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Sexual activities and concerns in persons with spinal cord injuries

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A survey of sexual activity and concerns of people with spinal cord injury living in the community was undertaken. A questionnaire was sent to 144 people, and 102 replies were collected. Of the sample, 59.8% reported having engaged in some aspect of sexual life. Sexual life ranked the lowest in terms of importance with respect to other aspects of life. However, 47.1% answered that they were not satisfied with their sexual life. It was indicated that the provision of information regarding sexuality should remain a high priority for health care providers.

Keywords: spinal cord injury; sexuality; life satisfaction

Introduction

Sexuality in people with spinal cord injury (SCI) has received increased interest in the past decade. In early reports, mainly male erectile function and fertility were considered. Relatively few systematic investigations have been devoted to attitudes on sexuality in this group of people.

In recent research, De Vivo *et al*[1] focused on the marital status of people with SCI, in whom fewer marriages and more divorces were noted. Nikas *et al*[2] studied World War II veterans with SCI. White *et al*[3] discussed this matter in terms of psychological and attitudinal aspects.

In Asian countries, it is difficult to find surveys which discuss sexual life in people with SCI. One of the reasons for this may be due to cultural and moral concerns.

The purpose of this survey was to understand sexual activity and concerns in people with spinal cord injury, and to provide information which would be useful to incorporate into educational programs for the spinal cord injured population.

The questionnaire used in this survey was designed to clarify the following points:

1 What proportion of persons with spinal cord injury talk about sexual life?
2 How do persons with spinal cord injury engage in sexual life?
3 What proportion of persons with spinal cord injury are satisfied with their sexual life?
4 What importance do people with SCI attribute to sexual life compared with other aspects of life?

Subjects and methods

This survey was carried out with the cooperation of the Fukuoka Spinal Cord Injury Association. Questionnaires were mailed to 144 members of this organisation in December 1993. Almost all respondents lived in the Fukuoka prefecture which is located in the north of Kyushu island, covers an area of 4834 km^2 and has a population of 4 800 000.

Of the initial 144 subjects, 102 (91 males and 11 females) replied (70.8%). Table 1 presents data on the sample age, residential status, marital status, duration of injury, level and completeness of injury based on the Frankel classification.

The questionnaire packet was composed of 'Self evaluation of activities of daily living' and 'Questionnaires about sexual life'. The former part contained 13 questions and was designed on the basis of the Barthel Index, in which totally independent people score 100 points. The validity and reliability of this self evaluation were checked by Hachisuka, Tustsui and Ogata (unpublished observations, 1994) who examined satisfaction in several areas of life.

This quesionnaire was developed by the authors because none exists to assess the area that is standardised for a spinal cord injury population. 'Satisfaction' was scored on a five point scale of 'very satisfied' 'somewhat satisfied' 'no opinion' 'somewhat dissatisfied' and 'very dissatisfied'. For the analysis, this scale was simplified as 'satisfied' 'no opinion' and 'dissatisfied'.

The χ^2 test was used for statistical analysis to test for significant differences between individuals on the basis of: Barthel Index Score groups and sexual activities; Barthel Index Score groups and satisfaction with sexual life; rate of satisfaction with sexual life and other areas.

Results

Seventy five (73.5%) participants said that they had experience in talking about sexual life (Figure 1). The

Table 1 Grouping variables: age, residential status, marital status, duration of injury, level and completeness of injury

Age in years	47.8 ± 11.1, range 27–82
Residential status	home n = 84 hospital n = 7 institution n = 10 others n = 1
Living with a spouse/partner	51.0% (n = 52)
Duration of injury in years	18.7 ± 9.3
Level of completeness of injury	Complete tetraplegia n = 33 Incomplete tetraplegia n = 8 Complete paraplegia n = 19 Incomplete paraplegia n = 9

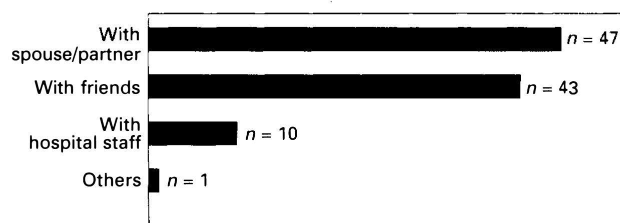

Figure 1 Experience of talking about sexual life. 75 (73.5%) respondents had experience in talking about sexual life

number of persons who had talked with hospital staff was small.

Sixty one (59.8%) stated that they had engaged in some facet of sexual life. Figure 2 shows sexual behaviour in which the participants engage. Twenty-seven answered that they engaged in a 'psychological relationship', following 'hugging' and 'kissing'. 'Self evaluation of activities of daily living' was converted to the Barthel Index score. As indicated in Figure 2, a large number reported 'no sexual life' and this was by people who showed a lower Barthel Index Score (less than 25 points), and it was statistically significant ($P < 0.05$).

Forty eight (47.1%) participants answered that they were not satisfied with sexual life. Ninteen claimed that they were too severely disabled for sexual activities, followed by 'no partner' (n = 13), 'no way of having children' (n = 7) and 'no orgasm' (n = 5).

The relationship between the Barthel Index Score and grade of satisfaction with their sexual life is shown in Figure 3. The most independent group (Barthel Index Score 76–100) contained more subjects who felt

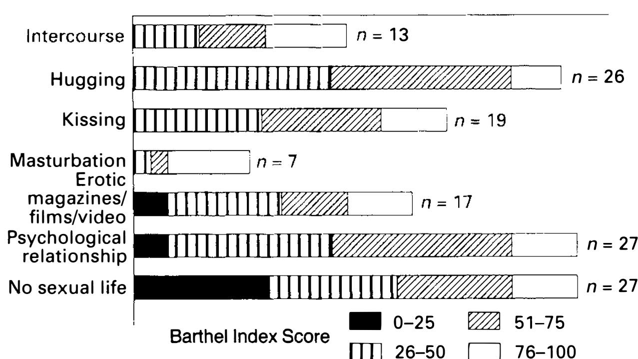

Figure 2 Sexual activities and activities of daily living. 61 (59.8%) respondents engaged in some facet of sexual life

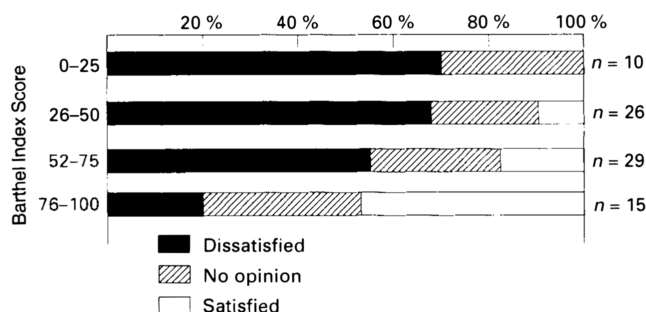

Figure 3 Activities of daily living and satisfaction with sexual life. Barthel Index Score was introduced to assess the activities of daily living

satisfaction with sexual life and it was statistically significant ($P < 0.01$).

In this survey, satisfaction in several items other than sexual life was included. Table 2 shows the degree of the satisfaction with reference to nine items, including sexual life. Sexual life showed a lesser degree of satisfaction than residual motor function ($P < 0.05$); employment ($P < 0.001$); social relationship ($P < 0.05$); spiritual life ($P < 0.001$); recreational activities ($P < 0.001$) or family relationship ($P < 0.001$). On the other hand, financial life and politics showed no significant difference compared to sexual life.

Participants were asked about their identified needs concerning sexual life. Six items were prepared by the authors, and participants were allowed to select more than one item. Thirty one said that they had 'no opinion' for this issue, and they were in the majority (Figure 4). Twenty six participants requested 'establishment of sexual counselling', followed by 'offering the latest information' (n = 19) and 'development of medicines and apparatus' (n = 15). Only three said that they 'prefer not to mention'; all of these respondents were over 40 years of age.

Participants were asked to indicate their three most important life areas. Nine areas including sexual life were specified. 'General health' was ranked as the most important area, and 'sexual life' least important (Figure 5).

Discussion

The mean age of the participants was 47.8 ± 11.1 years, and the duration of injury 18.7 ± 9.3 years. According to a nationwide survey by Shingu *et al*,[4] the mean age at the time of injury is 48.5 ± 19.5 years in Japan. The

Table 2 Degree of satisfaction: satisfaction in nine items including sexual life

	Dissatisfied *n*	*No opinion* *n*	*Satisfied* *n*	*Total* *n*
Residual function	45	17	34	96
Employment	22	25	34	81
Money matters	56	18	27	101
Social life	32	32	38	102
Spiritual life	24	31	43	98
Recreational activities	33	24	44	101
Politics	65	15	21	101
Family relationships	14	24	63	101
Sexual life	48	26	15	89

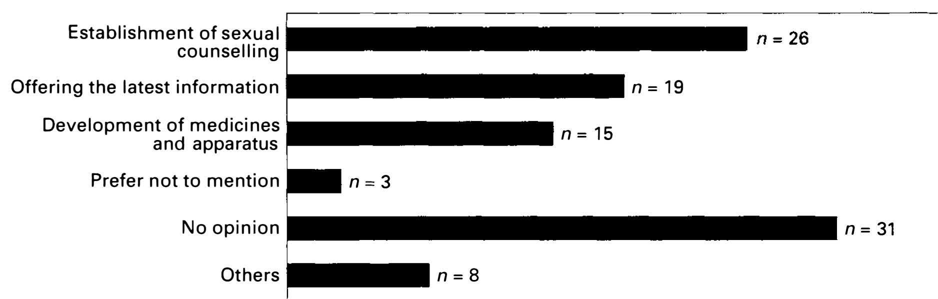

Figure 4 Identified needs. 'No opinion' was the majority followed by 'Establishment of sexual counselling'

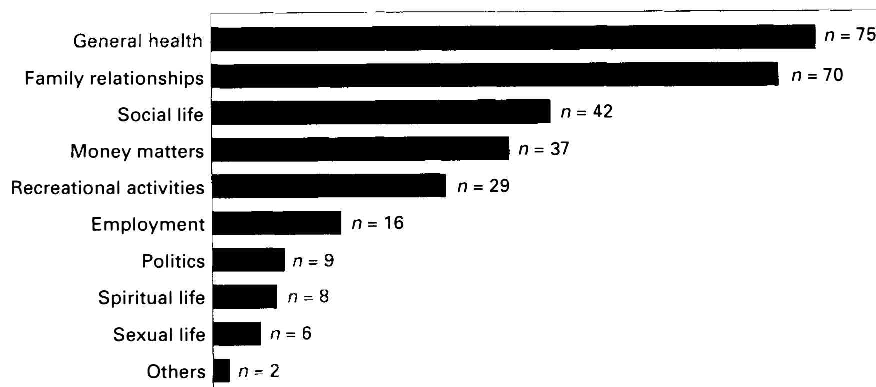

Figure 5 Importance of life areas. 'Sexual life' was ranked as the least important

present participants appeared to be younger than the general population of people with SCI in this country. Two reasons can be considered to explain this difference: (1) the questionnaire itself was not interesting to the elderly and (2) most participants were people with SCI who returned to the community, and only relatively younger persons could do this because of the shortage of community-based support systems.

More than 70% said they had discussed sexual life (Figure 1). In 1975, Teal *et al*,[5] reviewing a study of 30 men with SCI, reported that 65% of people with SCI had never discussed sexual concerns with anyone. This difference possibly indicates changes in sexual attitudes over the past 20 years.

Nobody who scored less than 25 points in the Barthel Index answered that they engage in 'physical sexual activities' (Figure 2). This survey used mailed questionnaires, and thus the neurological residual function of the participants could not be exactly determined. Those with poor residual function may score lower points on the Barthel Index. The sexual life of people with spinal cord injuries with poor residual function has been neglected in this country. Sexual activities other than intercourse should be introduced to this group via counselling. White *et al*[3] reported that having a physical relationship was related to receiving helpful information about sexuality, and Alexander *et al*[6] reported that preference for penis-vagina intercourse decreased in spinal cord injured males following injury.

In this survey, 47.1% of participants reported that

they were not satisfied with sexual life. Sipski *et al*[7] reported that 76% of subjects felt they had adjusted well sexually. This difference is notable, since all 25 participants in Sipski's survey were females. Nobody scoring less than 25 points in the Barthel Index said that they were satisfied with sexual life. Significantly more people who scored more than 76 points answered that they were satisfied in the group (Figure 3). It is clear that many participants value 'physical activities' in their sexual life. Devivo *et al*[1] concluded that the divorced group were likely to have a Barthel Index score of less than 80, and one of the reasons for a divorce in this group may be related to sexual life.

It is remarkable that many participants ($n = 31$) stated 'no opinion' as well as 'establishment of sexual counselling' ($n = 26$) (Figure 4). The lack of information and of counselling in this country may be reflected by this. The availability of information on sexuality showed a high priority for healthcare providers. Only a few disliked the approach by hospital staff concerning sexual aspects.

Compared with other areas of life, sexual aspects were the least important for these participants (Figure 5), as also reported in other countries (Nikas *et al*,[2] White *et al*[3]), even if taking into consideration the differences of listed items.

In conclusion, it was suggested that counselling and education regarding sexuality were required for people with SCI in this country. The authors perceived in the analysis of our survey the necessity to follow these further researches: (1) the sexuality of severly handicapped people; and (2) the sexuality of people in shelterd institutions.

This is not a comprehensive survey since the level and degree of paralysis has not been included, and there is only a small number of female participants. However, the results indicate not only the need for further research, but also that sexual education and counselling is an important part of the management of spinal cord injury patients, and unfortunately it is frequently lacking.

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