From contagious to chronic: a life course experience with leprosy in Taiwanese women

CAROL SHIEH*, HSIU-HUNG WANG**, + & CHING-FENG LIN**
*Department of Environments for Health, Indiana University School of Nursing, Indiana, USA
**Department of Health, The Executive Yuan, Taiwan
+ Kaohsiung Medical University, College of Nursing, Taiwan

Accepted for publication 28 March 2006

Summary This study used the narrative analysis method to explore stories told by Taiwanese women who had suffered from leprosy. Twenty-one women from a leprosarium, a long-term care centre, and the community participated in either focus group discussions or individual interviews. The age range for the participants was 54–88, with an average of 68 years old. Physical impairments and disabilities of the participants included skin scars, claw fingers, drop feet, amputated legs, and facial disfigurement. Their stories were analysed in two phases: structural and holistic content analyses. Structural analysis identified four life stages: before being diagnosed, after being diagnosed, living with leprosy, and the future. Holistic content analysis uncovered common themes in each life stage. Findings indicated that stigma was experienced throughout the life course of these women. At this stage of life, these women were facing not only physical impairments and disabilities from the leprosy, but also the usual chronic health problems of the elderly. This study suggests that prevention and treatment of leprosy-related physical impairments and chronic diseases are important.

Introduction

Tai Ge, the Taiwanese term for leprosy, describes open and ulcerative wounds as unclean, filthy, and foul. This linguistic term reflects a negative cultural-social perception of leprosy – the person with the disease is stereotyped as lowly, untouchable, unwelcome, and contagious. This negative perception is also prevalent in many other cultures in which leprosy is viewed as both a public health and a social disease.1

Leprosy control in Taiwan has long been a joint effort between the government and private sectors, including religious groups, charitable organizations, and the Taiwan Leprosy
Relief Foundation. Taiwan was under the occupation of Japanese military force for 50 years between 1895 and 1945. In the early 1900s, Christians from Canada, England, and Norway, many of them with medical or nursing training, had established small clinics for leprosy patients. Later in the 1930s, a few leprosaria were set up to house particularly indigent leprosy patients. For instance, the Taipei Happy Mount Leprosy Colony was initiated under the leadership of Dr G. Gushe-Taylor, a Canadian physician and minister. This colony offered treatment, Christian worship, and occupational therapy by encouraging patients to grow their own vegetables and rice in the colony. At about the same time, the then Japanese government authority built Lo-Sheng leprosarium, the largest and the only government-run leprosy institution, and actively implemented case finding and segregation of leprosy patients. After the end of World War II in 1945, Japan withdrew its military force from Taiwan. The operation of the Lo-Sheng leprosarium was returned to the Taiwanese government, which gradually expanded inpatient units in Lo-Sheng leprosarium and established leprosy clinics in the community health centers. Between the 1950s and 1960s, the government developed training programs for local public health workers in recognizing the disease, monitoring leprosy cases, and making referrals. Compulsory segregation, mainly in the Lo-Sheng leprosarium, was employed to control leprosy until 1962. Following that, the admission to Lo-Sheng leprosarium or charitable treatment centers was called voluntary segregation. Many leprosy patients chose to be in these institutions for the free treatment because of their family’s unwillingness to keep them at home, pressure from their neighbours or villages, worsening of their disease, inability to comply with medication regimen, and their poor socio-economic status. In 1976, the government developed overall objectives for leprosy control and has revised the objectives every 10 years. Multidrug therapy (MDT) for Taiwanese leprosy patients began in 1982 following the recommendation made by the World Health Organization. After that, special leprosy clinics in the community health centers were replaced with general skin clinics. Leprosy patients were encouraged to seek treatment in outpatient settings rather than in inpatient facilities. In 1994, a national health insurance policy was implemented to ensure all citizens’ access to health care. Leprosy treatment institutions went through changes after this policy was initiated. Lo-Sheng leprosarium maintained its inpatient facilities for existing leprosy patients, but starting in 2001 it no longer admitted new cases, and this leprosarium extended its outpatient services to include non-leprosy specialties. A few small leprosaria supported by religious groups, Christian hospitals, and the Taiwan Leprosy Relief Foundation had greatly contributed to the leprosy control and treatment throughout the years. These small facilities provided outpatient and inpatient care for leprosy patients. With the national health insurance policy in place, the financial constraints in recent years, and the diminishing number of new cases, these small facilities closed outpatient clinics, combined their inpatient leprosy treatment with other long-term care services, and renamed their facilities as nursing homes, long-term care facilities, or rehabilitation centres.

According to the Center for Disease Control in Taiwan, there were 1120 registered leprosy patients in 2005, with 343 living in institutions and 777 residing in homes. In the same year, nine new cases were identified including six foreign labours or immigrant brides from Southeastern Asia and three Taiwanese. The majority of leprosy patients in Taiwan are in their older adulthood, with a mean age of 68.6. The prevalence and incidence rates in 2005 were 0.24 per 100,000 and 0.3 per million, respectively. Recent efforts to control leprosy aim at surveillance, compliance with the MDT regimen, non-segregated treatment in leprosy special clinics and dermatology outpatient offices, and public education.
Leprosy in women is a complex health problem, not only because of women’s unique physiology, such as hormonal changes, childbearing, and lactation, but also because of their disadvantaged socio-economic status. Studies show that a high proportion of women begin the onset of leprosy in adolescence or young adulthood, and the likelihood of developing leprosy or having a relapse after cure increases during pregnancy and lactation. Research also indicates that, in cultures in which women are expected to be submissive to and economically dependent on men, this socio-economic disadvantage delays the process of diagnosis and treatment in women. Furthermore, when their leprosy is revealed, women are more likely to face isolation, rejection, and discrimination than men.

Although previous studies have identified risk factors and disease processes in women with leprosy, they have included data from third world countries such as Venezuela, Nigeria, and India. Very little has been reported about women’s experiences with leprosy in Taiwan, where the women’s life expectancy had lengthened to 78.9 years in 2003 and speedy economic development and western influence have gradually changed the society’s view of illness, family dynamics, and women’s roles.

This study used the narrative analysis method to examine stories told by Taiwanese women who had suffered from leprosy. These stories involved a lifelong perspective from the beginning of the disease to the recovery and beyond.

Subjects and methods

Narrative analysis is a qualitative inquiry method; it provides researchers with a means to investigate how respondents in interviews impose order on the flow of experiences to make sense of events or actions in their lives.

Participants in this study were recruited from Lo-Sheng leprosarium and a leprosy long-term care centre (LLTCC) in Taiwan. Lo-Sheng leprosarium, located in northern Taiwan, is a government-sponsored facility. It has inpatient and outpatient services, as well as a large area with housing quarters for leprosy patients. At the time of the data collection for this study in 2003, there were 334 leprosy patients living in Lo-Sheng leprosarium with 242 males and 92 females. Each patient received welfare support from the government, including money for food, a living subsidy, and a stipend. A church and a temple are located in the leprosarium for religious worship, and a central kitchen supplies patients with meals for a fee. Leprosy patients with severe disabilities may hire other leprosy patients who have mild physical impairments to attend to their daily needs. Housing quarters in this leprosarium include family units and group living arrangements. The current liberal visiting policy in the leprosarium allows family members or relatives to visit patients freely. Patients can also leave the institution to participate in family or community activities.

The LLTCC is in southern Taiwan and is funded by the Taiwan Leprosy Relief Foundation and Christian hospitals in southern cities. This centre was established in 1957 by a Norwegian physician and minister and was housed in a community health centre at that time to provide free leprosy diagnosis, counselling, and treatment. In 1960, the centre moved to the current location and began the construction of an exam room, a surgery room, a recreation room, a central kitchen, a large Christian worship room, and patient rooms. In 1980, the centre remodelled the kitchen, the dining room, and added a dormitory for nursing staff. The centre used to have leprosy outpatient services; however, it now only provides inpatient, long-term care. The centre can house approximately 24 patients with leprosy complications.
or chronic health problems. Nursing staff are available 24 h a day and 7 days a week in this centre. Nurses perform dressing changes, assess blood pressure and other vital signs, make medical appointments for patients, transport patients to other medical facilities, and arrange follow-up examinations for former leprosy patients who now reside in the community after discharge. In 2003, when this study was conducted, LLTCC no longer accepted new leprosy cases, but it continued to serve leprosy patients who had lived there for years. Leprosy patients in the centre received welfare, disability, and health benefits from the local city government.

Twenty-one women participated in this study; 12 lived in the leprosarium, five lived in the LLTCC, and another four were community-dwelling women who were former patients of the LLTCC. These four women had stayed in the centre from 6 months to 3 years and still utilized the centre for leprosy follow-ups after discharge. The rest of the women had lived in either the leprosarium for 30–64 years or the LLTCC for 4–16 years at the time of this study.

The mean age of these 21 participants was 67.7 years old, ranging from 54 to 88. Six of the 21 women (28%) had no formal education, 13 (62%) had either an elementary education or had attended school for 2 or 3 years, and 2 (10%) had received a middle school education. Only one woman in this study had a regular, paid job outside her home and she was from the community-dwelling group. At the time of the study, 12 (57%) were married, 8 (38%) were widows, and one (5%) was divorced. Twelve (57%) women currently married or had married a man who also had leprosy. Of these 12 women, 10 (83%) were from the Lo-Sheng leprosarium. Three (14%) of the women had never given birth, although one of these three women had adopted a son.

Most of the women (n = 15, 71%) had acquired their leprosy symptoms during childhood or adolescence, five (24%) during young adulthood (20–30 years old), and one (5%) in her 40s. The degree of physical impairments and disabilities related to leprosy varied from skin scars, to disfigured faces, blindness, claw fingers, drop feet, and amputated legs.

The information regarding MDT (ever received, the date it began, and the length of MDT treatment) for each woman was not collected because data were either not available or incomplete. None of the 21 women was on any leprosy medication at the time of the study.

The age, education, marital status, and physical impairments and disabilities were similar in the women of Lo-Sheng leprosarium, LLTCC, and the community-dwelling group. One major difference was that all of the women in the Lo-Sheng leprosarium were admitted before MDT was recommended in 1982, all the LLTCC women were admitted after 1982, and three of the four (75%) women in the community-dwelling group were treated in the LLTCC before 1982. Some women went to Lo-Sheng leprosarium as a result of the compulsory segregation; the women of the LLTCC and the community-dwelling group, however, chose to be treated in the LLTCC. More women in the LLTCC (three of five women or 60%) or the community (two of four women, or 50%) began leprosy symptoms in adulthood than the women in Lo-Sheng leprosarium did (one of 12 women or 8%). Further, the women in LLTCC reported receiving leprosy drug therapy in other charitable clinics or the community health centers. Their admissions to the LLTCC were primarily due to old or new ulcers or wounds in extremities caused by the loss of sensation. Detailed demographics and disease conditions of the participants can be found in Table 1.
<table>
<thead>
<tr>
<th>Subjects</th>
<th>Age</th>
<th>Marital status</th>
<th>Education (years)</th>
<th>Age symptoms began</th>
<th>Year (age) admitted to Lo-Sheng or LLTCC</th>
<th>Physical impairments</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 women from Lo-Sheng leprosarium, mean age = 67.9 years</td>
<td>1</td>
<td>M</td>
<td>6</td>
<td>12</td>
<td>1960 (13)</td>
<td>Left leg amputated</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>M</td>
<td>6</td>
<td>11</td>
<td>1973 (31)</td>
<td>Skin scars</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>M</td>
<td>6</td>
<td>13</td>
<td>1961 (15)</td>
<td>Claw fingers</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>M</td>
<td>None</td>
<td>18</td>
<td>1960 (27)</td>
<td>Claw fingers; skin scars in forearms</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>M</td>
<td>9</td>
<td>14</td>
<td>1953 (20)</td>
<td>Partially blind; leg numbness; loss of mobility between thumbs and index fingers</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>W</td>
<td>6</td>
<td>14</td>
<td>1943 (15)</td>
<td>Flattened nose; claw fingers</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>W</td>
<td>6</td>
<td>20</td>
<td>1952 (30)</td>
<td>Numbness in right elbow and knees; claw fingers; deformed toes; flattened nose</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>D</td>
<td>5</td>
<td>10</td>
<td>1964 (15)</td>
<td>Numbness in forearms; claw fingers</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>M</td>
<td>None</td>
<td>17</td>
<td>1961 (18)</td>
<td>Claw fingers; deformed nose and feet</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>W</td>
<td>3</td>
<td>13</td>
<td>1962 (42)*</td>
<td>Skin scars in upper arms; claw fingers; deformed toes; missing part of the fingers</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>M</td>
<td>None</td>
<td>8</td>
<td>1943 (12)</td>
<td>Claw fingers; drop feet</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>W</td>
<td>None</td>
<td>15</td>
<td>1942 (15)</td>
<td>Claw fingers; left leg amputated; partially blind</td>
</tr>
<tr>
<td>4 community-dwelling women, former patients of LLTCC, mean age = 65.5 years</td>
<td>13</td>
<td>W</td>
<td>None</td>
<td>40</td>
<td>1981 (49)</td>
<td>Legs numb; deformed toes; arms spasm</td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>W</td>
<td>3</td>
<td>20</td>
<td>1973 (48)</td>
<td>No toes; deformed nose</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>M</td>
<td>2</td>
<td>7</td>
<td>1987 (40)</td>
<td>Claw fingers; drop feet</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>M</td>
<td>9</td>
<td>17</td>
<td>1965 (19)</td>
<td>Slight claw fingers</td>
</tr>
<tr>
<td>5 women from LLTCC, mean age = 68.8 years</td>
<td>17</td>
<td>W</td>
<td>3</td>
<td>30</td>
<td>1985 (55)</td>
<td>Blind; deformed feet and hands</td>
</tr>
<tr>
<td></td>
<td>18</td>
<td>M</td>
<td>3</td>
<td>20</td>
<td>1986 (43)</td>
<td>Skin scars</td>
</tr>
<tr>
<td></td>
<td>19</td>
<td>M</td>
<td>6</td>
<td>13</td>
<td>1999 (53)</td>
<td>Claw fingers, drop feet</td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>M</td>
<td>6</td>
<td>17</td>
<td>1991 (54)</td>
<td>Claw left thumb and left foot ulcer</td>
</tr>
<tr>
<td></td>
<td>21</td>
<td>W</td>
<td>None</td>
<td>27</td>
<td>1986 (71)</td>
<td>Deformed nose, face, hands, and left leg; blind</td>
</tr>
</tbody>
</table>

M = married, W = widowed, D = divorced.

*Subject 10 lived in another leprosarium for 20 years before being admitted to Lo-Sheng leprosarium.

Compulsory segregation before 1962; multidrug therapy began in 1982.
PROCEDURE

This study was approved by the University Human Subjects Review Committee and the two institutions where the data were collected. Nurses in both the leprosarium and the LLTCC helped recruit and explain to the participants the purpose and procedure of the study. Participants could choose to attend focus group discussions or to have individual interviews. Three focus group discussions were conducted for 14 women, with one group in the Lo-Sheng leprosarium (six women) and two in the LLTCC (one group of five women from LLTCC and another group of three from the community). The length of each focus group discussion was about 2 h. A nurse in the LLTCC stayed with participants during focus group discussions. The nurse clarified issues and at times helped participants who had hearing problems.

Individual interviews, each for 30–40 min, were also completed for six participants from the Lo-Sheng leprosarium and one from the community-dwelling group. In the Lo-Sheng leprosarium, a female leprosy patient guided the researcher from one patient’s room to another.

Focus group discussions and individual interviews were audiotaped. The women were asked to tell their stories about their experiences with leprosy. The questions used to facilitate storytelling during the focus group discussions and individual interviews included, but were not limited to:

● How did leprosy start? How did you notice the physical changes in you?
● What did you do before and after the disease was diagnosed?
● What were your experiences with your family, the community, and the health professionals?
● What has changed since the time you knew about your disease?
● What are the most difficult things when dealing with leprosy?
● What would you do differently if you could do it again?
● How do you see yourself in the future?
● What will you do in the future?

DATA ANALYSIS

Transcripts were analysed in two phases as suggested by Lieblich, Tuval-Mashiach, and Zilber: structural analysis and holistic content analysis. The structural analysis serves the purpose of examining narrative data for a climax or a turning point that sheds light on important life stages. The holistic content analysis is used to find meaning in the part of the narrative data that emerges from the rest of the narrative or in the content of the story in its entirety. In this study, the structural analysis identified four turning points or life stages: before being diagnosed, after being diagnosed, living with leprosy, and the future. Meanings of the narrative in each life stage were compared and contrasted; similar meanings were then combined to generate broader themes.

Results

Several themes emerged in each of the four life stages. The following paragraphs describe the findings.
BEFORE BEING DIAGNOSED

Women in this study mentioned that their body went through changes in the beginning of leprosy. They often used home remedies to self-treat the symptoms before they knew they had leprosy. Two themes were abstracted from their stories.

AWARE OF BEING DIFFERENT FROM OTHERS IN THE EARLY STAGE OF THE DISEASE BUT DID NOT KNOW WHAT CAUSED THE PROBLEM

Almost all of the women in this study developed leprosy symptoms between the 1930s and 1960s, and two-thirds of them began the symptoms during childhood or adolescence. They noticed the changes in their face, skin, hands, fingers, or feet. For instance, one woman said that she would run around outdoors with other children; however, she would not sweat as other children did. Another woman mentioned that in school she was always left behind when walking with other children, due to her inability to hold up the sandals on her feet. Other women talked about how they often dropped rice bowls to the floor because their fingers and hands were unable to grasp the bowls tightly; they were scolded for being careless. Women whose symptoms began in adulthood noticed burn spots on their fingers, hands, and forearms, ulcers in feet, skin rash, and their sluggishness in cooking and doing domestic chores and fieldwork. Many women came from a poor family and they could not afford to be sick and neglect house care responsibilities. Further, they had no idea what caused the symptoms, often choosing to ignore the symptoms and hoping that they would go away.

SYMPTOMS WOULD NOT GO AWAY AFTER MANY ATTEMPTS TO GET RID OF THEM

Many women in this study did not receive leprosy diagnosis or treatment immediately from a health care provider after the leprosy symptoms had begun. Many women mentioned that they and their parents had limited education and no knowledge of the disease. To treat the symptoms, these women or their parents had tried home or folk remedies, such as pasting ashes or cement on their skin to remove a skin rash, avoiding certain foods, or inhaling smoke from burning herbs to expel toxins from their bodies. After these remedies had failed, they would seek help from spiritual gods. Before the 1960s, many general practice doctors with various training and credentials were not attuned to leprosy diagnosis and treatment. Some women in this study stated that even though they went to see doctors, a different diagnosis such as skin infection or arthritis was made and treatment did not help to get rid of the symptoms.

AFTER BEING DIAGNOSED

Many women had leprosy symptoms for months or years before the diagnosis was made by a qualified doctor. Some were told by experienced doctors in the hospital clinics that they had leprosy. The majority of them, however, were referred by church volunteers or public health workers to the community health centres, charitable clinics, Lo-Sheng leprosarium or the LLTCC for confirmatory diagnosis and treatment. These religious volunteers, mostly Christians, and public health workers visited local markets and neighbourhoods frequently and had seen similar symptoms presented by other leprosy patients. Women in this study talked about the following experiences after the diagnosis of leprosy was confirmed.
FEELING OF SHAME AND BEING STIGMATIZED

After they knew that they had contracted leprosy, these women stayed in the house as much as possible, wore long-sleeved clothes and gloves to cover their arms and hands, stopped going to school, avoided being seen when someone came to their house, and paid few visits to relatives and friends. When asked about their illnesses on unavoidable occasions, they would say that they had skin infections, arthritis, or polio. Some women who were admitted to the Lo-Sheng leprosarium during the era of compulsory segregation before 1962 recalled that they hid and went from place to place like a criminal to avoid being found by public health workers or police officers.

The women of the LLTCC and the community-dwelling group had a longer lapse between the diagnosis and the admission to the LLTCC. These women stated that public health workers’ visits to their homes sometimes caused neighbours or relatives who lived in the same village to become suspicious about the women’s leprosy diagnosis. Intentional or unintentional stigmatizing behaviours exhibited by others, such as staring, quickly walking away, or avoiding close contact with them, would worsen these women’s sense of shame. One woman mentioned that 1 day after her departure from a relative’s home, the relative washed the chair that she had sat on for just a few minutes. Another woman told a story about her older brother’s fear of touching her hands.

Several women could not face the stigma and had attempted or considered suicide. For instance, one woman had been ready to hang herself, but did not because her young son had come into her room. Another woman had prepared a bowl of poisoned soup to drink, but a relative came just in time to stop her.

CONFLICTING IDEAS ABOUT BEING ADMITTED TO INSTITUTIONS FOR TREATMENT

Some women who were diagnosed before compulsory segregation in 1962 had tried different ways to avoid being caught and sent away to the Lo-Sheng leprosarium. The public at that time held the misconception that the government would ‘terminate’ lepers. As one woman stated, ‘the belief was that lepers would enter the leprosarium alive and come out as ashes from the bottom of the chimney.’

Many women, however, opted for institutional care because they were unable to follow medication administration instructions at home, had worsening leprosy symptoms, developed recurrent skin ulcers, or had limited financial means and family resources to keep them at home. Seeking admission to treatment institutions such as Lo-Sheng leprosarium or the LLTCC either by being forced or voluntarily was not easy. Some women said that their relatives and neighbours would eventually find out what was wrong with them after they had been admitted for treatment and disappeared from their homes and neighbourhoods.

Women who entered the institutions when they were adults worried that their absence from home might cause marital problems, their offspring’s detachment from them, and unnecessary inconvenience or embarrassment in family members. One woman in the LLTCC talked about how a young man, a friend of her son, vomited all the way home after he had paid a visit to her at the LLTCC and had seen a leprosy patient with a disfigured face and other leprosy patients’ ulcerative feet. This woman was concerned that the young man would later learn about her leprosy and it might affect his friendship with her son.
Even though the journey to the leprosarium or the LLTCC was uncertain at the beginning, these women became motivated to receive treatment once they had settled in the leprosarium or the LLTCC. For those who were teenagers when treatment began, the motivation was to recover from the disease so they could someday find a man to marry. For adults who left children and husbands at home and began treatment in institutions, the motivation was to prevent worsening physical disfigurement and disability so they could return to their families. These women mentioned that patients in the leprosarium or the LLTCC had different degrees of physical disability and disfigurement; those in the early stage of the disease were afraid that they would come to look like the ones with severe disability and disfigurement if they did not comply with the treatment.

A couple of women in the Lo-Sheng leprosarium talked about how they waited in line patiently in order to receive chaulmoogra oil injections decades ago. Some women in the community-dwelling group and the LLTCC mentioned that before their admissions to the LLTCC, they received medications from the charitable clinics or the community health centres and overdosed themselves at home with DDS. They believed that taking more pills would rid the leprosy faster and more effectively. Two women in the community-dwelling group stated that while they were hospitalized in the LLTCC, they took a ‘new drug’ that turned their skins to black colour. They were scared, but in order to get well, they had to withhold their fears about the skin colour changes.

Even with treatment, these women had different degrees of physical impairments and emotional suffering. Their stories reflected how they developed coping mechanisms, struggled with maternal roles, and explored new meanings as the years passed by.

The babies of women who gave birth while living in the Lo-Sheng leprosarium between the 1950s and 1970s were taken away to a central nursery after birth to be cared for by female missionaries. These babies remained separated from their own mothers on and off for years to prevent being infected by their mothers. Some women arranged for their children to be cared for by their family or relatives after the infancy stage. Others rented a small apartment for their older children to live outside but near the leprosarium. The women who were in the community or the LLTCC and who had raised children after they were told that they had leprosy did not separate from their children, but they purposely avoided close contact with their babies for fear they might pass the infection to the babies. These women talked about the guilt and sorrow related to not being able to hold, kiss, have physical contact with, and breastfeed their babies during the infancy stage. As a woman stated, ‘The intimacy with my newborn son was missing. Now it’s too late to make it up.’

Many women talked about how their skin rash flared up during menstrual periods, during and after pregnancy, or when feeling stressed, but none of their children had been infected. They
prevented their children from getting the disease by frequently checking their children’s skin, washing hands, not holding or touching their children, and not sharing food, beds, or blankets with their children. Some women even said that in order to avoid embarrassment in their children because of their own physical appearance, they would not go to their children’s school meetings. Because of their own limited education, they rarely helped with their children’s learning. Without the financial means, they were not able to assist their children in advancing education or career development. The felt they were not as competent as the mothers who did not have the disease. Even with these limitations, their love for their children was strong and they were grateful that their children did not contract the disease and turned out physically well. They were especially proud when their children or grandchildren surpassed them by obtaining a vocational or college education and having a stable job.

STRIVING FOR FAMILY, SOCIAL, AND RELIGIOUS SUPPORT

About 57% of the women in this study were or had been married to a man with leprosy. Having a spouse with leprosy helped these women freely talk about their health problems within the family; they felt they could find emotional support from each other. The women who lived in the community with their family members also relied on the family’s instrumental and emotional support. In return, these community-dwelling women had a strong sense that they needed to contribute something to their family, such as helping with babysitting grandchildren or trying to be less a financial burden to the family.

Some institutionalized women stated that in the past 10 years (after 1995), they had reconnected with a number of family members, old friends, relatives and these people’s offspring who either had been reluctant for many years to reconnect or did not know how to engage in the relationships. This reconnection meant a lot to these women because they felt that after years of ‘being away’, they were able to reconstruct a web of social support. When asked what had made the reconnection happen, some women stated that this reconnection was sometimes facilitated by their children and grandchildren. Because these women’s offspring were not leprosy patients, during their weddings and childbirths, relatives and friends would come to help celebrate; and in these occasions, some would be willing to revive a relationship with the women. Some women also attended the funerals of their relatives and friends; the offspring of the deceased persons would return with a thank-you phone call or a visit to the women in the leprosarium or the LLTCC. A few women mentioned that the television would broadcast leprosy programs that educated the public not to be afraid of leprosy patients. They thought people might have changed their opinions if they had watched these programmes.

These women also talked about how religion played a big role in their adjustment to leprosy and its complications. Daily prayers and attendance at regular religious services helped them find emotional peace. Since the LLTCC was supported by Christian organizations, women living in LLTCC practised Christianity.

BEING AS USEFUL AND INDEPENDENT AS POSSIBLE

Although the women in this study had various degrees of physical impairments and disabilities, they made use of their remaining physical functions and talents to the fullest. Most of them managed their own daily needs, such as cooking, bathing, and feeding themselves as independently as possible even though they were often slow. One woman who lived in the community even recycled newspapers or magazines to exchange for cash.
Another community-dwelling woman helped care for grandchildren. One woman with mild physical limitations who lived in Lo-Sheng leprosarium did laundry and ran small errands for other leprosy patients who had more severe impairments. In LLTCC, one woman regularly helped in the kitchen. Many women volunteered in the Women’s Club or religious groups in the leprosarium or the LLTCC, or planted vegetables and flowers in the limited space surrounding their living quarters as long as their physical strength allowed.

**THE FUTURE**

None of the women in this study reported taking leprosy medications at the time of the study. They stated they no longer had the infection, but they faced a future full of challenges. Their stories implied the unresolved stigma and concerns about their physical impairments and chronic health problems.

**ONCE LEPROSY, FOREVER LEPROSY**

Women in this study mentioned that, even though they were physically free of the microorganisms, they would never be free of the leprosy emotionally. One major reason was the physical changes to their faces, hands, fingers, and feet. These physical changes (disabilities and deformities) could not be removed, and they interfered with daily routines and socialization. Many institutionalized women said that in recent years, some of their relatives and friends had treated them as a ‘normal person’; however, when they were invited to family gatherings, they would decline the invitations or, if they were in the gatherings, they would sit in a corner and hide their hands with handkerchiefs. Community-dwelling women continued to separate their bowls, plates, and chopsticks from other family members, and they did not share drinking cups or indoor slippers because they were still afraid of infecting others. They also mentioned that the periodic phone calls from the nurse for follow-ups were reminders of their leprosy. As one woman said, ‘It’s like there is a mark on your forehead that says you are a leprosy patient. Even now, I still call myself a patient and people without leprosy healthy persons.’

**RATHER STAY IN THE LEPROSARIUM OR THE LLTCC THAN MOVE OUT TO THE COMMUNITY**

Institutionalized women were asked if they could choose a place to live, would they prefer returning to the community or staying in the leprosarium or the LLTCC? None of those who had lived in the institutions for more than 10 years wanted to move out to the community. Women in the Lo-Sheng leprosarium were afraid that the community would not accept them, even though people are more open to talk about leprosy nowadays. They also said that they could not afford renting or buying an apartment in the community and after so many years in Lo-Sheng leprosarium, the leprosarium was their home. Without savings, many felt it was difficult to own anything in the modern time. As one woman said, ‘Everything is expensive.’ Some of them had no family to return to. Other women believed it would be unfair to their children to have to care for them now since they had not been able to care for their children when they were small.

Women in the LLTCC mentioned that their children or grandchildren had moved out of their home villages and their offspring did not have an extra room in their relocated apartment.
or house for them to stay; even if they did, their offspring did not have time to care for them because of their employment and other childrearing responsibilities. Some women stated that their adult children were aging too and had health problems. They did not want to become a burden to their children or other family members. Three women in the LLTCC stated they had a spouse, but they did not express their desire to reunite with their spouses.

Further, because of the women’s age and physical conditions, they did not feel confident enough to live independently in the community. They felt more secure living with people of their kind and having nursing staff around in the leprosarium or the LLTCC.

LIFE IS MORE DIFFICULT WITH PAIN, DISABILITIES, AND CHRONIC DISEASES

Many women in this study, regardless of their residence, had other chronic health problems such as hypertension, heart disease, cataracts, arthritis, cancer, diabetes, and asthma. They talked about how the nerve pain, a sequela from leprosy, crippled them in bad weather, but they also mentioned that chronic diseases made their lives harder and harder. They needed to take medications, check their blood sugar, watch their diet, and go to doctors’ offices – all extra work beyond the physical impairments caused by their leprosy. They believed that all these chronic health problems would become increasingly worse in the future.

WELCOME THE FINAL DAYS TO COME

Many women who were in their 70s freely talked about death. They welcomed the final days to come, especially when the nerve pain was severe. Some women expressed gratitude to God for allowing them to live this long despite physical limitations. They would not regret leaving this world if it was God’s will.

Discussion

Stigma is a major social complication from leprosy.1,17 Findings from this study suggest that two types of stigma were experienced in the life course by the women in this study. The first was a form of verbal or physical discrimination demonstrated by others toward the women during formal or informal encounters. Previous research has shown that the stigmatization process occurs during human interactions.18 The women in this study had experienced different degrees of stigma based on whether they were socially interacting with family members, relatives, friends, or neighbours. This type of stigma, however, was viewed, especially by the institutionalized women, as having decreased in recent years because of the opportunities to reconnect with the persons who were distant to them at the start of their disease. Being able to expand a social network seemed to revise the women’s internal perceptions of being a leprosy victim, in addition to the external factors such as the overall increased acceptance of leprosy in the society and the availability of MDT to cure leprosy.

Women in this study also described a self-inflicted stigma during their lives. For instance, they were careful not to share utensils, drinking cups, or blankets with family members, and they restricted or limited physical touch with their children and grandchildren even after they were considered cured. When they were in social gatherings, they continued to hide their disfigured body parts and attempted to avoid attention. In some way, this type of self-inflicted stigma reflected a maternal altruistic behaviour to care and protect others. It also was
probably an expression of embarrassment about their physical appearance. For these women, physical deteriorations were the realities, could not be changed, and interfered with their daily living activities. These physical changes had become the strong negative motivators to keep these women viewing themselves as still being affected by leprosy. According to Heijnders, a cure of leprosy may have different personal, social, and psychological meanings for different patients.19 Health education is important to reinforce the mechanisms for leprosy transmission; however, we believe prevention of physical impairment and disability may be more critical in reducing mental suffering from stigma.20 In addition, interventions to mitigate this type of stigma by forming self-help groups, empowerment initiatives, and community networks have been reported to be effective.21

These women’s stories illustrate a life trend in leprosy from being contagious to chronic. The life course began with a battle to remove the infection from the body, and later the life course was compounded with the physical impairments caused by leprosy and age-related chronic diseases. This life trend was observed in either institutionalized or community-dwelling women. Many women in this study had diabetes, asthma, hypertension, and heart diseases that required diet control, medication administration, frequent follow-ups with physicians, and sugar and blood pressure checks. Life became increasingly difficult when demands increased as physical strength declined. A previous study of 49 ex-leprosy patients between 49 and 83 years old in China also found that aging was positively correlated with disability status from leprosy and other medical problems, and ex-leprosy patients worried about their self-care ability in the years to come.22

Decades ago, some women in this study had been forced to segregate themselves in the treatment institutions; others chose to be in institutions for a variety of reasons, including their inadequate knowledge level and limited family and socio-economic resources. In public and charitable institutions, women could obtain leprosy medications, consultations, and other treatments that could not be found elsewhere or, if services were available, the quality of care could be different relative to the patient’s social, educational, and economic background.23 The institutions had become a home for many women. Especially in Lo-Sheng leprosarium, some women grew up, bore children, and managed to fulfil maternal roles while living there. The institutions also became the communities that provided these women with social and religious support at different stages of their lives. The women identified with patients of their kind in the institutions, and this identity was an important buffer against potential stigma from outside the institutions.

Scott reported that a lengthy hospitalization has negative effects on leprosy patients, such as loss of employment, marital problems, and discord in family ties.24 A common characteristic of the women in our study after many years of institutional life was their conflicting emotions, indicating the lack of confidence and comfort in living in the non-institutionalized community. Women in this study reported that their social networks had enlarged in recent years, but they could not predict what might happen to them if community living became a reality. They worried that they could face stigma and not be accepted to the community. They were concerned that the family could not accommodate their needs, if living with the family was possible, and they could become a burden to their children or other family members. These women had tried to be as useful and independent as possible in managing their daily routines when living in a structured institutional environment. With the society increasingly becoming complex and competitive, however, they were not confident that they had proper survival skills to live in the community. Moreover, chronic health problems escalated the financial and physical burden and compromised their ability to meet
their basic needs and medical demands. These women would require a myriad of family and community resources to make a transition from the institution to the community. Feenstra and Pannikar recommended that a holistic health plan with integrated physical and emotional care from a variety of partners be available for all leprosy patients. For older leprosy patients, regardless of their residence, we suggest that incorporating chronic disease education and prevention along with leprosy treatment should be considered.

In summary, this study used the narrative analysis method to explore experiences with leprosy in older Taiwanese women. Findings include that stigma was experienced by the women throughout life stages. Furthermore, these women in their old age faced not only complications from the leprosy but also from chronic diseases, which were more difficult for them to handle because of their leprosy-related disabilities. Prevention of physical impairments and disabilities from leprosy is important, but care plans for older women who have had leprosy also need to consider chronic health problems.

Acknowledgements

This study was partially funded by an International Projects and Activities grant from Indiana University. The authors would like to thank Dr Phyllis Dexter for offering scholarly input during manuscript preparation, Ms Shei-Shun Gi for helping data collection, and Ms Jennifer Yu for editing and giving technical support during manuscript completion.

References

7. Center for Disease Control, Taiwan. Current leprosy update in Taiwan, Department of Health, Taiwan 2005.


