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Original Article

Life satisfaction in persons with spinal cord injury: a comparative investigation between Sweden and Japan

M Ide*[,1] and AR Fugl-Meyer[2]

[1]*Rehabilitation Medicine, University of Occupational and Environmental Health, Iseigaoka 1-1, Yahatanishi ku, Kitakyushu, 807-8555, Japan;* [2]*Department of Rehabilitation Medicine, Uppsala University, S-751 85, Uppsala, Sweden*

Study design: A cross-sectional and comparative investigation using the unified questionnaire.
Objectives: To investigate the cultural (East Asian *versus* North European) differences in life satisfaction between long-term survivors of spinal cord injuries (SCI).
Setting: Uppsala county in Sweden and Fukuoka prefecture in Japan.
Methods: A questionnaire dealing with life satisfaction was prepared by the authors. It focused mainly on sexual life and accompanied a self-rating Barthel Index Score. The questionnaire was mailed to male SCI persons in the two communities, Uppsala county (Sweden) and Fukuoka prefecture (Japan). Forty (77%) Swedish and 85 (71%) Japanese SCI replied.
Results: (1) Swedish SCI appeared to be more satisfied than Japanese SCI in general health, economy, social activity, social service, family life and sexual life. (2) Several life domains indicated significant difference in life satisfaction between with- and without-partner group in Japanese SCI. No life domains indicated significant difference in Swedish SCI. (3) No statistically significant difference was indicated in all of life domains between the degree of life satisfaction and interval since spinal cord damage.
Conclusion: The more expanded cross-cultural study is expected to be helpful for discussing the QOL of SCI.
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Keywords: spinal cord injury; life satisfaction; sexuality; cross-cultural study

Introduction

Successful rehabilitation involves improving both physical disability and emotional elements. Through an adequate coping process, a person with disability can overcome them. The emotional elements have been discussed in relation to the severity of disability[1,2] or WHO's classification of disability.[1,3] However, it may be difficult for rehabilitation staff to discuss emotional aspects with their clients. Particularly, sexual aspects and satisfaction with life domains seem to be placed among the last steps of the ordinary rehabilitation program even today.

Aspects of 'sexual function' such as penile erection or ability to experience an orgasm, have often been described in spinal cord injury (SCI) patients. For example, the efficacy and safety of oral sildenafil in male SCI has often been discussed in recent years.[4,5] However, aspects of 'sexual concerns' apart from 'sexual dysfunction' have rarely been investigated.[6] Discussion from the point of partnership and quality of life (QOL) seems to be held in order to compensate this situation and provided good information.

This comparative investigation is an extension of a previously published report on the latter aspects of sexual life in southern Japanese victims of SCI.[7] It was designed as a comparative analysis of SCI patients in two selected commmunities, Fukuoka prefecture in southern Japan and Uppsala county in Sweden. The characteristics of Uppsala county and Fukuoka prefecture are: population, 286 000 *vs* 4 811 000; area, 6989 km^2 *vs* 4965 km^2; persons/km^2, 41 *vs* 969. The population of each community as a proportion of the respective total national population is: Uppsala county 3.3% and Fukuoka prefecture 3.9%.

This study aimed to answer the following questions: (i) are there any differences in sexual life and life satisfaction with other domains between SCI victims in

*Correspondence: M Ide, Rehabilitation Medicine, University of Occupational and Environmental Health, Iseigaoka 1-1, Yahatanishi ku, Kitakyushu, 807-8555 Japan

the two communities?; (ii) are there any differences in the influence of partnership in the two communities?; (iii) is there any relationship between the interval since SCI and life satisfaction?

Methods

Design

A questionnaire packet was mailed to persons with spinal cord injury (SCI) living in the two communities, Uppsala county in Sweden and Fukuoka prefecture in Japan. The packet sent to those living in Uppsala county was written in Swedish, and the packet sent to those living in Fukuoka prefecture was written in Japanese. This procedure, including the questionnaire, was ethically examined by Uppsala University Hospital in Sweden and by Fukuoka SCI Association in Japan.

A repeat mailing was sent to all persons who did not return the questionnaire, in order to maximize the number of responses.

The questionnaire was anonymous in accordance with the request of Fukuoka SCI Association, but a mark was made in it to identify the respondent. It was organized into two sections, and the first section consists of a self-assessed Barthel Index (0–100 points) which measures the performance of activities of daily living (ADL). The test–retest and inter-method reliability of this self-rating Barthel Index has already been confirmed.[8] In this scale, a higher score indicates that the respondent is more independent. The second section deals with sexual concerns, sexual activities, and services provided by medical professionals. Because this survey mainly focused on sexual concerns, the items did not deal with sexual function aspects such as the ability to achieve an erection or experience an orgasm. Questions regarding satisfaction with different life domains over an unspecified period of time were rated by the respondent on a 5-point scale: Dissatisfied, Rather dissatisfied, No opinion, Rather satisfied and Satisfied. Because the study in Japan had been conducted earlier on a 6-point scale by the second author[9], it was not adapted in this comparative study.

Microsoft Excel 5.0 and Stat View 5.0 softwares were used to analyze the collected data. Differences between groups were analyzed by the unpaired *t*-test or Chi-square test. The Mann-Whitney U-test was used to evaluate the level of life satisfaction in life domains. The level of significance was set at $P<0.05$.

Subjects

In this study, the replies from only male subjects were analyzed to simplify the analysis. The questionnaire had been mailed to 52 male SCI patients in Uppsala county and 119 male SCI patients in Fukuoka prefecture. Both of the two groups consist of a consecutive series of SCI persons in each registration pool.

In the Swedish community, all 52 male SCI subjects were treated at the Department of Rehabilitation Medicine at Uppsala University Hospital. Forty Swedish patients (77%) returned the questionnaire. In the Japanese community, all 119 male SCI subjects were members of the Fukuoka SCI Association. Eighty-five patients in Fukuoka returned the questionnaire, giving a response rate of 71%. There was no significant difference between the response rate in the two communities. No respondent was hospitalized at the time of data collection. The characteristics of the respondents in each community are summarized in Table 1. The paralytic condition of each respondent was classified according to Frankel's classification,[10] in which Frankel A presented as complete and Frankel B, C, D presented as incomplete.

Results

Talking about sexual life

According to the responses in the questionnaires, in the Swedish community, 20 (50.0%; of which nine had a partner) of the 40 respondents have talked about their sexual life with someone, and 17 (42.5%; of which seven had a partner) have not (three respondents did not reply to this item). In the Japanese community, 60 (70.6%; of which 37 had a partner) of the 85 respondents have talked about their sexual life, and 14 (16.5%; of which five had a partner) have not (11 respondents did not reply to this item). Regarding the reasons for not talking about his sexual life, no

Table 1 Grouping variables

	Japanese (n=*85*)	*Swedish* (n=*40*)	P-*value*
Age at the study			
mean	48±10.6 year	49±17.0 year	N.S.[a]
median	48.5 year	46.0 year	
range	27–82 year	21–75 year	
Interval since spinal damage			
mean	17±7.1 year	10±7.0 year	<0.01[a]
median	18.0 year	10.0 year	
range	3–38 year	1–35 year	
Barthel Index Score			
mean	51.7±23.3	67.3±28.2	<0.01[a]
median	54.0	74.0	
range	0–100	0–100	
Partner			
without partner	*n*=33	*n*=23	
with partner	*n*=44	*n*=17	N.S.[b]
no answer	*n*=8	*n*=0	
Levels and completeness of lesion			
complete quad.	*n*=28	*n*=8	
incomplete quad.	*n*=7	*n*=12	
complete para.	*n*=17	*n*=6	<0.01[b]
incomplete para.	*n*=9	*n*=8	
unknown	*n*=24	*n*=6	

[a]Student-*t* test, [b]Chi square test

respondent in either community answered 'immoral' or 'shameful' as a reason. Among the respondents who indicated that he had talked to someone about his sexual life, 16 (40.0%) in the Swedish community, and 42 (49.4%) in the Japanese community talked with his partner. Quite a few subjects ($n=6$) in the Japanese community talked about his sexual life with the hospital staff, and six (15.0% of the Swedish respondents) in the Swedish community did so.

Sexual activity

The sexual activities in which the subjects engaged are listed in Table 2. In this question, subjects were allowed to choose more than one answer. This table suggests that: (i) the percentage of respondents who engage in coitus is significantly higher in the Swedish community than in the Japanese community; (ii) the percentage of respondents who selected 'non-physical sexual activities (interpersonal)' as his sexual activity was significantly higher in the Japanese community than in the Swedish community.

Table 2 Sexual activities

	Japanese (n = *76*)	*Swedish* (n = *40*)	P-*value*
No sexual activity	22	12	N.S.
Coitus	11	16	<0.01
Sexual caressing	24	16	N.S.
Kissing	17	14	N.S.
Masturbation	5	6	N.S.
Magazine, film, video	18	4	N.S.
Non-physical sexual activities	25	2	<0.01

Chi square test

Among the Japanese community, a significantly higher percentage of respondents 'without a partner' answered 'no sexual activity' than those 'with a partner' ($P<0.05$). Among the Swedish community, there was no relationship between whether a subject did or did not have a partner, and 'no sexual activity' (data not shown).

Identified needs

The needs of the SCI patients for professional advice regarding sexual life are listed in Figure 1. Twenty-two respondents (25.9%) in the Japanese community answered 'Establishment of counselling settings', which no Swedish respondent had chosen. In the Swedish community, 12 respondents (30.0%) answered 'Offering up-to-date information', which was followed by 'Development of medicine and apparatus' ($n=11$) and 'No opinion' ($n=11$, 27.5%).

No statistically significant difference in needs was found between the two communities except for 'Establishment of counselling settings'.

Important life domains

Nine life domains were prepared in the questionnaire, and the subject was asked to choose the three items that he considers to be the most important (Figure 2). 'Sexual life' was chosen by six (15.0%) in the Swedish community and seven (8.2%) in the Japanese community.

Of the nine life domains, significant differences were found in the percentage of respondents in the Swedish and Japanese communities who chose 'Culture/ Spiritual life' and 'General health'.

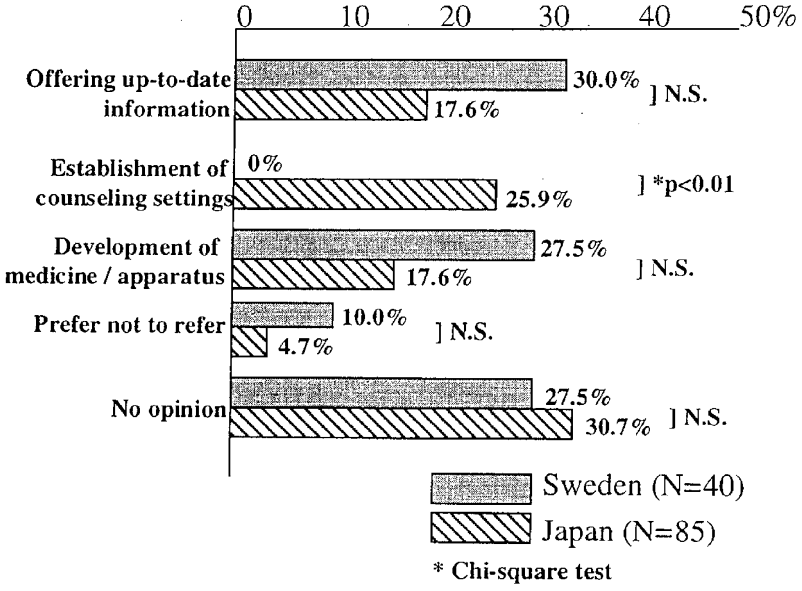

Figure 1 Identified needs: The needs of the SCI patients for professional advice regarding sexual life. No statistically significant difference in needs was found between the two communities except for 'Establishment of counseling settings'

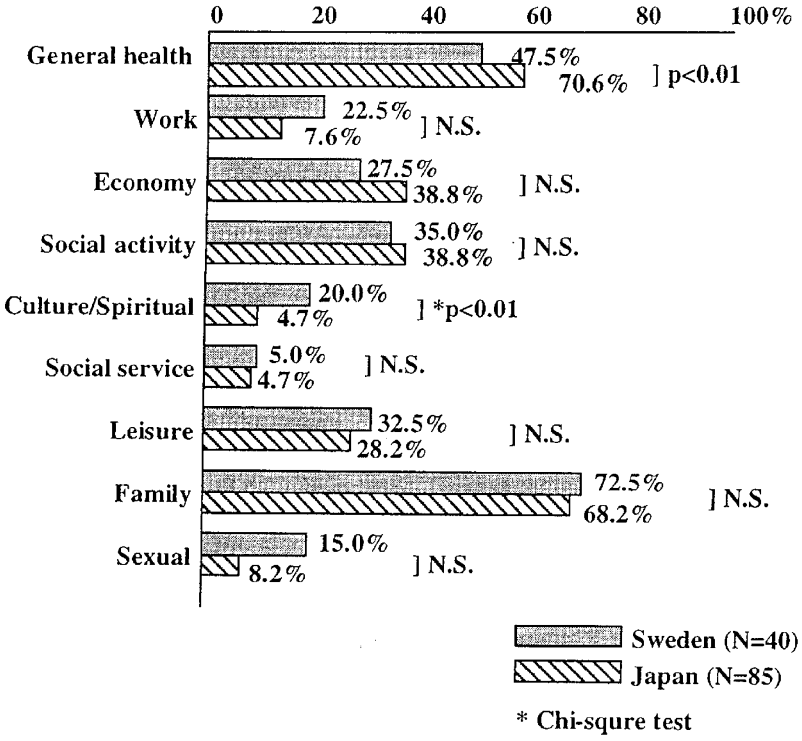

Figure 2 Important life domains: Significant differences were found in the percentage of respondents in the Swedish and Japanese communities who chose 'Culture/Spiritual life' and 'General health'

Life satisfaction

The degree of satisfaction in the nine life domains was ranked according to a 5-point scale from 'dissatisfied' to 'satisfied' (Figure 3). The Swedish respondents appeared to be more satisfied than the Japanese respondents with regard to their general health, economy, social activity, social service, family life and sexual life.

The influence of the existence of a partner was analyzed in each life domain (Table 3). The Japanese respondents who had a partner had higher satisfaction than those who did not have a partner with regard to their general health, leisure, family life and sexual life. Among the Swedish respondents, no significant differences in satisfaction in the nine life domains were found in relation to the existence or absence of a partner.

The relationship between the degree of life satisfaction and interval since spinal cord damage was analyzed in the pooled data (Japanese + Swedish, $n = 125$) (Table 4). In each of the nine life domains, there was no relationship between the degree of life satisfaction and the interval since SCI.

Discussion

The reason more Swedish respondents engaged in coitus (Table 2) is considered to be that the Swedish respondents had better physical function than the Japanese respondents, as indicated by the higher Barthel Index (Table 1). It is difficult to recognize 'non-physical' as a category of sexual activity. It is necessary to define what the sexual activities of disabled people are before we can discuss it.

Many researchers have described the sexuality of disabled people from the standpoint of partnership.[11–14] In this study, the existence of a partner influenced the subject's sexual activity only among the Japanese respondents. This may indicate that sexual activity is a rather inter-personal issue in the Japanese population.

The absence of sexual counseling for the disabled (and for the able-bodied population) is obvious in Japanese society (Figure 1) compared with the Swedish society, and improvement of this condition is definitely required in the near future. Few studies have surveyed the requirements of disabled people regarding sexual life, and more details should be inspected in each community.

A report in Sweden described the patients with SCI who had a partner, had greater life satisfaction than those who did not have a partner.[14] In our study, there were significant differences in satisfaction in four life domains between those who did or did not have a partner among the Japanese respondents. On the other hand, there were no significant differences in satisfaction in any life domain between those who did or did not have a partner among the Swedish respondents. It may be assumed that Japanese SCI patients tend to place value on their life satisfaction in relation to others, and that Swedish SCI patients do not. There is

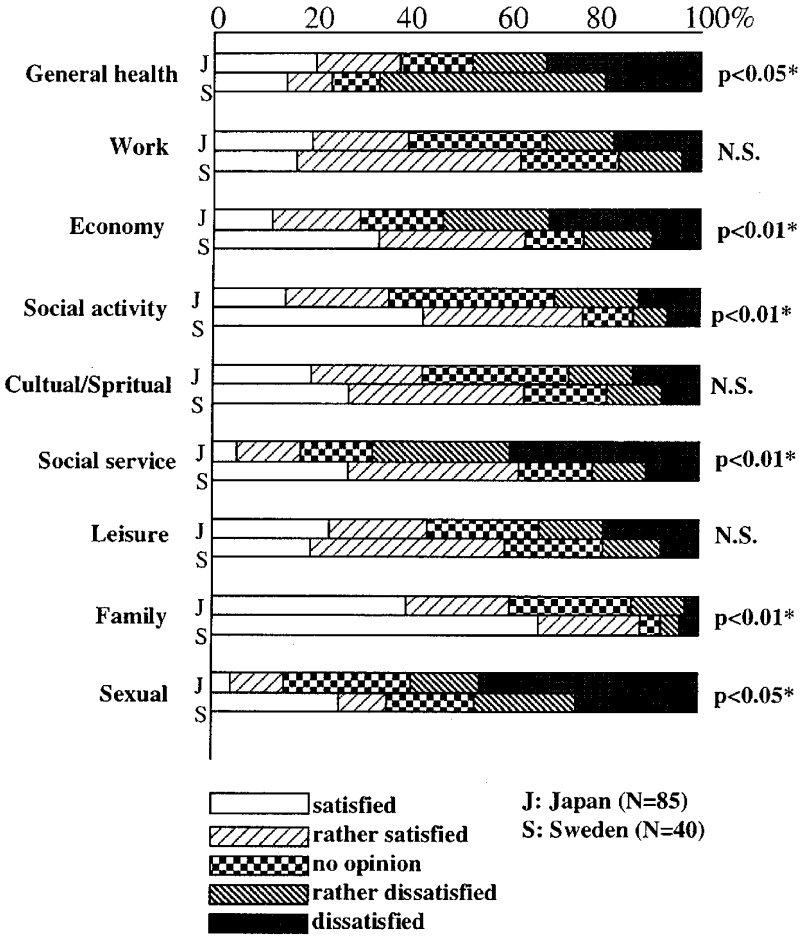

Figure 3 Life satisfaction: The grade of life satisfaction in each life domains are illustrated in the graph. Swedish subjects show higher satisfaction rate in six life domains compared to Japanese

Table 3 Life satisfaction ... with/without partner

	Japanese (n = *85*)		*Swedish* (n = *40*)	
General health	71	$P<0.05$[a]	39	N.S.
Work	62	N.S.	24	N.S.
Economy	76	N.S.	40	N.S.
Social activity	77	N.S.	40	N.S.
Culture/Spiritual	77	N.S.	40	N.S.
Social service	77	N.S.	40	N.S.
Leisure	77	$P<0.05$[a]	40	N.S.
Family	76	$P<0.01$[a]	39	N.S.
Sexual	68	$P<0.01$[a]	36	N.S.

Mann-Whitney U-test. *n* represents the number of respondents for each life domains. [a]Japanese subjects with partner show higher satisfaction rate in these life domains compared to subjects without a partner

a report which suggests that post-injury marriages in SCI individuals strengthened their satisfaction with life and with their adjustment,[15] and further discussions seem to be held in this aspect.

There were no significant differences between the degree of life satisfaction and interval since spinal cord damage in any of the nine life domains. Rehabilitation professionals have believed that the passage of time enables the disabled person to accept being handicapped. In fact, Krause described that some aspects of life improved with increasing time since injury.[16] Our result is in agreement with reports from the United States and Netherlands, in which no significant relationship between the degree of life satisfaction and interval since SCI was found among adolescents with SCI.[17,18]

The advantages of this study as a small epidemiological study are that the bias was minimized due to the facts that the same questionnaire was given to the two communities and a single analyzer was used for the two communities with different cultural back-

Table 4 Life satisfaction and interval since spinal cord damage

Satisfied or rather satisfied/ rather dissatisfied or dissatisfied	*1∼5 year*	*6∼10 year*	*11∼15 year*	*16∼20 year*	*>20 year*	P-*value*
General health	9/6	6/10	15/12	10/7	13/10	N.S.
Work	3/3	8/4	13/4	8/5	8/7	N.S.
Economy	7/6	7/10	17/12	6/11	10/15	N.S.
Social activity	9/3	10/6	16/9	4/6	18/7	N.S.
Culture/Spiritual	5/4	10/4	21/4	6/7	16/9	N.S.
Social service	6/7	6/8	11/16	5/16	9/17	N.S.
Leisure	6/6	9/6	18/8	9/9	16/6	N.S.
Family	11/3	15/1	22/4	14/4	17/7	N.S.
Sexual	4/6	7/8	4/17	3/12	5/13	N.S.

Mann-Whitney U-test.

grounds. The used instrument lacks the confirmation of conceptual and linguistic equivalence between Swedish and Japanese, and this disadvantage should be overcome in order to establish its epidemiological value. Studies involving larger numbers of subjects in Sweden and Japan, as well as a similar study in able-bodied people to serve as a control, are required for further discussion.

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Appendix

*Do not note your name.

1 Gender male/female
2 Age __ years
3 Family member 1 single, no partner
2 with spouse/partner
3 others
4 Gross level of lesion 1 complete quadriplegia
2 incomplete quadriplegia
3 complete paraplegia
4 incomplete paraplegia
5 Interval since spinal cord damage __ years
6 Are you satisfied with your general health?
1 satisfied
2 rather satisfied

3 no opinion
4 rather dissatisfied
5 dissatisfied

7 Do you work? yes/no

8 Are you satisfied with your working life?
1 satisfied
2 rather satisfied
3 no opinion
4 rather dissatisfied
5 dissatisfied

9 Are you satisfied with your financial situation?
1 satisfied
2 rather satisfied
3 no opinion
4 rather dissatisfied
5 dissatisfied

10 Are you satisfied with your social activity?
1 satisfied
2 rather satisfied
3 no opinion
4 rather dissatisfied
5 dissatisfied

11 Are you satisfied with your culture/spiritual life including education, reading or religion?
1 satisfied
2 rather satisfied
3 no opinion
4 rather dissatisfied
5 dissatisfied

12 Are you satisfied with leisure life including sports, travel or hobbies?
1 satisfied
2 rather satisfied
3 no opinion
4 rather dissatisfied
5 dissatisfied

13 Are you satisfied with social services?
1 satisfied
2 rather satisfied
3 no opinion
4 rather dissatisfied
5 dissatisfied

If you graded 4 or 5, what is the reason?
1 lack of financial support including pensions
2 poor environment including public transportation or architects
3 hard to get a job
4 others

14 Are you satisfied with your family situation?
1 satisfied
2 rather satisfied
3 no opinion
4 rather dissatisfied
5 dissatisfied

15 Do you have any experience of talking about sexual life?
1 yes.....with whom 1-1 spouse/partner
1-2 friends
1-3 hospital staff
1-4 others
2 no.....because 2-1 immoral
2-2 personal issue
2-3 shameful
2-4 no settlement
2-5 others

16 What are your sexual activities?
1 no sexual activity
2 coitus
3 sexual caressing
4 kissing
5 masturbation
6 erotic magazine/film/video
7 non-physical sexual activity (interpersonal)
8 others

17 Are you satisfied with your sexual life?
1 satisfied
2 rather satisfied
3 no opinion
4 rather dissatisfied
5 dissatisfied

If you graded 4 or 5, the reason is,
1 no partner
2 poor physical function
3 no feeling of orgasms
4 too small housing
5 no way of having a child
6 others

18 What do you hope for medical staff regarding the sexual life of spinal cord injury?
1 providing up to date information
2 providing counseling settings
3 development of medicines/apparatus
4 not to refer
5 no opinion
6 others

19 What do you value in your life domains (check three items)?
1 family
2 culture/spiritual life (religion, education...)
3 general health
4 social activity
5 hobby/leisure
6 economy
7 work
8 sexual life
9 social service
10 others