

An Investigation of Sexual/Reproductive Health Issues in Women with a Physical Disability

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Abstract Women with a physical disability continue to live with many physical, psychological, and social challenges. Long-term disability in women leads to negative consequences on their sexual functions. The study was designed to investigate sexual challenges in women with a physical disability. Employing a qualitative design, the study was conducted with ten married women with a physical disability, who fit into the inclusion criteria and had applied to the Physical Treatment and Rehabilitation Department of the Meram Medical Faculty, Necmettin Erbakan University, in Konya, Turkey. The data related to women's sexual experiences, were analyzed using descriptive and content analysis. All participants were homemakers from middle-income families, with at least one child, and were socially supported by their families since their disorder. In addition to physical disability in all cases, seven participants were diagnosed with concomitant hypertension with diabetes mellitus, and three with concomitant chronic obstructive pulmonary disease with diabetes mellitus. All were found to experience sexual problems. Sexual dysfunction is seen as a frequently encountered health challenge in women with a physical disability and should definitely be evaluated in each patient. In light of our findings, it may be suggested that healthcare professionals should be made aware of the sexual lives of women with a physical disability and should be trained for counseling.

Keywords Physical disability · Women's health · Sexuality · Turkey

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Introduction

Ten percent of the world's population have been reported to have a physical disability, and 20 % of the disabled have been found to be living in developing countries [1]. According to a study performed by the Turkish Statistics Association (TSA) and the Institution of The Disabled, Turkey, 12.29 % of the Turkish population consist of individuals with a disability. The official statistics revealed that 4.648.740 women have a physical disability, which constitutes 13.4 % of general population in Turkey. Of these, 44.5 % are married, and 40 % are of reproductive ages [2].

Women with a physical disability are faced with various physical, psychological, and social challenges during their daily living activities [3]. Women with a physical disability are known to have sexual and reproductive needs similar to healthy individuals; however, such individuals have to struggle with many challenges for access to both medical services and information [1]. Long-term disability has a negative impact on the sexual and reproductive lives of women. In society, women with a disability are considered asexual, and not eligible to be married or be mothers. In addition, physical beauty is considered important in sexual life. Thus, the sexual challenges faced by women with a physical disability per se, social values and the tendency to avoid talking about sexual problems with healthcare professionals due to cultural and religious beliefs, lead them to continue to live with such problems, without expressing them [4].

According to the WHO, health status is described as complete physical, social, and mental well-being, without a disease or disability [1]. Individuals with a disability often face social stigma and negative behaviors due to their disabilities. They tend to live in poor conditions owing to the discriminatory practices in education and at work places, and often do not utilize health services adequately [1]. Hence, it is important that healthcare professionals are sensitive to and attentive of the needs of those with a disability. In addition, they need to be aware of the cultural differences while tackling their sexual and reproductive health challenges, so that people with a disability avail health services to a satisfactory level.

In Turkey, women have to assume several roles at a time, such as those of a mother, a partner, a homemaker, as well as a member of the society. Additionally, discrimination against women brings extra roles and responsibilities onto women, which should have been shared by men [5, 6]. While it is difficult to be a woman in Turkey, being a woman with a disability is much more difficult. Women with a physical disability have to make greater efforts to perform their regular tasks. Findings obtained from an increasing number of recent studies related to women's sexual dysfunctions and their causes have led to significant developments in both the physiology of women's sexual dysfunctions and therapeutic options for the same. However, there have been no studies concerning disability and sexuality problems of disabled individuals in Turkey. Therefore, our study was designed to investigate sexual challenges faced by women with a disability.

Materials and Methods

As a qualitative one, this study was designed to investigate sexual health challenges faced by women with a physical disability and performed between April and June 2012, with ten married women with a physical disability, who were appropriate according to the study design, sourced from the Department of Physical Treatment and Rehabilitation of the Meram Medical Faculty, Necmettin Erbakan University in Konya, Turkey

Participants were those with a congenital or acquired physical disability, not diagnosed with any psychiatric disorders, had one sexual partner, and had voluntarily accepted to participate in the study. Obtaining an approval from the ethical board of the institution and consent from the participants were the ethical principles followed for this study.

Data were collected using the in-depth interview method. The questionnaire was used to collect socio-demographic data related to each participant such as age, educational status, marital status, profession, current settlement, quality of life, social security and economic status, and information related to dysfunctions. In terms of dysfunctions, the type of their physical disability, existence of other chronic diseases, existence of challenges related to women's disorders, experiencing problems with members of the family due to the disability, social support related to the disability, frequency of intercourse, challenges experienced during intercourse, reasons for the sexual challenges, educational status, and contraceptive methods were explored. An "interview questionnaire" was prepared to guide the participants during the interviews and was structured according to the data obtained from the literature [7, 8]. As sexuality is considered a taboo and cannot be spoken about in public, a physically appropriate, special chamber was allocated for the interviews to help the participants feel relaxed. Just before the interview, the participants were reassured about their safety and rights, by clarifying the following:

- Participants will not be harmed in any way during this study.
- Written records of interviews will be kept confidential and will not be revealed without the consent of the participants.
- Considering participants' discomfort and reluctance to audio/video tape the interviews, data were recorded only by taking notes.

Thus, a semi-structured questionnaire was used for the in-depth interview, and participants were asked the following questions:

- How do you think your disability affects your sexual life?
- What sort of challenges do you experience during intercourse?
- Do you share your sexual problems with your partner?

Data Analysis

The data were analyzed using descriptive and content analysis. All analysis was performed independently by the two researchers, which was then combined and revised to form the final version.

Results

All participants were homemakers from middle-income families, with at least one offspring. All of them were socially supported by their families from the initial phase of the diseases. In addition to their physical disability, seven participants were diagnosed with hypertension and diabetes mellitus (DM), and three with chronic obstructive pulmonary disease and DM. Two patients had a congenital disability, and seven had acquired disabilities. All the ten participants were found to experience sexual challenges (Table 1).

The family planning methods reported by the participants were coitus interruptus ($n = 2$), intrauterine device ($n = 1$), and depoprovera ($n = 1$). Five participants were

Table 1 Descriptive features of participants

Features initials	Age	Occupation	Educational status	Existence of chronic diseases	Duration of diseases	Family planning methods	Experiencing sexual problems
HA	54	HM	Primary school	DM + HT	1 year	Coitus interruptus	+
YC	31	HM	Primary school	–	1 year	Coitus interruptus	+
ST	50	HM	Primary school	DM + HT	4 years	Menopause	+
FU	55	HM	Primary school	DM + COPD	3 months	Menopause	+
GE	51	HM	Primary school	–	Congenital	Menopause	+
KC	53	HM	Primary school	DM	Congenital	Menopause	+
HÜ	32	HM	Primary school	–	1 year	Intrauterine device	+
ZG	48	HM	Primary school	–	1 year	3-month injection	+
EP	56	HM	Primary school	DM	6 months	Menopause	+
HC	47	HM	Primary school	HT	4 months	Tubal ligation	+

HM homemaker, *DM* diabetes mellitus, *HT* hypertension, *COPD* chronic obstructive pulmonary disease

found to be in the menopausal period, and one using no family planning methods due to tubal ligation.

The results obtained from the content analysis and the participants' experiences have been described below.

H. A. (54 years) is a homemaker, a primary school graduate, and has had hemiplegia since 1 year. In the in-depth interview, she reported:

We have been quarrelling especially within the last year. I do not want, but my partner insists on intercourse. I agree compellingly, and feel pain and lack of drive. I wish he did not force me, but he is inconsiderate. Especially for 1 year, I have wanted to do nothing both sexually and livingly, I have such moments that I can't stand seeing him.

Y. C. (31 years), is a homemaker, another primary school graduate and suffers from coxarthrosis since 1 year. She stated:

S. T. (50 years) is a homemaker, a primary school graduate, and was diagnosed with hemiplegia 4 months ago. She emphasized: My partner is patient, trying not to give rise to challenges and not insisting on intercourse due to my reluctance. However, I do not want to hurt him, to make him sad, and am having intercourse despite my reluctance and dissatisfaction. We communicate with each other on these topics. His patience and understanding feel me relaxed, but I feel guilty when I can't meet his needs. As a disabled person, my physical appearance makes me so sad.

I hate having had intercourse since my disability, and my husband is inconsiderate. Prior to my condition, my partner was inconsiderate in any case and did not care about me; now, he gives me hard time and does not understand me. Without my consent, he compels me to intercourse, I feel myself as if I had been raped. We have no communication, and he behaves me as if I were one of his possessions. I am sexually disgusting, we had no such problems previously. Since my disability, our problems have been increased. It is difficult for a disabled person to share life with a healthy individual.

F. U. (55 years) is a homemaker, another participant, a primary school graduate, and a hemiplegia patient with DM, was in the menopausal period. She stated:

I have already become diabetic. I feel pain during intercourse and do not want intercourse mostly. Fortunately, my partner is behaving thoughtfully. I am lack of sexual drive, and I feel dissatisfied in any case. Perhaps my husband feels pity for me, and this also makes me hurt.

G. E. (51 years) is in the menopausal period and was diagnosed with congenital hip dislocation. She too was homemaker and a primary school graduate. She reported:

I have no idea whether my disability has affected my sexuality or not, but I have been married for 23 years, and I have experienced no change related to sexuality in my life. As a matter of fact, I have had lack of sexual drive since I got married and am not sharing this with my partner. I think my partner is looking for satisfying only his drive, in that he does not care about me and understand me at all. I do not know if this is related to my disability. I haven't sought medical advice for the problem.

K. C. (53 years) is a homemaker with congenital hip dislocation and was a primary school graduate. She reported:

If a person feels bored and has pain, s/he doesn't want to have intercourse. I do not think my disability has affected my sexual life to a large extent. Having a partner is making me feel relaxed, but I am a bit tentative. I can't talk to my partner about sexuality. Sometimes I feel lack of sexual drive, too, but can't share such problems with him.

H. U. (32 years) is a homemaker, a primary school graduate, and a hemiplegia patient due to a brain tumor. She stated:

I haven't experienced so many problems, but my partner has experienced lack of sexual drive. We keep on an unproblemated sexual life. We can't get on well with my partner by communicating. I had experienced spousal abuse previously, so my health status had been impaired. However, I consider that I want his existence in my life despite all difficulties I experienced, such as the abuse. He looks after me whenever I feel sick. I am currently using urinary catheter, and my partner changes it. He feels sometimes disgusted due to stinking, and so not wanting intercourse.

Z. G. (48 years) is a homemaker. She has been married for 25 years, is a primary school graduate, and was diagnosed with hemiplegia a year ago. She informed:

I haven't been wanting to have intercourse since my disability, have always wished to have a rest. I don't want my partner to be around me, I always get tight and become annoyed. I experience dissatisfaction and pain. I can't talk to my partner on such subjects; whenever I feel arousal and want intercourse, my partner behaves me understandingly. I feel happy for him not to leave me and my children. However, I feel sad in order not to meet his needs and am tired of life.

E. P. (56 years) is a homemaker, a primary school graduate, and suffers from hemiplegia. She reported:

I don't want to have intercourse in general and can't get on well with my partner, either. I feel so unhappy, even I can't think of sexuality. I am aware of my responsibilities for my husband. In order not to carry out my responsibilities, I sometimes don't want to live on.

H. C. (47 years) is a homemaker, a primary school graduate, and was disabled by a spinal cord injury in a traffic accident, 4 months ago. She stated:

My partner is so tolerant on the condition, but I feel guilty because I can't make him happy. Due to my disability, lack of drive is always present. I have always neglected my partner due to operations I was exposed to and my disability, but this is due to reasons beyond my control. My partner is so thoughtful, we have intercourse only a few times since my disability, but I feel nothing. This makes me sad from time to time. As the disabled, it is really difficult for us to have a sexually active life, we are already disabled. Nothing makes me happy.

Discussion

Factors that influence the general health of women with a disability also indirectly affect their reproductive health. Sexuality is among one of the significant needs of human beings;

however, most of the people with a disability are considered asexual. Therefore, sexual health of women with a disability is neglected [7–9].

Studies investigating close relationships between individuals with a disability and other members of the society, especially on the sexual relationships of those with a disability, are limited. While some studies mention that those with a disability maintain a sexually active life, others report that individuals with a physical disability experience many common challenges related to intercourse [10–12]. In these studies, difficulties in intercourse and its maintenance that are experienced by those with a disability have partly been associated with sexual dysfunctions. Challenges experienced during intercourse are considered to decrease self-confidence related to intercourse and to prevent satisfaction [13]. One of the most significant sexual problems experienced by those with a disability is that other individuals in the society have negative perceptions about the disabled [14]. Decreased motility in individuals with a disability is reported to diminish the reflection of sexual desire. Problems such as muscle spasms, stiffness, lack of flexibility, and other issues related to motility may influence intercourse and sexual drive in patients [15, 16]. As consistent with our findings, a study by Nusbaum et al. (2003) revealed that nearly all women experience sexual problems, but seek no medical assistance or consultancy service to solve them [17]. In a study performed by Steinke and Patterson-Midgley (1996), only 15 % of nurses were found to offer information to patients on sexual issues [18]. In another study on 100 patients, it was found that the patients reported they wished to receive consultancy from healthcare providers concerning sexual issues and treatment options. However, the rate of those seeking this information from nurses was found to be lower [19]. Thus, nurses should be equipped with essential knowledge to talk about sexual challenges openly with patients. They should be given effective training and counseling to enable them to direct and encourage patients about ways of coping with stress related to their sexual problems.

Physical disabilities may lead to several challenges in the development and expression of sexual desire. Injury to the parasympathetic nervous system, which is aroused by touch, may prevent erection in men and vaginal lubrication in women. Thus, sexual functionality might be lost, in part or completely in cerebral or spinal cord injuries [20]. Similarly, problems such as spinal cord injuries, gaps in the spinal column or an underdeveloped spinal cord may prevent the transmission of sexual messages, as seen in people with paraplegia. Depending on the location or occurrence of neural injuries, the functionality of sexual organs is either completely lost or hampered [20]. In congruence with the literature, it was found in our study that sexual problems were experienced at a higher rate among women, especially with hemiplegia and a disability due to spinal cord injuries.

Further, increased dependence on partner, difficulty experienced in the adaptation to intrafamilial roles and concomitant loss of sexual functions could lead to new problems between couples [21]. In the interviews in the present study, most of the patients reported that they received satisfactory social support. As the level of perceived social support by patients increases, level of hopelessness is reported to decrease [21]. Thus, the social support that individuals with a physical disability receive from their partners and families is considered to contribute to both coping with the duration of treatment and maintaining healthy relationships with partners. In our interviews, only one of the participants reported that her partner avoided intercourse. However, this avoidance was found to be associated with the partner being actively involved in her care and the use of a urinary catheter by the patient.

Conclusion and Suggestions

In conclusion, sexual dysfunction is a commonly encountered problem in women with a physical disability and should be meticulously investigated in each patient. It is important that healthcare professionals should be aware of the effects of the physical disabilities on individuals' sexual lives. In addition, they need to be trained for counseling patients on such issues. Medical guidance related to sexual health is insufficient, and neither a model nor an educational program from another country is present for healthcare professionals in Turkey.

Therefore, further studies with larger populations are required in order to develop such a model. In addition, nationwide educational and in-service training programs for both patients and healthcare professionals should be arranged, and women with a physical disability as well as their partners should be evaluated for sexual problems.

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