The meaning of physical activity for older adults with leprosy: A life story inside the wall

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Accepted for publication 30 June 2017

Summary
Objective: This study was conducted to reveal the meaning of physical activity for older adults with leprosy who had previously experienced isolation and discrimination, and to motivate leprosy clients to participate in physical activity and keep an active lifestyle.
Method: A qualitative method with content analysis was used to understand the meaning of physical activity in older leprosy patients who had experienced isolation.
Results: After interviewing 23 subjects, four themes and nine categories emerged. The four themes were: physical activity is a natural component of life, physical activity is beneficial to one’s body and mind, difficulty with physical activity is a degrading reminder of leprosy, and physical activity is the acceptance of one’s life circumstances. This article discusses how subjects shaped their lives by communicating through their deformed bodies. This study found that the perspective about their lives became more positive as the subjects aged.
Conclusion: Understanding the complicated experiences of leprosy patients, which combine physical, psychological, and social stresses, as well as overcoming space- and time-related limitations, is the primary contribution of this study. This investigation identified a process of rebirth in the participants, and personal transformation might be involved in this rebirth process. Programme designs are suggested with incentives for community residents to interact with aged leprosy residents within a natural social atmosphere, applying narrative gerontology techniques and integrating the reflection on the meaning of physical activity into existing rehabilitation programmes.

Keywords: Aged, isolation, leprosy, physical activity, qualitative study

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Introduction

Before the introduction of effective medical treatments for leprosy, forced isolation was the only strategy used to treat leprosy. Despite the advancements in drug therapy that have occurred over the last 50 years, many isolated leprosy patients continue to live with their complications in sanatoria in various parts of the world. Isolating leprosy clients in sanatoria reminds us of the policies instilled in many countries, such as in India, China, and Africa. In addition, there are still many clients that voluntarily live in sanatoria, such as those living in Taiwan. These patients suffered from both leprosy-induced physical disabilities and age-related health problems. However, little attention has been devoted to these aged leprosy patients, and sanatorium residents have been particularly neglected.

Skin ulceration, facial disfiguration, claw fingers, and missing limbs are the physical sequelae of leprosy. These progressive deformities influence patients’ abilities to care for themselves, and the severe sensory and functional disturbances lead to disability and poor health. The fear and revulsion associated with deformities of the face, hands, and feet affect the views of lay people regarding leprosy. Social stigmatisation is a major complication of leprosy. Leprosy patients are forced to be segregated from, or to leave their families and are therefore considered exiles from their societies. Leprosy is not merely a physical disease; it also produces psychological and social problems.

Physical activity is a comprehensive term encompassing a variety of activities such as exercise, leisure-time activity and housework. And a large body of evidence supports the notion that physical activity significantly influences the health and quality of life of individuals of different ages and in different settings. However, few studies have examined the experiences of aged patients with leprosy participating in physical activity under the restrictive conditions imposed by physical limitations and social stigma. Previous leprosy projects have focused on the detection and assessment of disability, treatment, primary care, and surveillance in comparatively younger leprosy patients. It is unsurprising that aged leprosy patients exhibit a decreased capacity and motivation to be physically active.

O’Neill stated that the body is the foundation of our lives in this world and is the initial instrument that humans use to observe, think, and develop their world. In other words, the body constitutes the means and the vehicle that individuals use to interact with their environment. The body is composed of two parts, the physical aspect and the communicative aspect. The physical body can be seen and felt, and the existence of the communicative body can be perceived through individuals’ interactions with their society and their world. The body drives personal feelings about time and space in daily activities, and these feelings are then incorporated into personal experience. Thus from the perspective that leprosy influences the physical body and its interactions with its environment, a good starting point for this investigation was to explore the complicated ways in which aged leprosy patients participate in physical activity.

Previous qualitative studies of leprosy have focused on the stigma-related experiences of leprosy patients. From the rehabilitation view, it is important to promote participation by leprosy clients in physical activity and motivate them to keep an active lifestyle. Therefore, the main purpose of this study is to reveal the meaning of physical activity for older adults with leprosy who have previously experienced isolation and discrimination.
Methods

RESEARCH DESIGN, SETTING, AND SAMPLING

This research utilises a qualitative approach to explore the meaning of physical activity for elderly leprosy patients in a sanatorium. The Lo-Sheng leprosy sanatorium was built by the Taiwanese government during the 1930s and was the largest leprosy institution in Taiwan. The admission standards for the leprosy sanatorium were changed to voluntary segregation in 1962. The leprosy sanatorium maintained inpatient facilities for its existing leprosy patients, but no additional patients have been admitted to the leprosy sanatorium since 2001. During the investigation period from 2005 to 2006, residents were recruited to this study. The average age of the segregated leprosy patients in this sanatorium was 73 years (standard deviation $= 9.5$). Purposive sampling was used to recruit subjects. Residents who could communicate in Chinese or Taiwanese and were willing to participate in this investigation were the candidate subjects.

PROCEDURES

Following approval for the study from the Research Ethics Committee of Kee-long Hospital, Department of Health, Taiwan (No. 94-8), posters and flyers were distributed to recruit participants among the residents of the leprosy sanatorium.

After the study was explained and the study subjects had consented to the investigation, a face-to-face in-depth interview with a semi-structured interview guide was performed to collect data. This guide was designed in accordance with the results of the previously published literature. The following questions are examples of this content: What types of physical activity do you perform? What does physical activity mean to you? What influence has leprosy had on your physical activity?

The duration of each interview was around 20–40 minutes. With the consent of the study participants, the entirety of each interview was recorded. The researcher collected information throughout the entire interview and directed assistants to transcribe the content of each recording to a hard copy. The researcher then compared the sentences of the hard copy of each interview with the content of the recording of the interview in question to verify the accuracy of these hard copies. During the process of data collection and analysis, the primary researcher sought help and counsel from experts in the physical activity behaviors of the elderly and qualitative research authorities to ensure the accuracy of the study’s data analyses.

DATA ANALYSIS

The analysis of this study was conducted in accordance with the suggestions by Colaizzi. The researcher listened to the recorded information and read the typed texts to understand the subjects’ experiences. Subsequently, the researcher wrote down significant statements and extracted the meaningful category of these statements. The core themes of the results were then organised from these meaningful categories and compared with the original data, the meaningful categories, and the other core themes of the study. Finally, an exhaustive description of the findings was performed.
Results

There were 23 subjects who participated in this study; 16 of these subjects (70%) were men. The subjects were 78 ± 8 years of age (range: 60–88 years) and had lived in sanatorium for an average of 49 ± 9 years (range: 29–65). Five of the subjects (22%) were amputees, 11 of the subjects were single (48%), and 17 of the subjects lived alone (74%). Many of the study participants had received 6 years of formal education ($n = 9, 39\%$); 8 participants were literate (35%), 5 were illiterate (22%). Thirteen subjects (57%) lived independently, and 10 subjects were partially dependent on the assistance of others. Thirteen of the subjects (57%) participated in various physical activity, such as sports (walking, stair climbing, or gymnastics), housework (cooking or doing laundry), leisure time activities (gardening or singing), and self-care activities (bathing). Simple gymnastics was the most frequent type of physical activity ($n = 10, 43\%$), followed by walking ($n = 8, 35\%$).

Four themes were extracted from the content analysis. These four themes, categories, and original data are listed in Table 1 and described in the following paragraphs.

THEME 1: PHYSICAL ACTIVITY IS A NATURAL COMPONENT OF LIFE

Physical activity is an integral part of certain subjects’ everyday lives and it is as natural as breathing. Two categories were identified. To these subjects, physical activity is an instrumental aspect of their daily lives.

The first category is that physical activity is a natural part of daily life. To some of the interviewed subjects, physical activity was as natural to their lives as eating and sleeping. These subjects made the following types of statements: “Nothing is special. I go out after I get up in the morning.” “Our body feels strange if we don’t exercise.” and “It’s natural.”

Conversations with these study participants about their physical activities demonstrated that most of the activities that the participants mentioned were integrated into their daily routines. The subjects could freely engage in these activities whenever and wherever they wished. One subject said, “I go for a walk after I get up in the morning.”

The second category is “Physical activity is part of an everyday routine”. Physical activity might be seen as habitual. The subjects said, “This is something we must do. It’s a routine.” “We do not get to choose. We have to do it every day.” Physical activity is similar to a job to these subjects; it is a habit and the focus of their lives.

THEME 2: PHYSICAL ACTIVITY IS BENEFICIAL TO ONE’S BODY AND MIND

For certain study participants, physical activity counteracts the threat of disease and aging-related maladies and promotes hope and peace. Thus, three separate categories were grouped into this theme.

First of all, “Physical activity gives health benefits” is identified. Some of the study subjects believed that participating in physical activity was beneficial to their health. These subjects offered the following sentiments: “It’s good for our body.” “It’s good for our health.” Physical activity can prevent bodily failures. Many of the subjects believed that physical activity could maintain their ability to move without limitations. These subjects said, “I do not often feel pain in my body. It also makes me look better.” “My body will become more flexible instead of more rigid.”
Table 1. The themes, categories and original data of meanings of physical activity in isolated older adults with leprosy

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Original data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical activity is a natural component of life</td>
<td>Physical activity is a natural tendency</td>
<td>Nothing is special. I go out after I get up in the morning. Our body feels strange if we don’t exercise.</td>
</tr>
<tr>
<td>Physical activity is beneficial to one’s body and mind</td>
<td>Physical activity is part of an everyday routine</td>
<td>This is something we must do. It’s a routine. We do not get to choose. We have to do it every day.</td>
</tr>
<tr>
<td>Physical activity is beneficial to one’s body and mind</td>
<td>Physical activity gives health benefits</td>
<td>It’s good for our body. It’s good for our health. I do not often feel physical activity in our body. It also makes me look better.”</td>
</tr>
<tr>
<td>Physical activity brings me the joy, peace and hope</td>
<td>Physical activity brings me the joy, peace and hope</td>
<td>I am doing rehabilitation. I feel peaceful. I feel relaxed and enthusiastic.</td>
</tr>
<tr>
<td>Physical activity empowers me</td>
<td>Physical activity empowers me</td>
<td>I can still walk and I do not want to die so soon. I keep an active life-style.</td>
</tr>
<tr>
<td>Difficulty with physical activity is a degrading reminder of leprosy</td>
<td>Physical activity brings out bitterness and frustrations from my past</td>
<td>Look at me. I cannot even walk well, let alone run or jump.</td>
</tr>
<tr>
<td>Physical activity exposes my inferiority</td>
<td>Physical activity exposes my inferiority</td>
<td>If I were not amputated, I could walk the whole day. I am afraid of how others view me. How can we exercise with people without leprosy?</td>
</tr>
<tr>
<td>Physical activity is the acceptance of one’s life circumstances</td>
<td>Physical activity reminds one’s coexistence with leprosy</td>
<td>How could we dare to exercise with people outside the sanatorium? I do not move that well, so I do what I can do</td>
</tr>
<tr>
<td>Physical activity provides a field for one’s cultivation</td>
<td>Physical activity provides a field for one’s cultivation</td>
<td>Sometimes, I think it’s better to see my life from another perspective, so that I do not feel depressed. Because my hands do not move anymore, I quit cigarettes and alcohol. It’s better!</td>
</tr>
</tbody>
</table>
The second category is “Physical activity brings me the joy, peace and hope”. The subjects were aware of the peace and joy that were generated by physical activity. Subjects described physical activity as “I am doing rehabilitation. I feel peaceful.” In the interviews, the researcher noted the joy in the subjects’ eyes as they discussed interactions with their families. For example, one subject said, “I feel more alive and less dull when I am with my grandchildren.” The study subjects also looked forward to group leisure activities, as evidenced by the following statements: “The reason I go there is that many people are there. It’s not fun to be alone.” In addition, physical activity can provide energy: “I feel relaxed and enthusiastic!”

The third category “Physical activity empowers me” which indicated that subjects gained the sense of control when participating in physical activity. The subjects sought mastery over their bodies. The subjects who participated in physical activity were self-motivated. One of these subjects said, “I am old. If I do not move, my health will become worse.” “I can still walk and I do not want to die so soon. So I keep an active life-style.”

Physical activity also represents the patients’ abilities to care for themselves. Thus, physical activity provides a strong motivation for these patients. One of the study subjects said, “If you have a movable body, you do not need to rely on others.” The subjects revealed that engaging in activities allowed them to feel independent. One subject stated, “If possible, I would try my best to perform physical activity, and I can still care for myself.”

Physical activity also provided an opportunity for the study subjects to exhibit the ability to make decisions for themselves. “If you want to do physical activity, you will find a way.” The determined study subjects adopted their own strategies for participating in physical activity; “Do not over-exercise. Do it slowly. Do not ask yourself to achieve inappropriate goals.”

**THEME 3: DIFFICULTY WITH PHYSICAL ACTIVITY IS A DEGRADING REMINDER OF LEPROSY**

In the past, segregation policies, physical deformities, social stigmas, and discrimination restricted the opportunities and the willingness of subjects to participate in physical activity. The participants continue to face leprosy-related physical, mental and social frustrations with respect to participation in physical activity. Two categories were grouped into this theme.

“Physical activity brings out bitterness and frustrations from their past” is identified as the first category in this theme. The researcher found that the isolated sanitarium environment and other leprosy-related limitations caused bitterness and helplessness in subjects. Participants felt powerless because of the issues that their leprosy had created with respect to physical activity. “Look at me. I cannot even walk well, let alone run or jump.” The neuralgia and deformities caused by the progression of leprosy restricted the subjects’ abilities to perform physical activity and engendered sorrow. In a disturbed tone, one melancholy subject stated, “If I were not amputated, I could walk the whole day.” The subjects also cared deeply about the influence of leprosy treatments. One subject said, “There was no medicine available at that time. The function of my nervous system has eroded. Gradually, I became unable to do anything.”

The second category of this theme is “Physical activity exposes my inferiority”. The researcher found that the forced isolation policy produced feelings of inferiority in the minds of leprosy patients. Judgment and discrimination regarding the physical appearance of leprosy patients from individuals outside the sanatorium limited the fields and types of the subjects’ physical activity. The subjects provided the following descriptions: “I am afraid of
how others view me. How can we exercise with people without leprosy?” “Others’ hands are straight, but ours are crooked. We are afraid that others would look at us.” In addition, social stigma was the main reason that the study participants limited themselves. The subjects’ statements included the following concerns: “Leprosy does not sound good. I dare not go out of sanatorium to exercise.” “How could we dare to exercise with people outside the sanatorium?” “If others do not know much about leprosy, they would be afraid of touching us.”

**THEME 4: PHYSICAL ACTIVITY IS THE ACCEPTANCE OF ONE’S LIFE CIRCUMSTANCES**

Participants calmly interpret the meaning of their lives and to define leprosy as a life-long assignment or a test from a supreme God. The subjects addressed their challenges and improved their internal development by participating in physical activity. At first, the subjects considered their disease a punishment that rendered them unequal to healthy individuals. However, as the subjects grew older, they began to view their lives from a more positive perspective. The turning points in many subjects’ minds were identified during the course of the interviews. Two categories were grouped into this theme.

The first category of this theme is “Physical activity helps one to coexist with leprosy”. From the interview data, the researcher found that as the study subjects gradually learned to live with their disease, they became accustomed to their new lives. Regardless of the factors that caused their difficult situations, the subjects realized that leprosy would be an ineradicable stigma in their lives and that they needed to learn to cope with their disease. For example, one subject said, “I do not move that well, so I do what I can do.” The subjects learned to accept reality and face their fate. Although the subjects sighed about the passage of time, they eventually began to reach realistic compromises and participate in the activities in which they could be successful. Thus, over time, the subjects developed a clear understanding and acceptance of their coexistence with leprosy.

The second category is “Physical activity provides a field for one’s cultivation”. These subjects redefined their life philosophies, incorporating more positive attitudes and continuing their lives. Subjects identified the transitions in their minds that occurred when they employed the coping strategy of adjusting their attitudes and facing their futures. At this point, these subjects began to adopt a positive perspective that made them feel better and more comfortable. One subject said, “Sometimes, I think it’s better to see my life from another perspective, so that I do not feel depressed.” Based on their life experiences and introspections, the subjects learned to solve their problems in their own ways. One subject said, “Because my hands do not move anymore, I quit cigarettes and alcohol. It’s better!” This subject scoffed at his past life and at the restrictions that were imposed by his physical limitations.

Similarly, another subject said, “I have to get used to the environment. No environment is absolutely good or bad.” According to the data, the subjects practiced coping with their frustrations and life concerns until they eventually lived peacefully with themselves and their environment.

**Discussion**

Physical activity is a natural aspect of everyday life that produces beneficial health and anti-aging effects in older adults. However, physical activity frequently induced negative
feelings in these patients. In particular, feelings of inferiority were identified in both the current study of leprosy patients and individuals with cerebral palsy. This study’s findings are similar to the results of other investigations that have explored physical activity in aged or disabled populations.

**THE LIFE STORY INSIDE THE WALL**

According to the results of Theme 3 and Theme 4, this study found that aged leprosy patients could enjoy life inside the sanatorium wall despite their previous hatred of their sanatorium-centred lives. Thus, the passage of time allows the same wall to represent two opposite meanings to the study subjects. In the past, the wall of the sanatorium was used to isolate leprosy patients from their families and their society, depriving these patients of their rights as humans and citizens. As time passed, the isolated patients aged, and these elderly patients now live peacefully inside the wall. The wall has been transformed into a protective and safe construct that shields these patients from discrimination. The leprosy patients can live inside the wall without worries or fears. By reviewing the meanings of their participation in physical activity, the subjects reflected on their experiences and ultimately recognised the radical changes within themselves through their deformed physical bodies. In the unique time and space that existed inside the wall, the subjects constructed their worlds and used their bodies to weave their life stories.

**THE BODY OF LEPROSY SUBJECTS IS THE INSTRUMENT FOR THEM TO COMMUNICATE WITH THE WORLD**

This study found that subjects used their deformed physical bodies to participate in daily physical activity. The results of this study indicated how subjects frame the world through their physical bodies and how they communicate with their bodies within the confines of the sanatorium wall. This study found that subjects’ bodily sensations (e.g., painlessness) evoked the content of corporeality. The subjects felt that their disabled bodies restricted them from engaging in physical activity. Through their participation in physical activity, the study subjects perceived the limitations of type, partner and space of physical activity that were caused by leprosy. When they understood and defined leprosy as a lifelong condition, these subjects underwent internal development. This result relates to the concept of the phenomenology of perception, which addresses the way that each subject’s experiences are associated with bodily habits and immediate modes of sensation. These associations generate feelings that possess characteristics of time and space.

The results also indicate the three types of body memory that are incorporated into the concept of corporeality: the customary, trauma, and pleasure aspects of body memory. The subjects felt that physical activity was habitual and was a natural tendency. This feeling represents customary body memory. Shieh and Wang and Tsutsumi et al. found that stigmatisation by the lay population and verbal or physical discrimination occurred during formal and informal encounters involving individuals with leprosy. The current study also found that the study subjects felt inferior to healthy individuals during the course of their participation in physical activity. This feeling represents traumatic body memory. Furthermore, the current study found that the subjects felt happiness, energy, and peace because of their participation in physical activities and that physical activity generated relief and hope for these subjects. In other words, the subjects gained pleasurable body memories.
through the interactions between their bodies and the external environment. This study provides a perspective for understanding the complicated human experiences of leprosy patients, which are combined with physical, psychological, and social stressors, and also transcend space and time. This understanding is the primary contribution of this study.

**REBIRTH OF SUBJECT’S SELF-INTEGRITY**

This study found that the subjects viewed their lives negatively when they were younger, but their perspectives became more positive as they aged. People will re-identify and re-build their sense of self from these experiences, producing a transformation from the past to the present self. A disability provides an opportunity for change and growth in a person’s sense of self.21 This study reported findings similar to the results of McAuley, Courneya, and Letunich22 who reported that the personal self can be transformed through participation in physical activity.

By experiencing their external physical and social environments as well as the limitations of their deformed bodies, the study subjects were able to generate self-dialogue. The content of the transformations that these subjects experienced was noticed by the researcher and by the subjects themselves during the course of the interview process. The subjects initially talked about various concrete objects, such as the inconveniences of their deformities, their physical isolation, and their social discrimination. Gradually, they stopped focusing on the objective losses because of their illness. The subjects faced their challenges by executing physical activity. The subjects continued to develop their self-existence through an integrative process and finally attained a state of existential well-being. Consequently, the subjects began to perceive the value of their existence and the meaning of their lives after their initial experiences of uneasiness and frustration. Through ongoing self-dialogue and self-reflection, the subjects accepted and conquered their challenges and tests. This process allowed the subjects to finally achieve physical, psychological, and social well-being and satisfaction and to calmly accept themselves and the meaning of their lives. The subjects developed a sense of ego-integrity and achieved the goal of successful aging.23,24

**CLINICAL APPLICATIONS**

The subjects reflected about the meanings of physical activity and perceived they live healed, therefore it is highly recommended that these reflections should be integrated in their existing physical activity programs or rehabilitation programs to promote a successful aging process in the individuals. This study also found that the subjects used physical activity as a means of developing their internal cultivation processes. Also, the subjects existed in harmony with themselves, others, their environments, and nature, thereby surpassing disease, space, and time restrictions. Just as Kenyon, Bohlmeijer and Randall proposed narrative gerontology and using life story-telling or narrative methods to realise the meaning and uniqueness of the life situation of the elderly.25 Thus, applying narrative gerontology techniques in leprosy care and encouraging the elderly who live in isolated institutions to reflect on the meaning of physical activity as an aspect of existing physical activity programs is suggested.

Supporting community-based rehabilitation for people with leprosy-related disabilities is one of the key activities in “Global Leprosy Strategy 2016–2020”.7 Currently, the main strategy is to encourage subjects with leprosy to venture out of their isolated areas in search for integration with their communities. Even though there are programmes or services that
allow for volunteering college students to visit them inside their confined areas, there are few situations where the community comes into the environment where people with leprosy reside. Furthermore, the elderly subjects’ declining physical abilities make it inconvenient for this option. Therefore, it is recommended to design new programmes that give incentives for community residents to participate in leprosy sanatoria under a natural social atmosphere. By doing so, the hope of the mental barriers of the sanatoria being eliminated within the communities’ and minds of the leprosy subjects can be met.

A qualitative method was used to reveal the meanings of physical activity for older adults with leprosy, thus, the possible influencing factors of these qualitative responses cannot be explored in this study. Conducting quantitative studies to examine the demographic characteristics, functioning and health status on the meanings of physical activity in this population was suggested.

**Conclusion**

This study provides a perspective for understanding the rare but complicated human experience of leprosy patients, which includes a combination of physical, psychological, and social stressors and surpasses the restrictions imposed by disease, space- and time-related limitations. This perspective might constitute the primary contribution of this study. By asking the subjects about the meaning of their physical activity, this study provides the opportunity for the subjects to recall their life stories. Leprosy patients who were disabled faced their personal challenges and clarified their beliefs about their meaning and purpose as well as the meaning of other people, the environment, and the supernatural. By participating physically in daily activities, the subjects shaped their values and lives by communicating with the mortal world (e.g., the lay population and physical environment) through their own bodies, feelings, and life philosophies. This investigation also identified a process of rebirth in the study participants and personal transformation might be involved in this rebirth process.

Designing programmes with incentives for community residents to participate in leprosy sanatoria and to interact with aged leprosy subjects within a natural social atmosphere is recommended. Furthermore, applying narrative gerontology techniques and the reflections on the meanings of physical activity into a component of existing physical activity or rehabilitation programmes is also suggested.

**Acknowledgements**

This work was supported by Department of Health, Executive Yuan, Taiwan (DOH94-TD-05).

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