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Actual conditions of sexuality and sexual perceptions among IBD patients in Japan

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Abstract: The aim of this study was to clarify the conditions of sexuality and sexual perceptions in patients with Inflammatory Bowel Disease (IBD). Patients at 15 self-help groups and 14 hospitals were surveyed using a self-administered questionnaire. The questions' basic attributes included sex, age, type of disease (Ulcerative Colitis (UC) or Crohn's Disease (CD)), and presence of stoma. The questions also included conditions such as frequency of sexual activity, and sexuality satisfaction index "SEXSI-IBD (Sexuality Satisfaction Index for IBD)," and sexual perceptions. A total of 195 valid responses from IBD patients was obtained and subjected to analysis. With regard to the frequency of sexual activity in terms of the number of occasions of sexual intercourse, "approximately once or twice a month" was given as most frequent response, but overall, the largest number of responses indicated "no physical contact and no sexual intercourse" and "physical contact but no sexual intercourse." In the results of the SEXSI-IBD, the highest score was for the "importance of skin ship," and the lowest scores were for "sexual communication" and "sexual difficulty." As concerns sexual perceptions, 60.0% of the responding patients said sick and disabled people can generally engage in sexual activity, but as opposed to this, only 7.7% said they were able to discuss matters related to sexual activity with a healthcare professional, and 29.7% of participants said they believed healthcare professionals can conduct consultations on matters related to sexual activity. The frequency of sexual intercourse among IBD patients in Japan is low, and it was clear that in terms of the degree of satisfaction of sexuality, these problems necessitate emphasizing the importance of skin ship and support for sexual communications. With the exception of healthcare professionals' reluctance to discuss sex problems, it is desirable to recognize the actual conditions of sexuality among IBD patients, and provide specific forms of support.

Keywords: Sexuality, Sexuality Satisfaction Index, SEXSI-IBD, Inflammatory Bowel Disease

INTRODUCTION

Inflammatory bowel disease (IBD) represents a group of idiopathic chronic inflammatory intestinal conditions; ulcerative colitis (UC) and Crohn's disease (CD) are the two major types [1]. CD most commonly affects the colon and the last part of the small intestine, and UC affects the colon. Both UC and CD usually involve severe diarrhea, abdominal pain, fatigue, and weight loss. These forms of IBD can be debilitating and sometimes lead to life-threatening complications. Most people who develop IBD are diagnosed before the age of 30.

Sexual problems tend to occur at all developmental stages, because IBD often develops in adolescence and assumes a

chronic course. A significant proportion of patients report lack of intimate relationships due to IBD [2], with sexual dysfunction reported in from 35% to 58% of cases, thereby indicating that it is common for IBD patients to suffer from problems related to sexual health [3]. Persons with problems in sexuality due to a disease or disorder experience anxiety in their daily lives and lack adequate support from healthcare professionals [4].

Most healthcare professionals in Japan are generally reluctant to intervene in sexual problems for all patients, not only those with IBD, and few healthcare professionals are willing consult with patients regarding their sexual problems. Whether due to discomfort in providing sexual health care,

feelings of uncertainty about the patient's acceptance and so on, concerns over incorrect assumptions stand as a barrier that prevents support [5]. Only healthcare professionals with advanced specialized knowledge and extensive clinical experience deal with sexuality. Thus, it is necessary to understand the actual conditions for suitable support.

The aim of this study was to clarify the conditions of sexuality and sexual perceptions among IBD patients. It is hoped the results will be useful to provide support for sexual issues of patients with IBD.

METHODS

Participants:

The form of the study was a self-administered questionnaire survey concerning basic attributes, actual conditions of sexuality and sexual perceptions among IBD patients. We recruited participants at 15 self-help groups and 14 hospitals. The age of the participants was limited to between the ages of 20 to 79 years. The offices of the self-help groups sent survey forms to the patients who were members of the group. Hospital staff distributed survey forms to the outpatients who had consented to participate in the study, with the support of the attending physicians. For the collection of the survey forms, the participants were asked to send them back directly to the researchers. The survey was conducted between June 2013 and February 2015.

Questionnaires:

Operational definition of sexuality:

The operational definition of sexuality was defined as "individual sexual characteristics and interaction with sexual partners." We developed this operational definition using conceptual analysis methods from a previous study [6].

Basic attributes:

For basic attributes, we inquired regarding sex, age, disease (specifying either UC or CD), and presence of stoma.

Actual conditions of sexuality:

As for frequency of sexual activity, one of nine possible choices was selected from the following: "over three times a week," "approximately once or twice a week," "approximately once or twice a month," "approximately once a month," "approximately once every two months," "Approximately once every six months," "Approximately once a year," "Physical contact but no sexual intercourse," and "No physical contact and no sexual intercourse."

As for sexuality satisfaction index "SEXSI-IBD" (Sexuality Satisfaction Index for IBD), Table 1 shows item examples for each of the five domains. SEXSI-IBD consists of 28 items and five domains with a five-grade scoring system, from 0 (bad) to 4 (good) points for each item. A higher score indicates a greater level of satisfaction. The mean scores of the SEXSI-IBD scales were calculated as the item average scores, so the scores are not affected by missing values [7]. The five domains of the SEXSI-IBD are as follows: daily interaction; sexual communication; sexual difficulty; sexual interest; and importance of skin ship. The skin ship is a Japanese English word which means physical contact.

Table 1. Item examples for each of the five domains of the SEXSI-IBD

Domain	Item example
Daily interaction	I think that my partner shows consideration toward me. My partner tries to understand my wishes and needs in everyday life.
Sexual communication	I verbally express sexual contentment to my partner. My partner verbally expresses sexual desire to me.
Sexual difficulty	I am satisfied with the frequency of our sexual relations (including the absence of sexual relations). I sometimes feel mental distress over sexual relations.
Sexual interest	I think that sexual relations with my partner are important.
Importance of skin ship	I think that physical contact such as hugging or holding hands in everyday life is necessary.

Sexual perceptions:

With regard to sexual perceptions, four question items were raised: 1) Were you brought up in a household where sex was treated with an open mind?; 2) Do you think that sick and disabled people can generally engage in sexual activity?; 3) Do you have access to a healthcare professional with whom you can discuss matters related to sexual activity?; and 4) Do you think healthcare professionals can conduct consultations on matters related to sexual activity?

Ethical considerations:

Written explanations were provided to the participants, stating that participation in the survey must be based on their own free will, they had the right to refuse to participate, they would not be subjected to negative treatment if they refused participation, and their personal data would be treated as strictly confidential.

In the self-administered questionnaire survey, returning the questionnaire was regarded as the consent for participation in the study. For patients who were members of the self-help groups, the survey forms were sent via the offices of the self-help groups by mail. The outpatients received survey forms from the hospital staff in charge. To give due consideration to confidentiality, we asked the participants to send back the survey forms directly to the researcher. These data are to be stored in a locked safe for five years after the completion of the study, and are to be discarded thereafter.

The present study was conducted following the obtaining of approval of the Institutional Review Board of Shikoku University and Kagawa Prefectural University of Health Sciences in Japan.

RESULTS**Demographic data:**

Table 2 shows the demographic data of the 195 participants. Average age was 46.8 years, with 48.2% of the participants male and 51.8% female. The percentage having stoma was 30.8%. Participants with UC only were 60.5%, CD only 39.0%, and with both UC and CD, 0.5%.

Table 2. Demographic data of the participants (n = 195)

Characteristics	n	%
Sex		
Male	94	48.2
Female	101	51.8
Age	46.8 (11.1)	
Age groups		
20-29	7	3.6
30-39	56	28.7
40-49	58	29.7
50-59	45	23.1
60-69	22	11.3
70-79	7	3.6
Disease		
UC	118	60.5
CD	76	39.0
UC and CD	1	0.5

Presence of stoma		
Yes	60	30.8
No	132	67.7
No answer	3	1.5

UC: Ulcerative colitis, CD: Crohn’s disease.

Values are numbers and %; age refers to mean years and SD.

Actual conditions of sexuality:

Frequency of sexual activity:

Table 3 shows frequency of sexual activity. “Approximately once or twice a month” was the most frequent response for sexual intercourse, but the largest number of responses indicated “no physical contact and no sexual intercourse”, and the next was “physical contact but no sexual intercourse.”

Table 3. Frequency of participants’ sexual activity (n = 195)

Frequency	n	%
Over three times a week	1	0.5
Approximately once or twice a week	15	7.7
Approximately once or twice a month	33	16.9
Approximately once a month	22	11.3
Approximately once every two months	17	8.7
Approximately once every six months	15	7.7
Approximately once a year	11	5.6
Physical contact but no sexual intercourse	35	17.9
No physical contact and no sexual intercourse	43	22.1
No answer	3	1.5
Total	195	100

Percentages may not add up to 100% because of rounding.

Score of SEXSI-IBD:

Table 4 shows score of SEXSI-IBD. The overall average score on the SEXSI-IBD was 2.29. The highest score was for the “importance of skin ship”. Lowest score was “sexual communication” and “sexual difficulty”.

Table 4. Participants’ SEXSI-IBD score on each domain (n = 195)

Score	Mean (SD)
Domain	
Daily interaction	2.62 (0.87)
Sexual communication	1.68 (1.18)
Sexual difficulty	1.71 (1.14)
Sexual interest	2.42 (0.92)
Importance of skin ship	2.80 (1.11)
Overall score	2.29 (0.79)

Sexual perceptions:

Table 5 shows the sexual perceptions of the participants. For the question, “Were you brought up in a household where sex was treated with an open mind?” 45.6% answered “strongly agree” or “agree.” For “Do you think that sick and disabled people can generally engage in sexual activity?” 60.0% answered “strongly agree” or “agree.” For “Do you have access to a healthcare professional with whom you can discuss matters related to sexual activity?” only 7.7% answered “strongly agree” or “agree.” And for “Do you think healthcare professionals can conduct consultations on matters related to sexual activity?” 29.7% gave a positive reply.

Table 5. Sexual perceptions of the participants (n = 195)

Item	n	%
1. Were you brought up in a household where sexual activity was treated with an open mind?		
Strongly agree	10	5.1
Agree	79	40.5
Disagree	68	34.9
Strongly disagree	29	14.9
No answer	9	4.6
2. Do you think that sick and disabled people can generally engage in sexual activity?		
Strongly agree	51	26.2
Agree	66	33.8
Disagree	50	25.6
Strongly disagree	16	8.2
No answer	12	6.2
3. Do you have access to a healthcare professional with whom you can discuss matters related to sexual activity?		
No	167	85.6
Yes	15	7.7
No answer	13	6.7
4. Do you think healthcare professionals can conduct consultations on matters related to sexual activity?		
No	120	61.5
Yes	58	29.7
No answer	17	8.7

Percentages may not add up to 100% because of rounding.

DISCUSSION

IBD patients being treated by healthcare professionals who were able to provide sex consultation were lower than 10%. This is because in Japan, most healthcare professionals are reluctant to intervene in sexual matters. Healthcare professionals are expected to help patients in autonomously re-establishing their sexuality. IBD patients in Japan are characterized by approximately 50% no sexual intercourse, and 30% skin ship (physical contact) without sexual intercourse. Answers from IBD patients in Japan indicated that skin ship is considered important, and that sexual communication is generally lacking. Healthcare professionals may be able to increase the satisfaction of sexuality by supporting the need for sexual communication, by emphasizing the importance of skin ship. We think that a

positive approach by healthcare professionals is necessary for patients to maintain sexual communication. Nurses, in particular, can be expected to assume this role.

The percentage of IBD patients replying that they had access to healthcare professionals with whom they could discuss matters related to sexual activity was below 10%, making clear the situation that most healthcare professionals are disinclined to provide support for matters related to sexuality. On the other hand, patients who said they wished for a consultation related to sexual activity reached 30%, nearly three times the percentage of those actually receiving such consultations. It is hoped that support from healthcare professionals will enable IBD patients to engage in spontaneous activity. The environment in which IBD patients were raised was generally tolerate towards sexual

activity, and because it is not believed that resistance exists in the foundation related to sexual acts or discussing sexual matters, it can be supposed that it is the healthcare professionals who tend to avoid the topic of sexual activity. A relationship exists between sexual health and depression, anxiety and other problems [8]. This relationship and resulting problems extends to all aspects of living, and diminishes the quality of life (QOL) [2]. To reduce psychological problems, and maintain and improve QOL, specific support toward sexuality is important. In the approach to sex consultations by healthcare professionals as indicated by the PLISSIT model (composed of permission, limited information, specific suggestions, and intensive therapy), the first step to participation is permission, in other words, clearly stating the message that “the healthcare professional also accepts consultation regarding sexual activity” [9]. By encouraging consultation and approaching the subject in a positive manner, it will be possible for the person on the consulting side to effectively reduce hesitancy. It is essential for the healthcare professional, by assessing the degree of satisfaction in sexuality, to comprehend individual sexual problems and provide strategic support in response to each individual. IBD patients in Japan are characterized as placing a high importance on skin ship, while lacking in sexual communications. Japanese have a tendency toward finding it difficult to verbalize matters related to sexual intimacy, and support is needed to overcome such reticence. In previous research [10], IBD patients themselves identified a desire not only for a sense of well-being through “satisfaction of sexual desires,” but also “good communications” and “realization of skin ship.” Irrespective of sexual dysfunction, it is important to grasp what the patient desires in terms of condition to improve his or her QOL, and adopt an approach in which goals that can be shared are set. Healthcare professionals, through support of the necessity of sexual communication via instruction of the importance of skin ship, have the potential of raising the degree of satisfaction concerning sexuality. In order to maintain sexual communication, it is believed that healthcare professionals must take an affirmative approach.

CONCLUSIONS

The frequency of sexual intercourse by IBD patients in Japan is low, and from the degree of sexual satisfaction it is clear that problems exist in terms of emphasizing support for skin ship, sexual communications and so on. Along with the need for healthcare professionals to overcome their resistance to discussing sexual topics, it is desirable for them to have an awareness of the actual conditions of IBD patients’ sexuality, as well as to provide them with specific forms of support.

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