino, Samoan, and other ancestries residing in the settlement. There has evolved a type of reverse isolation among the patients, reinforcing a culture different from mainstream Hawaii.

Most of the residents at Kalaupapa are Hawaiian or part-Hawaiian (almost 60 percent). Yet within the State of Hawaii they make up less than 20 percent of the total population and may be considered a displaced minority within their homeland. As with the American Indian, Kalaupapa may represent a type of reservation, a special place for maintaining alienation from the larger culture of Hawaii. The Hawaiian reservation of Kalaupapa, the maintenance of alienation and a different culture, are forms of a socially-sanctioned protection of identity and beliefs which serve not only to protect from the stigma, shame and discreditability of association with the "outside" world (which leprosy patients attest to suffer in association with outside people), but more importantly the maintenance of alienation and a different culture may represent the preservation of a "last Hawaiian place." The culture of differentness may be like the culture of originality which existed before the coming of the Western discoverer, the trader, missionary, administrator, and the coming of the "Mai Pake" itself. Although Mai Pake took away something precious from them as did the trader and missionary, unlike the latter, Mai Pake may have also given something back. And that is a final home, a place of belonging, to the community or extended family (ohana) and the land (the aina). That is very important to Kalaupapa people today. That is why they wish to remain at Kalaupapa (in the face of a rapidly diminishing population) and at their old treatment facility in Honolulu, Hale Mohalu (closed down in 1978 by the Hawaiian State Health Department). They are familiar places, home, a place earned after a lifetime of banishment and ostracism.

Perhaps Hawaii's leprosy victims symbolize leprosy victims throughout the world, and their reflections about society's treatment of them may be a valuable footnote to the history of the disease. State law mandates Kalaupapa people may remain in the community as long as they wish. Ninety-five percent of the residents wish to remain there for the rest of their lives, but they are the last of their kind. Sulfones made that possible. There will be no future generations. There have been no new admissions to the settlement since 1969.

In this book, the patients speak of their lives, their pasts, and their hopes for the future, at Kalaupapa. It is precious land, the Kalaupapa land. Although the people at Kalaupapa will be allowed to remain, the community has become smaller each year and use of the peninsula remains unsettled. There are possibilities of a national park there, or maybe a State of Hawaii or County of Maui Park (in consort with the current residents). There is also talk--most unpopular among Kalaupapa residents--about resort development. However, one resident missionary has hopes for a Pacific research and treatment center there in keeping with the community's history and record of dignity, in the face of human suffering.

The newly-established fifteen member Kalaupapa National Historical Park Advisory Commission has been mandated by federal law to examine the possibility of turning Kalaupapa into a national historical park. The alternatives and future use of the land are yet to be decided. In the midst of the studies, alternatives, debates, and uncertainties, here, then, are some of the life stories from the few people remaining at Kalaupapa.

Ted Gugelyk

worker was always looking for others in my family with the mai Pake. She used to go to people's homes and try and catch them by surprise. She came in an official marked car, driven by a chauffeur, dressed in a white gown. Terrible! She used to upset everyone, because the neighbors would know. The family felt shame. After her visits she used to gossip about my family saying things like, "they pilau (dirty)." The family—they wanted to forget me, and I don't blame them. My sister came here to see me, maybe twenty years ago. We lost touch with one another.

I don't know if people are prejudiced against me. I keep to myself here, and I try to keep my self-respect. When the doctor comes for the medical clinics, I try to make sure that I am clean before I see him. I know that is something the doctor appreciates. I want to please him. So, I take a shower or bath and try and make myself presentable. But sometimes, later, I learn that I had a spot of coffee on my shirt, or maybe some gravy. But I don't know that unless somebody tells me. They should tell me those things. Is that what you call self-respect?

(Two months after this interview, the patient died at Kalaupapa. He was buried by his fellow patients on the 4th of July.)

Female, Hawaiian
Partly Disabled
Age: 69
51 Years at Kalaupapa

MY FAMILY: THEY HOKAI ME

They caught me when I was eighteen or nineteen. The Board of Health gave the neighbors ten dollars for reporting me. That was the policy in those days. One evening the Health Department inspector came to our house to examine me and pick me up. He said I had to go with him to Honolulu. If I said no, he would put me in handcuffs and drag me off. They threatened us that way. But I did not want to go, because I had this little boy who was my hanai boy. I loved him so much. But they said I would give him the sickness—mai Pake to the little boy—so for his own good, went. They took me from _____ to Mahu-Kona, then to Kalihi Hospital in Honolulu. I was put on the ship Kaala. The same ship that later sank on the reef off Kalaupapa.

At Kalihi they kept us separated. Boys on one side, girls on the other. The next morning, I had my physical examination. I went into a room where six doctors waited. I was naked except for one white sheet they wrapped around me. Those doctors examined me, looked at the spots on my body. They talked among themselves for a few minutes, then they said I should return to the girls' ward. In a few days I received a large envelope with a letter in it. The letter had my name on it, and it said, "You have been declared a leper." So I was sent to Kalaupapa. I wish I still had that letter. I would show it to you, but it was lost in the tidal wave that hit Kalaupapa in 1946.

After that, I hate to tell you this, my family hookai (rejected) me. All of my relatives hookai me. They were sad and disappointed in me for getting this sickness, and after I got it they did not want me anymore. That's what the mai Pake sickness does. It hookai you from your loved ones. The

name of leprosy is a fearful thing, they fear this disease. That's why they hookai me (separated me).

You know, when I was a little girl in _____, I saw this one sick man who lived like a dog. He lived in a shack. It looked like a dog house. At that time I didn't know it, but he was a man with leprosy. He lived in a lean-to, a little dirty place with a roof made of old boards. There were three sides to his shack, with one part open to the wind and rain. It was tacked on to the side of his family's house. His family lived in the big house and he lived in the dirty shack. He always stayed in that little place. He would hardly ever come out. He would just stay in there dirty and huddled up. When he wanted to eat, they would make him feed himself. He had to cook his own food. He had his own dish and fork. He could only eat after others finished eating. They did not let him touch anything of theirs. Sometimes they would allow him to use the kitchen stove to cook his food. But his family did not take care of him, and I used to watch him when I was a little girl. He was hookai too, just like I am now. Yes, I remember that poor man sleeping outside, all disfigured and twisted. I was just a little girl, and I did not know he had the leprosy sickness and that later I would get the same thing. I can say today, and I am ashamed to say it; but my family was no better than his.

After I was discharged, paroled or declared negative, I could have returned home. But my family asked me not to return home. They said not to come around. Do not try and live with the family. You know, when we die, our families will come to Kalaupapa and ask to see our graves. They also want to see our wills, but they will be surprised. I have no money.

Today, living on the outside, it's not so bad. But because of what happened to me with my family and friends, I don't feel comfortable outside. I have my own home here. This is where I will stay. Some of our people still have problems outside Kalaupapa. That's why they come back to Kalaupapa, even though they could live on the outside.

Female, Hawaiian
Married
Age: 70
46 years at Kalaupapa

LEAVE YOUR BONES AT KALAUPAPA

I was born on Maui, in the little community of Hana. I was twenty-seven when my mother noticed red spots on my body. I was married; I had two children. My family sent me to the doctor in Wailuku to look at the spots. Right away he knew. He said, if you go to Kalihi Hospital in Honolulu, they will cure you in three months. He promised me a cure for this disease. But my mother knew of this illness, and after the doctor examined me, she looked at me with sad eyes. She said, you have the ma'i hookaawale (the separating sickness). I think she knew I had the sickness before I went to see the doctor.

My mother did not want me to go to Kalihi Hospital. She knew more about the sickness than I did. Maybe she knew I would not be cured. So, she suggested I not show myself to anybody. She said, "Go hide. Hide inside the house. When someone comes to the house, run out the back door into the bushes on the mountain side." And I did that for three months. I went into hiding and the Health Department inspector did not find me. But, I had a husband and two children. There was so much crying over me, and I began to tire of the hiding life. I thought, I will try the cure. Maybe in three months I will get well. After all, the doctor promised. So, I left for Honolulu. My family told our neighbors I was going to visit relatives.

When I arrived at Kalihi Hospital, right away they put me into isolation on the women's side of the place. The next day they gave me a physical examination. My body was covered with red lesions--round rings with lumpy spots in the center, bumpy little spots. The doctors gathered around me while I stood there naked in the white tile room. I was cold, and I only had a sheet around me. The doctors said they

Male, Hawaiian
Widowed
Age: 81
67 years at Kalaupapa

WHY DID IT HAPPEN TO US HAWAIIANS?

My wife passed away at Kalaupapa. We celebrated our fiftieth wedding anniversary right here. She was a patient too. Like many of our people, we married one another inside Kalaupapa. Me, I am eighty-one now. Old man, eh? I have been confined since I was twelve. That is when they first diagnosed the sickness in me. I have been in hospitals for sixty-nine years--two years at Kalihi and sixty-seven years at Kalaupapa.

Things are not too bad with me. I am disabled, but it could be worse. I have no feeling in my hands and feet. My eyes are not too good either. Also, I have kidney trouble. But for my age, I'm OK.

They sent me to this place when I was fourteen years old. Like the other patients, they caught me in school. The teacher knew that I was what you call 'a contact.' You see, my ohāna had leprosy through my father. My father died from this sickness at the old Kakaako Hospital in Honolulu. My brother died from this sickness here at Kalaupapa. So they all figured I was 'a contact.' I think they first found the sickness when they gave me the vaccinations in school. The teacher told the doctor that my father had the mai Pake, so I think she turned me in. People were so scared of this sickness. But I was lucky. Even though we had the disease in our ohāna, my family never rejected me. Many people lost their families after they were sent here. That was real isolation then.

I think Chinese people were most scared of this disease, but the Japanese and Hawaiians were too. Today, maybe people are not so scared, but I know people still look at my hands when I go outside. I think people still fear us,

especially the older ones. But some folks look at my crab hands and think I had an accident. Plenty of us say that. What are you going to say to one stranger? I am a leper? The ones who recognize the signs of this sickness, those people shy away.

I don't believe you catch this disease from contact with leprosy people. Plenty people lived together in the ohāna where one had it, and the rest never caught it. For instance, I know about one case that happened right here in Kalaupapa, and there were plenty like this one. There was one wife who loved her husband so very much. He caught the leprosy sickness. She knew they would send him away to Kalaupapa, so she wanted to catch it too. She loved him so much that she used to rub herself with the pus from her husband's leprosy sores. But she never caught it, no matter how hard she tried. Finally they caught him and broke them apart. They sent him to Kalaupapa. Later, the wife could not stand being apart from her husband, so she volunteered to come to Kalaupapa as a kokua (helper). That way, she stayed here with her husband until he died. There were so many cases like that, so I don't believe you catch the sickness from contact. That wife, she never caught it. Plenty other kokuas never caught it either. But the teacher turned me in. She thought I was a contact, and the law said contacts must be turned in and examined.

The worst thing about being a leprosy patient is that they shove you around like cattle. They take you here to die, and still they push you around--like this problem at Hale Mohalu. First they sent us to Kakaako, then to Kalihi, then to Kalaupapa, and now up to Leahi. Of course, we do get good things too. The government takes good care of me. I get my medical attention, my housing, food, like that. Sometimes, though, I think I may leave this place now that I am old. I think about my children and grandchildren, moopunas, you know? But maybe my family might be hurt if I get too close to them. Maybe people will talk. Maybe patients should live here with their own kind and not shame their families. But I wish the Health Department would let us be. We have been sent away enough. They move us from one place to another, against our wishes.

I think Hale Mohalu is a good place for us. It's easy for family to visit us there. We have privacy and plenty of space. It is like our home away from home in Honolulu. So close to shopping, friends, and I think we get good care there too. The people in Pearl City are used to us. The shopkeepers, they open their doors for us. In the beginning, they were frightened of us, just like other people. Maybe Leahi people will fear us, then we have to go through the same thing all over again. We are too old for that. No, I don't like Leahi. We have been shoved around all these years. Maybe, this is one more time of being shoved around. Always the same thing for us.

About my medicine--I never take it any more. Some other patients feel the same way. The medicine for this illness is no good for our kidneys. Me, I got well by myself. I think most people at Kalaupapa die from taking the treatment. They don't die from leprosy, but from the treatment! First, they gave us chaulmoogra oil. That killed people. Maybe with these other drugs the same thing happened. I think it's better not to take medicine. I don't take anything, except some Vitamin C. This sulfone treatment gives people kidney trouble, and they all die from that.

The worst thing about being in here is missing my children. I have twelve children and they were all born inside. Nine of my children lived. I delivered all of my own babies. They were all born inside Kalaupapa. Twelve children I delivered. The first few times, the midwife showed me how to do it. With the other nine, I delivered them myself.

You know, the babies that were born inside here were not allowed to stay with their parents. After the babies were born, the law said they had to be taken away to the baby nursery in Kalaupapa. They were afraid of the contact--afraid the babies would catch the disease from their parents. But some of my children, I will tell you this, some of them I kept longer. Most times, the babies were born in the night. We kept everyone quiet so the administrators and nurses would not hear the baby being born. All my babies were born in my own home, right here. After I delivered the babies, we

were so happy. I called the young girl patients and they would come running in the night to look at the newborn one. Everyone was so happy to see baby children. And us, we were so proud of our new babies, we had so much love. My babies stayed with me that way, longer than the law said they could. But my children never caught the sickness. We would try to keep the babies as long as we could, but most times, we kept them only until morning. Then we would carry them to the nursery. I didn't want any trouble with the administrators, or with the Board of Health. So we gave them up. That was the law. They allowed the children to live one year inside Kalaupapa nursery. There we could see them only through thick glass, but no can touch! Then after one year, they were removed. They were either hanai by family members, or "issued" out for adoption by the Board of Health.

It was so hard to give up your children like that, especially to the Board of Health. Seven boys and five girls we had. But three boys died in the nursery. They never took good care of them, yet they would not let us care for our own children, even when we knew they were sick. It was hard. You love them, and then they are taken away, just like we were taken away. But the children would never know us as parents. Well, I try to make the best I can of this disease. I have to like this disease. I have to make the best of it.

Tell me, why were there so many of us Hawaiians in here? Why did so many Hawaiians die in here? Why did it have to be that way, with us Hawaiians? Maybe when we were kids in school, maybe they gave us the wrong medicine, the wrong vaccinations? They caught me at vaccination time, like the others. Sometimes I think maybe they wanted to get rid of the Hawaiians. The plantations wanted our land, so they tried to get rid of us. I don't know. Our family had land on Maui in Hana, and the plantation there tried to take away our land. Who do I blame for this disease? I don't know. But why us Hawaiians?

Male, Part-Hawaiian
Partly Disabled
37 years at Kalaupapa

I WAS A GUINEA PIG

My uncle turned me in. He was so afraid of this sickness. Actually his own wife had it--my auntie. It was she who took care of me when I was a little boy. When she showed the signs of the sickness, they took me away from her. When my uncle saw I had the same signs, well, he turned me in. Can you imagine that? My father had much hate for my uncle after that. My father had been treating me with Hawaiian medicine at home. He took me to medical kahunas for help. I was ten years old. I had red spots on my face and some numbness in my fingers.

Even with the sulfone drugs, this illness gets worse. It knocks me down more. The new medicine doesn't help make your feeling come back in your nerves. It doesn't help your crab-twisted hands; and my club feet and legs still have no feeling. As I grow older, it grabs hold of me that much more.

One of the worst things about this illness is what was done to me as a young boy. First, I was sent away from my family. That was hard. I was so sad to go to Kalaupapa. They told me right out that I would die here; that I would never see my family again. I heard them say this phrase, something I will never forget. They said, "This is your last place. This is where you are going to stay, and die." That's what they told me. I was a thirteen-year-old kid.

The worst thing about being a leprosy person is that it deprived me of my happiness. I am not happy if I am one leper. I cannot live like other people live. I cannot do what other people do. I cannot get a good job. I can't have a good married life. I cannot have children. And when I go outside, even some old friends, how strange they look at me. Old friends show no pity. They only show a kind of scary feeling of me. So I don't want to go outside because of my

appearance. I know, when I touch something on the outside, sometimes others will not touch it. They shy away. That is why we stay among our own people, our own kind, and try and enjoy the life we have left. Here, among our people, we understand one another.

Truly, the worst thing about this whole program is how they used us children for guinea pigs. They used to experiment on us, against our will. They injected us with different kinds of medicine. They also used to "nose trip" us. We could not refuse. They said we were minors. If we did not cooperate, they would punish us kids. No can resist that "nose trip." They would stick one applicator stick up each nostril. That way they would force open the nose, since the nose was blocked up with mucus. They put opium on the stick to soften up the tissue, and shove the stick all the way up our nose. Then, they would take some metal instrument and pull out the applicator stick from deep inside the nose passage. With the stick would come the stuck mucus, tissue, and plenty of blood. Boy, that used to hurt. Every day they did that to me for two years. I could not resist. Every day I would bleed. That's why my nose is like it is, broken down and flat. For two years they slowly broke away the bridge of my nose. Because of that experiment I had almost constant bleeding for two years. That experiment did more harm than good. Look at me today--I'm the loser. I can't face other people. Other new patients are lucky, because later the new drugs came. They didn't have to go through what we did.

I only leave Kalaupapa about once a year. I like to meet friends. But I don't go to their homes. We meet in public places. I think people are afraid to let you into their homes.

Am I bitter that I contracted leprosy? Yes, I am very bitter. I think, why me? Why did I have to suffer? But I can't blame anyone for this illness. It just happened. But I do blame the doctors who used me as a guinea pig.

When I die, I don't want my family notified. I am alive now. Why don't they come to see me when I am alive. When I die, what's the use? It's too late. Now is the time to show care.