

The Meaning of Relocation among Aging Hansen's Disease Survivors in Japan

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Abstract

Purpose: To clarify the meaning of relocation among aging Hansen's disease survivors; to discuss care aiming to manage the negative effects of relocation and promote adaptation to new dwellings.

Methods: 1) Participants: Hansen's disease survivors who intended to move house within B sanatorium in Japan. 2) Data collection methods: Semi-structured interviews. 3) Data analysis: Qualitative and inductive analysis.

Results: Five categories of meaning regarding relocation were extracted from survivors' responses: 1. The burden of relocation after the community's power of mutual aid and mobility had failed due to aging; 2. The burden of creating new strategies to live with multiple severe sequelae in a new environment; 3. Displeasure at the disruption of routines; 4. Dissatisfaction with the decision-making process regarding structuring the building and rooms' layout; 5. Thinking positively to accept moving house and enjoying the new environment.

Conclusion: The following points are important: 1) Patients' living environment can affect both the occurrence and management of Hansen's disease sequelae; 2) Hansen's disease survivors have multiple requirements of their living environment in order to manage multiple severe sequelae; 3) Patients who have lost their sight create mental maps of their living environment; relocation entails the loss of these maps.

Introduction

Historically, Hansen's disease has been stigmatized. Until about 1950, patients with Hansen's disease around the world were forced into isolation in leprosaria. Following the development of the medicine Promin, Hansen's disease could be cured and the WHO recommended cessation of isolation [1, 2]. In Japan, however, laws requiring isolation remained effective until 1996, although in practice isolation ceased gradually. Hansen's disease survivors therefore lost the chance to be reintegrated into society, and continued to live out their lives in sanatoria.

The government abolished laws requiring isolation, apologized to and compensated Hansen's disease survivors, and implemented new laws in 2009. The new laws state that the government will provide lifelong support to Hansen's disease survivors, including the provision of suitable medicine and continued accommodation at sanatoria, and will continue to memorialize the dead, work to promote contact between Hansen's disease survivors and the public, and promote public awareness activities in order to restore Hansen's disease survivors' public image [3].

The incidence of Hansen's disease decreased after 1960 in Japan due to improving public hygiene. In consequence, the population of Hansen's disease survivors is aging (survivors' average age was 82.1 years at 2012), and the number of survivors is decreasing due to survivors' aging and death. The total number was 1840 at 2012; most of these live in 13 national and two private sanatoria. Survivors were rendered infertile by vasectomy; most had broken off their relationships with relatives in order to prevent discrimination against those parties. Sanatorium staff must therefore care for the survivor population for the remainder of their lives. This raises questions regarding the optimal operation and maintenance of facilities following the extreme decrease in total survivor numbers: the sanatoria's operation and maintenance is costly and labor-intensive.

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Some sanatoria have attempted to also accommodate aging people in general, and thereby convert from Hansen's disease-specific facilities to general geriatric health services facilities; however, not all sanatoria are able to do this. The remaining facilities' integration with general aged care therefore requires consideration.

B Sanatorium, which is this paper's participant, is one of the 13 national sanatoria, and is located on an isolated island in the Seto inland sea. The sanatorium owns almost the entire island. The sanatorium is only accessible by ship; it is eight kilometers from the mainland. This isolation impedes B Sanatorium's efforts to make plans for its future; however, B Sanatorium's total number of residents is decreasing faster than that of other sanatoria (eg. 122 person at 2008, 67 at 2015). This means that B Sanatorium must prioritize considerations regarding caring for its residents for the remainder of their lives. We intend to relocate B Sanatorium's residents. Historically, the residents have lived in terrace houses dispersed across the island as married couples or individual persons; however, these houses have become dilapidated, and as residents' physical functioning decreases due to aging, the risk of injury and emergency rises. We intend to construct a new building for geriatric health services, which will permanently accommodate nursing staff, and which residents may visit if they require care.

Nonetheless, although relocation and integration are unavoidable, these changes will strongly affect the resident Hansen's disease survivors due to their age and sustenance of multiple severe sequelae.

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The optimum temperature of mycobacterium leprae is lower than human body temperature; it therefore causes pathological changes in peripheral nerves, skin, and the eyes and nose. These changes are irreversible: sequelae remain after the extinction of the bacterium in the patient. Yamaberi et al. [4] examined the causes of and coping strategies for multiple sequelae before the development of Promin. The loss of pain sensation, which serves as a caution against wounding, and patients' having to work due to poverty, were found to result in common injury; further, primitive medical care, poor hygiene, inadequate infrastructure, and superstitions contributed to debilitating injuries. In sanatoria, residents easily sustain injuries due to sensory and motor nerve paralysis, which in turn makes an appropriate living environment critical to injury prevention. Further, aging tends to diminish individuals' capacity to maintain homeostasis, making aging persons more susceptible of illness and limiting their ability to adapt to environmental change [5]. Changing the living environment may therefore critically affect aging Hansen's disease survivors; however, we have found no ameliorating factors except for air conditioning, which prevents residents suffering heat accumulation due to perspiration disorders [6].

Many Hansen's disease survivors have been made bitter by experiences of discrimination. Sanatorium nurses have a responsibility to promote their health and well being. In this contest, we must minimize the negative effects of relocation, and promote survivors' adjustment to a new living environment.

This study's objectives are as follows: 1) identifying care strategies that will minimize the negative effects of relocation; solving emerging problems in B sanatorium; 2) gathering basic evidence regarding survivors' care requirements and preparing for survivors' relocation, since integration is made necessary by the decreasing number of survivors in Japan; 3) making suggestions regarding the living environment's effect on aging Hansen's disease patients, and regarding survivors' perceptions of relocation, given that the incidence of Hansen's disease is increasing in developing countries; 4) the possibility of generalization to other aging handicapped populations, given that Hansen's disease sequelae are characteristically multiple and severe.

Purpose

The purposes of this study are to clarify the meaning of relocation among aging Hansen's disease survivors, and to discuss care strategies that may minimize the negative effects of relocation and promote adaptation to new living environments among Hansen's disease survivors.

Method

1. Participants: Hansen's disease survivors who intended move house in B sanatorium and volunteered to participate.
2. Data collection: Semi-structured interviews were conducted 7–8 months before relocation. The researcher listened to and empathized with the participants' accounts. Questions were sometimes added in order to clarify responses' meaning. Participants' accounts were recorded; verbatim transcripts were created with permission.
3. Interview guide: Hansen's disease survivors were asked the following questions: 1) what is worrying about preparing to move, 2) what is worrying about life after moving, 3) how are those worries related to your sequelae, 4) what are your wishes regarding your final abode, 5) what pleasure is there after moving, 6) what are your wishes regarding nurses and care staff.

3. Data analysis: Qualitative and inductive analysis were performed as follows, to understand the meaning of relocation as a topic: 1) individual analysis: a) close reading of the verbatim transcript; identifying utterances relating to relocation and expressing their meaning in one sentence, b) grouping sentences with similar meanings, expressing the meaning of the grouped sentences, and creating labels. 2) Holistic analysis: a) reading all labels thoroughly, collating similar labels, expressing their meaning, and creating categories, b) continuing this process, increasing the level of abstraction. 3) Ensuring the results' authenticity and validity: a) supervision by a qualitative researcher during the research process, b) obtaining confirmation from participants regarding categories and subcategories' correct capturing of their meaning.
4. Ethical considerations: Participants were informed that participation was voluntary, that all data would be kept confidential and used only in the study, and that they were free not to answer questions or provide information. Participants also received a description of the research's objectives and procedures. All participants indicated consent orally and in writing. The proposed research was approved by the ethical committee at the National Sanatorium Oshima Seisho-en (Authorization number: H25-2)

Results

Participant characteristics

Participants were ten residents (five male, five female; average age: 80.7±4.9 years). Five participants had spouses; five did not. Regarding sequelae of Hansen's disease, three participants had enucleated eyeballs, and all participants had motor and sensory paralysis. Regarding independence in activities of daily life (ADLs), four participants did not require support, three required partial support, and three required considerable support (Table 1).

The meaning of relocation among aging Hansen's disease survivors

The meaning participants ascribed to relocation was sorted into five categories (Table 2).

1. The burden of relocation after the age-related decline of our community's powers of mutual aid and mobility

This category contained five subcategories: 1. Our power of mutual aid is decreasing because we are all getting old (by the death of other survivors and our spouses, and the decreasing function of the survivors' self-government association and of individuals' physical functioning). 2. Increasing fear of dementia and early death due to environmental changes and overwork due to moving house. 3. Indeterminate anxiety due to inability to imagine life after moving house. 4. Bitter memories of past relocation events. 5. The burden of packing and carrying household goods in a deteriorating living environment.

2. The burden of creating new strategies to live with multiple and severe sequelae in a new environment

This category contained the following subcategories: 6. Participants who had lost their eyesight expressed misgivings regarding being watched while eating, because they felt their manner of eating was disgraceful. 7. Participants who had lost their eyesight felt the burden

Case	Year	Sex	Spouse (presence)	Sequelae of Hansen's disease			Independence in daily life activities
				Lost eyesight	Motor paralysis	Sensory paralysis	
A	85	male	yes	enucleation of eyeball & artificial eye (left), amblyopia (right)	dropping legs (both, using bandage)	anesthesia (hand & foot)	partial support
B	85	female	no	enucleation of eyeball & artificial eye (both)	dropping legs (both, using bandage)	anesthesia (hand & foot)	partial support
C	85	female	no	amblyopia (both)	Charcot's joint (both foot joint), arthrodesis due to splintered fracture (one side), dropping legs (one side, using brace)	anesthesia (hand & foot)	partial support
D	84	female	no	none	none	anesthesia (only right forearm)	no support
E	82	male	yes	amblyopia (right)	none	anesthesia (hand & foot)	no support
F	82	male	no	amblyopia (both)	Charcot's joint (elbow, using brace), transformation by Charcot's joint (both foot joint, using brace)	anesthesia (hand & foot)	full support
G	80	female	yes	none	dropping legs (both, using bandage)	anesthesia (hand & foot)	no support
H	79	female	yes	enucleation of eyeball & artificial eye (both)	dropping legs (one side, using bandage)	anesthesia (hand & foot)	full support
I	75	male	yes (outside sanatorium)	none	amputation (both legs), amputation (fingers at both hands)	anesthesia (hand & foot)	full support
J	70	male	no	lagophthalmos (both)	dropping legs (both)	anesthesia (hand & foot)	no support

Table 1: Participant characteristics.

Category	
Sub category	Lower category
1. The burden of relocation following the age-related decline of our mobility and our community's mutual aid ability.	
1. Because we are all getting old, our ability to help each other is decreasing (e.g., due to the death of colleagues or spouses, and the decreasing functioning of the survivors' self-government association, as well as age-related decreases in individual physical functioning)	1) Mutual aid among Hansen's disease survivors has decreased due to colleagues' death and aging
	2) The functioning of the residents' self-government association has decreased due to residents' death and aging
	3) Relocation is an age-related burden for us, because of decreasing physical functioning, perception, memory, and visual ability.
	4) I hesitate to request support from the sanatorium staff or resident's helpers, because the staff must care for many other residents as well as for me. Additionally, helpers who have light sequelae and who have continued to help residents with severe sequelae for a long time are also aging and feel the burden of caring for residents with severe sequelae.
2. Fear of increasing dementia and early death due to changing environment and overwork from relocation	5) I think if we move house now we are old, dementia among us will increase.
	6) I think if we move house now that we are old, the overwork will cause sickness and death to increase.
	7) I feel anxiety for the future due to aging.
3. Indeterminate anxiety due to the impossibility of imagining life after house-moving	8) I will not know unless I go to the new house
4. Bitter memories of past instances of relocation.	9) After a former relocation, I had difficulty becoming acclimatized to my new life and I have just now become acclimatized.
	10) I had disagreeable experiences in previous moves.
5. The burden of packing and damaging the living environment by carrying household goods	11) Packing is a burden for me.
	12) Carrying household goods brings the deterioration of the living environment; for example, by bringing noise and dust.

2. The burden of creating new strategies in order to live with multiple and severe sequelae in a new environment	
6. Misgivings about being watched while eating among blind survivors who are embarrassed of eating messily	13) I don't want people to see me eating because my blindness causes me to make a mess.
7. The burden of living with blindness and sensory paralysis, and having to lose one's mental map of one's environment and create a new map of a new environment.	14) I have a mental map of my house because I have lost my eyesight and cannot identify items by touch due to sensory paralysis. I have memorized the position and arrangement of items in the room and made a mental map of them over a long time. After house-moving, I would need to make a new mental map of the new house; this is a great burden for me.
	15) Because I had gotten used to my old house and my body understands how I must move, I can move like a person with good vision.
	16) Because I cannot see and cannot perceive by touch, I know my direction by the sound of the radio. And when I change my course I know when I have come to a dead end because I can feel the resistance against my body.
	17) I must re-remember the new layout and position of items at the new house, although I am aging and my memory is failing. I have no confidence about re-learning and feel anxious about becoming familiar with the new house because I am blind and have sensory paralysis, and decreasing memory function.
	18) I will have difficulty, because my spouse who could see is dead.
	19) I cannot understand the layout of the new house, because I cannot see its blueprints.
8. Suffering the loss of a good residential environment that accommodated ones' sequelae, neuralgia, thermal regulation disorder, and poor vision	20) I hope not to lose this living environment that is currently perfect, where natural wind may enter. Natural wind alleviates both my neuralgia and my thermal regulation disorder.
	21) I hope not to lose this living environment that is currently perfect, where I can understand the time, weather, changing seasons, and my direction by the sunlight that entered my room.
9. Fear of increasing injuries that are liable to be more severe due to the characteristics of Hansen's disease, because of loss of a living environment that had been adapted to accommodate hand and leg sensory disorders and prevent injuries.	22) Because of sensory paralysis, I cannot feel when I am injured, and our injuries often become severe and lead to osteomyelitis. So we adapt everything in my room over a long time to prevent injury.
10. Loneliness of a comfortable residential and personal environment as one's final abode.	23) My favorite house is my old house, my old house is comfortable for me.
	24) I hope to continue living here with my familiar neighbors and staff until end of my life.
11. The increasing burden of caring for an aging blind spouse.	25) Because my blind spouse will not adapt to a new house easily, my burden of care for my spouse will increase.
3. Disagreeableness of having one's life disturbed	
12. Misgivings about being disturbed from a familiar daily rhythm built for long time.	26) I don't want to break from my daily rhythm that I have preserved for a long time.
13. Concerns about being disturbed due to living with trouble makers.	27) I don't want to live with troublemakers.
	28) I am worry that nurses will not give me much care, because they will be busy with other residents who cannot perform daily life activities alone due to weak physical functioning from aging and multiple severe sequelae.
4. Dissatisfaction with the decision-making process managing building structure and room layout	
14. Dissatisfaction about inconvenient building structure and room layout.	29) The layout and arrangement of the new houses will be inconvenient for our lives.
	30) Because caregiver convenience will decide things, our familiar Japanese style of the good old days is lost.
	31) I want to live in a house that allows natural wind and sunshine to enter.
15. Angry and resigned about not being able to agree in the process of deciding on the structure of the new building.	32) The new house is not suitable as a place to die.
	33) We cannot accept the process that decided the design and layout of the new building. I feel angry and oppose the move
	34) I don't want to accept the move but I have no choice.
	35) I feel discontent to gather residents at one place due to decreasing number of residents.

5. Thinking positively to accept relocation and enjoy the new environment.	
16. There is no anxiety about moving if our requests will be met.	36) I will overcome the move, because my relationships with my colleagues and the sanatorium's staff are good and I will receive the nurses' care.
	37) My sequelae is light: I have eyesight and no motor paralysis or sensory paralysis. I will overcome the relocation.
	38) Because my spouse will help me/our couple will help each other, if my spouse will be in good, I will overcome the relocation.
	39) If others will help with packing the baggage, I do not feel anxious.
17. All that is necessary is enjoying a full and independent life before and after relocation.	40) I understand and consent to the circumstance that we must move.
	41) I wish to live with independence and autonomy.
	42) I will have a new life after relocation, I feel joy and expectation.
	43) I had hoped to leave this island and live in an apartment in the mainland, but this hope was not fulfilled. So I am looking forward to this move.
	44) I hope to fully enjoy my remaining years of life at the new house, because I understand that the new house is where I will die.

Table 2: Meanings of relocation for aging Hansen's disease survivors.

of losing their mental map of their living environment and having to create a new mental map of their new surroundings. 8. Suffering the loss of a good residential environment that had accommodated the participants' sequelae, neuralgia, thermal regulation disorder, and poor vision. 9. Fear of increasing injuries (which were more likely to be severe due to the characteristics of Hansen's disease) due to the loss of a living environment in which we had contrived to prevent injuries and offset sensory disorders affecting participants' hands and legs. 10. The loneliness of a comfortable residential and personal environment as one's final abode. 11. The increasing burden of caring for an aging blind spouse.

3. Dislike of having one's daily life disturbed

This category contained the following subcategories: 12. Misgivings about being disturbed from a familiar daily rhythm built up over a long time. 13. Worries about being disturbed in daily life due to living with trouble-makers.

4. Dissatisfaction with the decision-making process for structuring the building and room layout

This category contained the following subcategories: 14. Dissatisfaction with inconveniences in the building's structure and room layout. 15. Anger and resignation about not being able to agree in the decision-making process for structuring the building.

5. Thinking positively to accept moving house and enjoying the new environment

This category contained the following subcategories: 16. There will be no anxiety about relocation if our requests are met. 17. All that is required is an enjoyable, full, and independent life before and after relocation.

Discussion

The meaning of relocation for aging Hansen's disease survivors was sorted into five categories. This section will further discuss the extracted meanings, and discuss care aiming to minimize the negative effects of relocation and promote adaptation to life in new accommodation, as well as this study's limitations and implications.

The meaning of relocation among aging Hansen's disease survivors

1. Meanings of aging for Hansen's disease survivors

The burden of relocation following the age-related degradation of mobility and of our community's mutual aid ability—an illustration of the meaning of aging among Hansen's disease survivors.

This burden had two aspects among Hansen's disease survivors: packing baggage and carrying furniture, and adaptation to a new house. These two types of burden are common to general people's experience; however, participants anticipated greater difficulty than in previous experiences of relocation due to an increased number of household effects and large and heavy furniture. The participants were very poor in previous forced isolation, and were therefore unable to acquire household effects. In turn, that meant they were only required to move a small amount of baggage in previous relocations. In contrast, the participants now lived more abundantly, and relocation was an accordingly large-scale endeavor.

Additionally, survivors were critically worried about increasing dementia and death by overwork following relocation. Before and after the Great East Japan Earthquake, the amount of required insurance for long-term aged-care nursing support (measured in terms of approved support) increased by 1.2 times; however, it increased by 1.9 times in 42 towns directly affected by the earthquake and tsunami, and by as much as 4.9 times in 10 towns whose populations were required to relocate following the accident at the Fukushima nuclear power plant. Increasing nursing support was required due to decreasing physical functions, increasing dementia and depression, and loss of care givers due to the death or relocation of their relatives [7]. This data indicates the negative effects of forced relocation. Aging persons typically have decreased physical resilience, adaptability, recuperative power, and homeostatic stability [5]; nurses must therefore provide sufficient support, and assess if aging residents have developed physical or psychological disorders.

Aging residents found house-moving difficult due to decreased mutual aid ability (for example due to the death of their spouses or other survivors, and the decreased functioning of the survivors' self-government association, as well as the residents' own decreasing physical functioning). During forced isolation, this study's participants

received no governmental assistance, and overcame poverty by constructing a mature patients' community that includes sub-systems for self-sufficiency, self-preservation, and social security [8]. They had subsequently taken pride in not depending on the sanatorium staff, and had believed that the staff were unhelpful and merely endured the patients' presence. This self-government association has managed and decided all daily concerns until recently. Additionally, this community is composed only of elderly persons, as by law the survivors were not permitted to have children. Hence, due to the residents' aging and death, this community has weakened and lost its ability to manage daily affairs. This community's diminished coping ability, as well as the participants' individual aging, led this study's participants to feel helpless and anxious about adapting to new accommodation, and these feelings led to concerns of dementia or death. Decreasing defensive strength, endurance, adaptability, and resilience affected the residents' community as well as affecting individual residents, diminishing the community's ability to preserve homeostasis.

Further, the first category of meaning ("The burden of relocation after the age-related decline of our community's powers of mutual aid and mobility") indicates the meaning of aging for this study's participants: the entire community is aging. Nurses therefore carefully assessed the residents' personal physical and psychological functioning, and compensated for decreasing functioning in the community while respecting the residents' autonomy and independence.

2. The significance of the living environment among Hansen's disease survivors with multiple and severe sequelae.

Category 2 ("The burden of creating new strategies to live with multiple and severe sequelae in a new environment") illustrates the significance of the living environment for Hansen's disease survivors with multiple and severe sequelae.

The optimum temperature of mycobacterium leprae is lower than the human body's temperature; it therefore multiplies in the skin, nose, peripheral nerves, etc. Regarding eye symptoms, retrograde infection of mycobacterium leprae had caused some survivors to lose their eye sight or their eyes, or to develop amblyopia through corneal injury resulting from lagophthalmos or iridocyclitis. Regarding peripheral nerves, some participants' sensory, motor, and autonomic nerves were damaged due to damage to the nerve trunk. Regarding sensory nerve disorder, patients easily injure their hands and legs due to loss of perception (resulting from narcosis), and osteomyelitis often necessitated the amputation of fingers. Regarding motor nerve disorder, some patients' facial expression was changed due to facial nerve paralysis; patients also suffered foot drop and claw toes, wrist drop, ape hand, and claw hand. Regarding peripheral nerve disorder, patients may suffer heat accumulation due to perspiration disorders.

Before the development of Promin, people with Hansen's disease were often poor and therefore commonly injured themselves due to being forced to work in hazardous environments; additionally, osteomyelitis commonly led to amputation of extremities [4]. Patients' living environment thus affected the occurrence of sequelae. Additionally, this study showed that the living environment affects the management of sequelae. For example, participants who had been blinded and sensory paralysis had created a mental map of the furniture and other objects in their accommodation, allowing them to navigate their living space freely. Cool natural wind relieved heat accumulation on hot days without exacerbating patients' neuralgia. Survivors with amblyopia could discern the time, weather, and

change of seasons from sunshine entering the room. This illustrates that survivors had constructed an environment that suited them and accommodated their sequelae as well as possible over a long time. Relocation meant the loss of this environment; it was therefore different from a normal persons' experience of relocation.

Currently, new cases of Hansen's disease are appearing in developing counties such as India, Brazil, and Indonesia; in contrast, almost no new cases are appearing in developed countries. The prevention and management of sequelae are critical issues in developing countries. Our study indicates that the living environment importantly affects Hansen's disease patients and survivors regarding the prevention and management of sequelae. Very few studies have examined this topic; further research is therefore required.

Multiple severe sequelae are characteristic of Hansen's disease; these sequelae impede adaptation to new living environments. For example, patients who have lost their eyesight but retained their sensory nerves may understand objects by touch; however, Hansen's disease survivors with poor eyesight and sensory paralysis cannot understand objects by touch. Survivors must therefore create and memorize a mental map of their surroundings, and for instance be able to determine their location and direction by the sound of a radio or by feeling resistance from colliding with a wall, or with the help of a spouse with good eyesight. Similarly, survivors with perspiration disorders resulting from autonomic nerve disorders accumulate heat easily, and in west Japan peak temperatures reach 37 degrees Celsius and the average humidity is 70% during summer. We therefore control the temperature using an air conditioner; however, excess cooling can provoke neuralgia. Capturing the natural sea breeze resolves this issue by providing sufficient cooling to prevent heat accumulation while avoiding provoking patients' neuralgia. Additionally, survivors with dropped and unclosed lips due to facial nerve paralysis, absent nasal septa, saddle nose, amputated fingers, and blindness experience difficulty eating, and commonly drop or soil their faces with food. These survivors therefore aim to eat alone in order to preserve their self-esteem. Survivors' living environments must thus simultaneously fulfil multiple requirements in order to accommodate the multiple severe sequelae that are characteristic of Hansen's disease. Relocation therefore entails the loss of this specially-suited living environment that fulfills multiple requirements; it is critical that nurses understand the importance of this loss.

Hansen's disease survivors protect themselves from physical injury by adapting their living environment. Survivors are injured easily due to anesthesia caused by nerve damage; further, their injuries may easily be severe and become intractable. They compensate for this lack of perception by continually touching objects, and thereby becoming able to safely navigate their environments. The loss of this environment due to relocation thus directly increases the risk of severe and intractable injury.

Of all sequelae, blindness has perhaps the most severe effect on survivors. Before the development of Promin, blindness was one of the so-called three great sufferings (with the other two being the disease's diagnosis and tracheotomy). At that time, an economic differential existed between patients who were and were not able to work. Blind men experienced the greatest poverty because they could not work; this caused the self-government association to feel pity and led to the establishment of the mutual aid system [1,8]. Before the development of Promin, blindness was a severe sequela that brought poverty; currently, blindness remains the factor that most impedes

survivors' adaptation to new living environments. Caregivers must understand survivors' difficulty in creating a mental map of a new house at an advanced age, given that the process is likely to lead to injury and will necessarily take place in a context of weakened mental function and homeostatic stability.

As mentioned above, survivors' sequelae are affected by the living environment regarding both occurrence and management. Multiple severe sequelae are characteristic of Hansen's disease; survivors' living environments must accommodate survivors' sequelae, and blind survivors have the most difficulty adapting to new environments. In Japan, the shrinking survivor population will eventually necessitate laws requiring the amalgamation of survivors and sanatoria with general aged care, due to tight national medical budgets and sanatoria's high costs of operation and maintenance. Nonetheless, governmental and facility administrators' integration plans must be informed by an understanding of the essential meaning of relocation among survivors of Hansen's disease, which differs from that of relocation among the general aging population. Nurses' management of survivors' daily life must reflect the same understanding. We regard transmission of this information to medical administrators and national Hansen's disease survivors' self-government organizations as constituting advocacy on behalf of the survivors. Further, we must measure the effect of relocation in this population and integrate the resulting data into future reforms.

3. Adaptation to the loss of an old, familiar, and emotionally important house

Category 4 (dissatisfaction with the decision-making process for structuring the building and room layout) and category 5 (thinking positively to accept moving house and enjoying the new environment) illustrate different patterns acceptance of relocation.

During the initial decision-making process, the sanatorium's staff explained the relocation plans to the residents' self-government association and engaged the association in discussion; however, the residents expressed anger and dissatisfaction, reflecting survivors' anticipation of loss due to moving house. Most importantly, relocation involves the loss of a living environment that is palliative of multiple and severe sequelae and which has been constructed over a long time, as explained at above.

Additionally, this study's participants have lived in their established accommodation for between 60 and 70 years, due to the isolation imposed historically by the government. Currently, they are free to go, but are incapable of doing so and feel despair at the prospect of being unable to leave until their death, seeing the sanatorium as a tomb. The participants described attempting to improve their living environment in the understanding that it was where they would remain until their death. They had lived in their old houses while comforting a bereaved spouse or in the vigor of their youth, and therefore held attachments

to and important memories of their house, and had formed relationships with their neighbors. Withdrawal and solitary death among elderly people increased following the Great Hanshin Earthquake (January 1995) partly because officials inadvertently severed elderly people's relationships with their neighbors while providing assistance. In light of our analysis of this phenomenon, following the Great East Japan Earthquake (March, 2011), victims entered temporary accommodation on an area-by-area basis in order to preserve relationships between neighbors. Relocation may entail the loss of a familiar and emotionally important place, and the loss of relationships between neighbors.

Further, aged individuals are confronted with their own aging and imminent death, and failing physical abilities may cause the loss of autonomy and independence through inability to perform ADLs, which in turn may disrupt the survivors' community (e.g. in section 1.1 above). These multiple losses may cause aging residents to experience multiple layers of grief. Additionally, the weakening of the survivors' community entails the loss of social support. In this context of multiple losses, the additional loss of an emotionally important house is likely to provoke an angry, resigned, or dissatisfied reaction, making acceptance of relocation difficult for aging residents. Nurses must understand and care for abstruse grief that manifests as anger, resignation, and dissatisfaction in response to relocation. Further, the experience of repeated loss may cause individuals to enter exhaustive crises [9]. Nurses must assess residents' recognition of this situation and organize sanatorium staff to provide social support, for instance by using Aguilera's crisis intervention model.

In contrast, a small number of participants accepted the relocation plans positively and awaited relocation with pleasure. One such participant has relatively light sequelae and finds value in gardening, and had hoped to live outside the sanatorium one day. Another participant has heavy sequelae but is curious, and likes eating, shopping, and interacting with others. The sanatorium therefore needs to allow for value in residents' lives, as well as compensating for decreasing physical and psychological functioning due to aging and providing end-of-life care. Nurses at B sanatorium should listen to survivors' life stories and work to pass the history of Hansen's disease and patients' sufferings on to future generations [10]. Listening with empathy and helping to pass down experiences importantly helps patient to find value in life. In old age, developmental tasks use integration to protect against despair, and it is important for elderly people to be able to listen to their own life story in order to feel that they have used their wisdom to strengthen society [11]. Nurses must support this process to protect elderly people from despair resulting from multiple losses and provide end-of-life care that makes life worth while for elderly people.

Care plan for aging Hansen's disease survivors in order to minimize the negative effects of relocation (Table 3)

1) Government medical administrators responsible for planning nation-wide integration, sanatorium administrators responsible for planning and implementing relocation in sanatoria, and nurses and sanatorium staff who care for aging residents must fully understand the meaning of the living environment and of relocation for aging Hansen's disease survivors.		
2) The above parties must aim to minimize the burden of relocation in the context of a survivor community whose mobility and mutual aid ability has been degraded by aging.	(1) Sanatorium staff must compensate for the above age-related degradation in order to avoid fatiguing the residents during relocation	a) Assist with packing and unpacking baggage, and tell residents not to pack things themselves.
		b) Help residents to pack who do not require support in their daily life.
		c) Have places prepared for residents to rest during packing and transporting baggage.
		d) Actively assist in ADLs following relocation.

Continue...

	(2) Strengthening care that supports age-degraded physical and psychological functioning	a) Prioritize physical assessment for early detection of physical deconditioning and chronic illness.	
		b) Continue early detection of and suitable care for dementia	
		c) Particularly provide care to prevent accidents (e.g. falling).	
		d) Detail-oriented care supporting residents' ADLs.	
	(3) Future research should confirm the effects of relocation; subsequent strategies should be revised to reflect the confirmed effects.		
3) Care aiming to alleviate the burden of developing new strategies to live with multiple and severe sequelae in a new environment	(1) Educate nurses and residents regarding the need for the living environment to accommodate multiple severe sequelae; support this environment's re-creation.	a) Nurses should assess and understand each resident's requirements.	
		b) Before entering new accommodation, nurses and residents should repeatedly and collaboratively consider how to best prepare the new house to meet the resident's requirements.	
		c) After entering the new accommodation, nurses should identify and improve unsatisfactory elements.	
	(2) Supporting blind residents with sensory paralysis	a) Nurses should empathize with residents' grief over losing their mental map of their accommodation, and understand the resulting inconvenience.	
		b) Nurses should aim to prevent accidents and minimize inconvenience due to residents' loss of their mental map.	i) The nurse and resident must repeatedly preview the new house in a preparatory period before moving into the house.
			ii) The layout and position of objects should be as similar as possible between the resident's old and new houses.
			iii) Blind persons with sensory paralysis require the most considerate care; nursing administrators should therefore implement systems permitting nurses to care thoroughly for such residents.
			iv) Thinking collaboratively about how to use residents' remaining functions, for example if blind residents aim to determine their orientation using their hearing, staff should consider using the sound of radios or bells. Likewise, if blind residents aim to recognize distance by feeling resistance on colliding with a known object such as a door or pole, staff should cover that object with protective padding.
			v) If a spouse with good eyesight is supporting a blind resident, staff should particularly monitor the spouse for fatigue or loss of physical condition. If the spouse feels burdened by a particular care requirement, for example helping the blind resident to bathe, staff should discuss supporting that care requirement with the spouse and the resident.
			vi) Provide adequate support for residents' ADLs.
vii) Implement strategies that prevent accidents.			
c) Prevention of withdrawal	i) Staff should plan to regularly interact and have conversations with residents and other staff in order to prevent withdrawal due to relocation.		
	d) Promoting creation of new mental maps	i) Nurses should encourage residents to take their time and be patient, as residents' memory functioning may have decreased since they first created mental maps of their living environment. If residents remember a little, staff should recognize and affirm it.	
		ii) When previewing and attempting to mentally apprehend a new house, a blind resident may feel his or her way into the new house using remaining sensory functions, for example by using tactile sensory function in the tongue or by feeling bodily resistance on collision with an object. Staff should aim to identify further means of helping residents to use their remaining functions to understand the building's structure and layout three-dimensionally, for example by using a three-dimensional printer to create a model of the building.	
	e) Staff should avoid relocating blind residents with sensory paralysis and no spouse.		
(3) Care aiming to diminish injury risk among residents with sensory paralysis	a) Nurses and residents should conduct a safety patrol to identify high-risk places and consider strategies for preventing injury. Including residents and nurses in such patrols will help to minimize rebound and preserve the chosen strategies by increasing resident acceptance of those strategies [12].		

		b) Any dangerous places that cannot be made safe due to resident opposition should be recognized as hazardous by nurses and nurse assistants; nurses should particularly monitor such places to prevent injury.
		c) Regarding residents with good eyesight and sensory paralysis, nurses should develop strategies to make risks easily visible, for example by using a thermometer to prevent burn injuries in bathing.
	(4) Support residents' privacy while eating	a) Nurses should prepare private dining rooms for blind residents.
	(5) Support for managing neuralgia and heat accumulation	a) Nurses should suggest using air conditioners during hot and humid days.
		b) The air conditioner' temperature should be set slightly high and combined with an electric fan.
4) Managing displeasure at having daily routines disturbed	(1) Nurses should value long-standing daily schedules, and adjust the timing of complete sections of residents' schedules.	
5) Care aiming to alleviate multiple losses and make life worthwhile	(1) Preventing residents' descent into an exhaustive crisis; understanding residents' suffering due to multiple losses	a) Facility administrators should arrange for nurses to form relationships with the residents, and implement systems encouraging nurses to listen to residents' accounts of their suffering.
		b) Nurses should understand and empathize with multiple losses, including that of the resident's house, spouse, friends, or community.
		c) Nurses should care for residents as quasi-family until the end of the residents' life, and then pass on the residents' life stories.
	(2) Care aiming to sustain and ensure acceptance of relocation and enjoyment of life	d) In order to prevent residents falling into crises of exhaustion, nurses should use Aguilera' crisis intervention model to promote realistic perception of situations and provide adequate situational support [9].
		a) Nurses should maintain a positive attitude.
		b) Nurses should identify potential sources of pleasure in the new houses with the residents, and work to actualize them.

Table 3: Care plan for aging Hansen's disease survivors in order to minimize the negative effects of relocation.

Applications and Limitations

1) This study's limitations

This study's primary purpose was to resolve a critical issue at B sanatorium in Japan, using scientifically rigorous methodology. B sanatorium is located on an isolated island and its resident population is decreasing rapidly; these facts differentiate it from other sanatoria. This study examined the obtaining situation in B sanatorium. Further, the considered relocation was within the sanatorium, and not to a location outside the sanatorium. This study's results may therefore differ from those that would be obtained in the integration of several sanatoria.

2) Applicability to the general aging and handicapped population

In this study, handicapped residents managed their sequelae by changing their living environment and by developing adaptive behavioral strategies. Particularly, blind residents created mental maps of their environment over long periods. Relocation entails the loss of these specially adapted environments and strategies. Additionally, aging was observed to occur in the community as well as in individuals. These results may be applicable to general rehabilitation and gerontology; however, this generalize ability is limited by the facts that Hansen's disease is characterized by multiple severe sequelae, that Hansen's disease survivors in Japan do not have children, and that their community is therefore composed of aging persons.

Conclusion

The meaning of relocation among aging Hansen's disease survivors was categorized as follows: 1. The burden of relocation after the age-

related degradation of our mobility and of our community's mutual aid ability. 2. The burden of creating new strategies to manage multiple severe sequelae in a new environment. 3. Displeasure at being disturbed from established routines of daily life. 4. Dissatisfaction with the process for deciding the structure of the buildings and rooms' layout. 5. Thinking positively to accept relocation and enjoy the new environment.

This study has the following important points: 1) the living environment affected the occurrence and management of Hansen's disease sequelae, 2) Hansen's disease survivors must adapt their living environment to meet multiple environments in order to manage multiple severe sequelae, 3) blind survivors created mental maps of their living environment; relocation entails the loss of these maps.

Competing Interests

The author declare that she has no competing interests.

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