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# Changes in Health Status among Institutionalized Hansen's Disease Patients

Mari Kataoka

Questionnaire surveys to measure the health status among patients of one of the national leprosariums in Japan were conducted in 1991 and 1995. In the first survey, a total of 243 patients answered the questionnaire, of which the response rate was 73.6%. As for the second survey, 241 patients answered the questionnaire of which the response rate was 91.9%. The questionnaire asked the participants on their health status which were comprised of physical health status aspect, degree of life satisfaction, and social aspects that consisted of participating in group activities.

Improved physical health status, increased level of life satisfaction, and decreased participation in group activities were found among patients. These findings suggest the effects of the abolition of the Leprosy Prevention Law that took effect in April, 1996 and improvement of treatment environment for the patients. The difference in method of data collection between the first survey and the second one showed the limitations of the study.

## Key Words

Hansen's disease,  
leprosarium,  
physical health status,  
life satisfaction,  
social aspect.

## INTRODUCTION

Recently the incidence of leprosy has decreased in Japan. As a result, the total number of Japanese leprosy patients who were in the national leprosariums in 1996 was 5,479 and the average age has been prolonged to 70.6 years.<sup>1)</sup> The patients had been restricted to the leprosariums under the control of the Leprosy Prevention Law promulgated in 1907. After a

long dispute, this law was abolished in April, 1996, and they were free to go out of the leprosariums. However because of their advanced age, their decreased physical health status, and sparse social network, it is difficult for them to live by themselves without any assistance. As a result, most of the patients remained in the leprosariums.

Many publications about Japanese leprosy patients focussing on their stigmatic and discriminated lives have been written by the patients themselves,<sup>2-4)</sup> leprosarium workers,<sup>5-7)</sup> reporters,<sup>8)</sup> and writers,<sup>9)</sup> whereas few researches regarding health status on leprosy patients were reported.<sup>10-12)</sup> This study was carried out identifying the changes in physical, psychological, and social aspects of leprosarium patients within a four-year period.

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## SUBJECTS AND METHODS

The subjects of this study were all the institutionalized patients who were registered and living in one of the national leprosariums located at the Seto Inland Sea. The first survey was conducted in 1991, and the second one, carried on in 1995 to examine the health status and social aspect of the patients using the same questionnaire. In this report, the subjects whose gender and age were unidentified were excluded in the process of data analysis. The response rates of the first survey and the second survey were 73.6% (71.4% for male and 77.8% for female) and 91.9% (92.0% for male and 91.8% for female), respectively.

A self-administered questionnaire on life styles and health status was distributed and collected individually. The patients were asked about their physical health status, life satisfaction, and social aspects. Physical health status evaluated three aspects: 1) the level of independence in the Activities of Daily Living (ADL), 2) experience of medical check and 3) subjective health prior to one month. Most questions were stratified in four responses. As for life satisfaction, there were seven answers ranging from 'delighted' to 'terrible' according to the Delighted Terrible Scale<sup>13)</sup> and stratified into three categories. Social aspects were examined by attendance of group activities, having friends, and frequency of contact with family.

Those patients who could not fill out the questionnaire by themselves by reason of poor eyesight, impaired

hand writing, or difficulty in reading were asked and the answers were written by nurse aids or nurses on their behalf in the 1991 survey. In the 1995 survey, the researcher or investigators, instead of nurses and nurse aids filled out the questionnaire. Data were collected and each item of the question in the first and second surveys was analyzed by comparing the gender and age groups. The age groups were divided into three which were 40-59 years, 60-69 years, and 70 years and over. Chi-square was used to compare the rate of categories of each item in 1991 and 1995.

## RESULTS

### *The age distribution*

Table 1 provided a comparison of age distribution in 1991 to 1995 by age groups by gender. The ratio of 40-69 years old age groups in 1995 tended to be lower than that of 1991 (except 50-59 age group of female), while 70 years old and over age groups in 1995 tended to be higher than that of 1991 for both male and female patients.

### *Treatmental aspects*

Table 2 showed the comparison of the ward where patients belong to the leprosarium in 1991 and 1995 by gender. The ratio of each ward which was for medical treatment, for physically disabled, and for physically abled in 1991 and 1995 were similar to each other for both female and male.

### *Physical health aspects*

Table 3 presented a comparison of physical health status which was com-

prised of ADL items, medical check, and subjective health in 1991 and 1995 by age groups and by gender. In ADL items, independence ratio tended to be higher in 1995 in 1991 among all the age groups for male and female patients. As for male patients, 3 out of 18 items were found to be significantly higher in independence among all age groups while for female patients, one out of 18 items was found significantly higher in independence in 1995 than in 1991.

The ratio of received medical check up received in a month among 40-60 year old age groups of 1991 and

1995 were similar for both genders. Concerning the over 70 years and over age group, the ratio of medical check up received in 1995 tended to be higher than in 1991 for both genders. In subjective health, the ratio of 'moderate' was higher and 'poor or terrible' tended to be lower in 1995 than that of 1991 for all the age groups for male patients whereas this tendency did not apply to female patients. However, there was no significant difference between the ratio of all the subjective health categories in all the age groups for both genders in 1991 and 1995.

Table 1 Comparison of the age distribution of the subjects between 1991 and 1995 by gender ( ):%

Gender		Male		Female	
Year		1991	1995	1991	1995
Age	40-49	5( 3.3)	1( 0.7)	4( 4.4)	1( 1.0)
	50-59	24( 15.8)	17( 11.8)	14( 15.4)	17( 16.8)
	60-69	63( 41.4)	55( 36.7)	35( 38.5)	29( 28.7)
	70-79	41( 27.0)	52( 34.7)	28( 30.8)	39( 38.6)
	80-	19( 12.5)	25( 16.7)	10( 11.0)	15( 14.9)
Total number		152(100 )	150(100 )	91(100 )	101(100 )

Table 2 Comparison of the types of the ward distribution of the subjects between 1991 and 1995 by gender ( ):%

Gender		Male		Female	
Year		1991	1995	1991	1995
Ward for medical treatment		10( 6.6)	18( 12.0)	3( 3.4)	7( 6.9)
Ward for physically disabled		85( 55.9)	81( 54.0)	55( 61.8)	56( 55.4)
Ward for physically abled		57( 37.5)	51( 34.0)	31( 34.8)	38( 37.6)
Total number		152(100 )	150(100 )	91(100 )	101(100 )

**Table 3** Comparison of physical health status of the subjects between 1991 and 1995 by age groups and gender

Age	40-59		60-69		70-	
Year	1991	1995	1991	1995	1991	1995
Male	N=29	N=18	N=63	N=55	N=60	N=77
ADL						
Walking						
Independent	74.1%	88.9%	60.3%	75.9%	54.4%	59.2%
Dependent	25.9	11.1	39.7	24.1	45.6	40.8
Bathing						
Independent	88.5	94.4	72.4	85.2	64.9	70.1
Dependent	11.5	5.6	27.6	14.8	35.1	29.9
Toileting						
independent	92.3	100	94.8	94.4	84.2	89.6
dependent	7.7	0	5.2	5.6	15.8	10.4
Grooming						
independent	85.2	88.9	58.6	66.0	50.0	58.4
dependent	14.8	11.1	41.4	34.0	50.0	41.6
Chores						
independent	60.7	88.9 *	36.7	59.3 *	47.4	51.3
dependent	39.3	11.1	63.3	40.7	52.6	48.7
Dressing						
independent	80.8	94.4	48.2	81.5 ***	60.0	71.4
dependent	19.2	5.6	51.8	18.5	40.0	28.6
Medical check up						
Not received	10.7	11.7	9.8	9.1	5.5	11.7
Received	89.3	88.9	90.2	90.9	84.5	88.3
Subjective health						
Excellent or good	10.3	16.7	11.3	16.4	19.0	13.0
Moderate	58.6	66.7	37.1	52.7	43.1	58.4
Poor or terrible	31.0	31.0	51.6	30.9	37.9	28.6
Female	N=18	N=18	N=35	N=29	N=38	N=54
ADL						
Walking						
independent	93.8%	100%	71.9%	75.9%	51.4%	50.0%
dependent	6.3	0	28.1	24.1	48.6	50.0
Bathing						
independent	93.8	100	80.6	82.8	71.4	68.5
dependent	6.3	0	19.4	17.2	28.6	31.5
Toileting						
independent	100	100	100	100	91.4	96.3
dependent	0	0	0	0	8.6	3.7
Grooming						
independent	81.3	100	78.1	79.3	57.1	42.9
dependent	18.8	0	21.9	20.7	42.9	57.1
Chores						
independent	66.7	100 **	59.4	65.5	45.7	48.1
dependent	33.3	0	40.6	34.5	54.3	51.9
Dressing						
independent	86.7	100	74.2	82.8	52.9	64.8
dependent	13.3	0	25.8	17.2	47.1	35.2
Medical check up						
Not received	18.8	16.7	19.4	20.7	25.0	31.5
Received	81.3	83.3	80.6	79.3	75.0	68.5
Subjective health						
Excellent or good	18.8	16.7	3.1	6.9	16.7	13.2
Moderate	68.8	61.1	71.9	62.1	50.0	52.8
Poor or terrible	12.5	22.2	25.0	31.0	33.3	34.0

\*:p&lt;0.05, \*\*:p&lt;0.01, \*\*\*:p&lt;0.001

**Life satisfaction**

Table 4 presented the comparison of life satisfaction in 1991 and 1995 by age groups and by gender. The ratio of life satisfied which combined 'delighted', 'pleased', and 'mostly satisfied' of 1995 tended to be higher than that of 1991 for both genders. Specifically for the age group of 70

years and over for male and 60-69 age group for female, this ratio was significantly higher in 1995 than 1991. On the other hand, the ratio of 'mixed (about equally satisfied and dissatisfied)' in 1995 tended to be lower than 1991 for all the age groups for both genders.

**Table 4** Comparison of life satisfaction of the subjects between 1991 and 1995 by age groups and gender

( ) : %

Age	40-59		60-69		70-	
Year	1991	1995	1991	1995	1991	1995
<b>Male</b>						
Delighted, pleased, or mostly satisfied	5( 18.5)	5( 27.8)	19( 31.1)	26( 48.1)	23( 43.4)	56( 72.7)**
Mixed (about equally satisfied and dissatisfied)	19( 70.4)	9( 50.0)	33( 54.1)	21( 38.9)	23( 43.4)	14( 18.2)
Mostly dissatisfied, unhappy, or terrible	3( 11.1)	4( 22.2)	9( 14.8)	7( 13.0)	7( 13.2)	7( 9.1)
Total number	27(100 )	18(100 )	61(100 )	54(100 )	53(100 )	77(100 )
<b>Female</b>						
Delighted, pleased, or mostly satisfied	4( 22.2)	9( 52.9)	13( 40.6)	24( 82.8)*	14( 42.4)	33( 66.0)
Mixed (about equally satisfied and dissatisfied)	12( 66.7)	6( 35.3)	13( 40.6)	1( 3.4)	16( 48.5)	14( 28.0)
Mostly dissatisfied, unhappy, or terrible	2( 11.1)	2( 11.8)	6( 18.8)	4( 13.8)	3( 9.1)	3( 6.0)
Total number	18(100 )	17(100 )	32(100 )	29(100 )	33(100 )	50(100 )

\*:  $p < 0.05$ , \*\*:  $p < 0.01$

**Social aspects**

Table 5 presented the comparison of social aspect of 1991 and 1995 by age groups and by gender. The ratio of attending group activities of 1995 was lower than that of 1991 of all age groups for both gender. The ratio of having friends was not found

to be different between 1991 and 1995 (except 60-69 age group for male). The ratio of frequent contact with family tended to be higher in 1995 than that of 1991 for both genders while the ratio of not having contact tended to be lower in 1995 than 1991.

**Table 5.** Comparison of social aspects of the subjects between 1991 and 1995 by age groups and gender

( ) : %						
Age	40-59		60-69		70-	
Year	1991	1995	1991	1995	1991	1995
<b>Male</b>						
Group activities						
Attending	14( 50.0)	7( 38.9)	37( 62.7)	23( 41.8)*	29( 53.7)	23( 30.3)**
Not attending	14( 50.0)	11( 61.1)	22( 37.3)	32( 58.2)	25( 46.3)	53( 69.7)
Friends						
Having friends	21( 77.8)	13( 72.2)	40( 69.0)	48( 87.3)*	49( 90.7)	59( 77.6)
Not having friends	6( 22.2)	5( 27.8)	18( 31.0)	7( 12.7)	5( 9.3)	17( 22.4)
Contact with family						
Frequent contact	8( 28.6)	7( 38.9)	12( 20.3)	15( 27.8)	14( 25.9)	25( 32.9)
Little contact	13( 46.4)	1( 38.9)	36( 61.0)	33( 61.1)	22( 40.7)	35( 46.1)
Not having contact	7( 25.0)	4( 22.2)	11( 18.6)	6( 11.1)	18( 33.3)	16( 21.0)
Total number	29(100 )	18(100 )	63(100 )	55(100 )	60(100 )	77(100 )
<b>Female</b>						
Group activities						
Attending	17( 94.4)	10( 55.6)**	13( 43.3)	6( 20.7)	17( 53.1)	14( 26.4)*
Not attending	1( 5.6)	8( 44.4)	17( 56.7)	23( 79.3)	15( 46.9)	39( 73.6)
Friends						
Having friends	15( 88.2)	13( 72.2)	27( 90.0)	27( 93.1)	25( 78.1)	42( 82.4)
Not having friends	2( 11.8)	5( 27.8)	3( 10.0)	2( 6.9)	7( 21.9)	9( 17.6)
Contact with family						
Frequent contact	3( 16.7)	8( 44.4)	10( 31.3)	12( 42.9)	9( 28.1)	11( 22.4)
Little contact	13( 72.2)	8( 44.4)	19( 59.4)	10( 35.7)	12( 37.5)	26( 53.1)
Not having contact	2( 11.1)	2( 11.2)	3( 9.4)	6( 21.4)	11( 34.4)	12( 24.5)
Total number <sup>1)</sup>	18(100 )	18(100 )	35(100 )	29(100 )	38(100 )	54(100 )

\*:  $p < 0.05$ , \*\*:  $p < 0.01$

1) Subjects those who did not answer were excluded.

## DISCUSSION

Table 1 showed progressive aging during four years (1991-1995) among male and female leprosarium patients. These findings identified the increased average age of the Japanese leprosarium institutionalized patients as well as the decreased number of new leprosy cases.<sup>14)</sup>

Table 2 showed no change was found during four years in the type of the ward where the patients belonged according to the assistance needed by their physical and mental conditions. This fact also identified the findings shown in Table 3 that the physical status of the patients have been improved as far as ADL were concerned especially for male patients. This finding could be explained as follows. The efficiency of the daily care by the staff may have contributed to their improved physical health status. As for male patients, their independence level in ADL items were lower in 1991 when compared to female, the increase in 1995 was significant. The finding suggested that the improved structural environment and facilities of the institution contributed to increased ADL.

Table 4 showed improved tendency of life satisfaction of the patients in 1995. This fact might be the effect of the aging of the subjects. Araki<sup>15)</sup> conducted a research on a community-based rehabilitation program for the elderly to measure the participants' morale. He found that more aged elderly had higher score on morale to participate in the program. He explained the reason of his findings that elderly people become

more mature and they accept themselves with their disease more easily when they grow older. These changes could also be observed among the patients of the leprosarium. Improvement of leprosarium treatment and living environment such as increased social welfare, and efficiency of the caring staff also might effect the increased life satisfaction.

Table 5 showed the social aspects that the social networks of the patients have been changing from group activities to individual ones such as having friends or contact with family. This tendency may be the effect of the changing attitudes of the people toward leprosy which effected abolition of the Leprosy Prevention Law in 1995. This finding may have been influenced by the then up-coming abolition of the Leprosy Prevention Law. Moreover, since this was based on a self-administered survey, the answers might be affected by their feelings at the time that the survey was conducted.

The limitations of this study were as follows. First, since this research was conducted anonymously, the 1995 survey did not follow the subject of the 1991 survey. Identifying the changes of individual patients could not be possible. Secondly, the disparity of the response rate in 1991, which was 73.6 %, and 1995, which was 91.9%, might have biased the results. The larger number of nonresponse patients in 1991 might have affected the lower results. Thirdly, the different methods of data collection used in the first and the second surveys might have affected the answers. In the first survey, for the patients who could not read and



write, the staff of the institution filled the forms on behalf of the participants. On the other hand, the researcher or the investigators filled the forms for similar patients in 1995, so the patients might have chosen better answers by themselves. Fourthly, since patients have a long treatment history in the leprosarium that more than 70% of them had a history of treatment over 40 years.<sup>11)</sup> measuring life satisfaction after four years might not be long enough to compare. Further research is recommended to be conducted on a long term basis.

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