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ORIGINAL PAPER

In Her Own Words: Living with Urinary Incontinence in Sexual Life

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Abstract Urinary incontinence (UI) is an extremely private, disturbing health issue with negative sexual effects for women. The aim of this study was to identify the feelings and experiences of women with UI effects on their sexual lives through a qualitative research method. Twelve Turkish women participated in this study. The mean age of them was 47.08 ± 6.12. Data was collected using both a demographic data form and a semi-structured interview form. Interview form was performed open-ended items which were designed to gather data on the experiences in sexual life, thoughts and perceptions of the participants about the impacts of UI on their sexual lives. Data was analysed by Colaizzi's analysis method. The findings that attempt to describe how women with UI live their sexuality were presented under four themes such as experiences of women when the symptoms first occurred, feelings, negative effects on sexual functioning, behavior for coping with UI. Seven of the women described the feeling that the involuntary UI caused during sexual intercourse as "shameful." The women reported that UI or the feeling of embarrassment during sexual intercourse has led to an inability to enjoy sexual intercourse by causing loss of sexual desire (five women), not having sexual intercourse (three women), and distraction (two women). There should be high degree awareness for UI and its sexual effects, not only by women but also by the healthcare staffs.

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Introduction

Urinary incontinence (UI) is defined by the International Continence Society as "a complaint of any involuntary loss of urine" [1–3]. Called the "silent epidemic," UI is not a life threatening condition, but it is a worldwide problem, affecting approximately 250 million adults in the world population [4]. It is observed as a common problem in all age groups among women in the adult population [5, 6].

UI is recognized as an important global health problem that disrupts the quality of life of women. UI has negative effects on the physical, social and psychosocial lives of women [7–9]. Women with UI are forced to restrict their daily activities such as traveling, shopping, and exercise due to involuntary urine leakage and fear of going outside [10, 11]. UI has been reported to lead to feelings of failure, embarrassment, and social isolation, all of which cause the individual distress and emotional problems, including depression [12, 13].

UI also has negative effects on the sexual lives of women [14–16]. Uncontrolled urine loss during intercourse causes the woman to feel ashamed, inadequate, and guilty toward her partner [17]. Women are known to restrict their sexuality for this reason [18]. Studies have reported that women with UI were found to have less-frequent sexual activity (and this may include not having sexual activity for fear of UI occurring) [16]. Among the most common sexual complaints in women with UI are low desire, vaginal dryness, and dyspareunia [19]. UI can also cause a decrease in closeness and sharing between spouses and negatively affect marital relationships [20, 21].

The literature emphasizes that women affected by UI are reported to be uncomfortable talking about this issue with health care professionals [22, 23]. In fact, they may receive treatment for their problems in their social lives late or even not at all because of UI symptoms [24]. Previous research in Turkey has indicated that many women with UI do not consult a doctor about their condition, although their sexual and social lives are affected [6, 25]. Reasons for not seeking medical advice include seeing UI as a minor problem that can be self-managed, not regarding symptoms as abnormal or serious, regarding incontinence as a normal part of aging and childbirth, and being embarrassed to discuss it with a doctor [6, 25]. Therefore, health care staffs, especially gynecology and urology nurses, have an important responsibility to enhance the awareness of women regarding UI and to make early diagnoses within this context. Although there has been an increase in the number of studies about UI's effects on the quality of life in Turkish women, especially in the last 10 years, we have not encountered any study focusing on the effects of UI on sexuality by way of qualitative methods. It is hoped that the findings of this study will contribute to the literature currently available to health care professionals who provide services related to this issue. During the process of planning this study, we thought that face-to-face interviews would be suitable and useful for women suffering from UI to talk with nurses about their sexual life experiences. The aims of the study were to identify the sexual life experiences of women with UI in terms of their own perspectives and increase the awareness of the healthcare staff working in the outpatient centers on this issue.

Materials and Methods

This study was conducted in the Obstetrics and Gyneacology and Urology Departments of a research hospital using qualitative design and phenomenological approach from

September to December 2010. Phenomenology refers to a methodological approach that focuses on enhancing understanding of experience and meaning of the disease [26].

Participants

Twelve patients with UI were enrolled in this study. The inclusion criteria were; patients over the age of 20, with a complaint of UI over a 1-year period or longer presenting at the urology and gyneacology department of a training hospital in Ankara, had an active sexual life, married and could speak and understand Turkish. On the other hand, there were some exclusion criteria such as reporting husband's sexual dysfunction and other health problems such as gynecological cancer, vagnismus etc. impacting the women's sexual functioning, and having inadequate time for the interview.

Data Collection

A completed consent form was obtained from each participant who complied with the inclusion criteria of the study by a researcher. Each participant had taken part in the study after receiving detailed information about the voluntary nature of participation and about confidentiality and the aims of the study. They are also informed that the interviews would be audio-taped. Data was collected using both a demographic data form and a semi-structured interview form. Interview form based on the literature was developed by the researchers, and it included open-ended items which were shown in Table 1 to gather data on the experience, thoughts and perceptions of the participants. The data of the study was collected through individual in-depth interviews by a researcher. The reason for choosing individual in-depth interviews was that the individual interviews can be regarded as more appropriate for the participants to reveal their experience more freely. The researcher started to interview by asking sociodemographic (age, education status, jobs etc.), obstetric and gynecological status (number of pregnancies, giving birth, menopause, or having any gynecological surgery etc.). The interviews were carried out in the silent room at clinics and lasted 30–40 min.

Data Analysis

Data was analysed by Colaizzi's phenomenological data analysis method (Table 2) [27]. All the participants' oral descriptions were read by researchers to gain a general understanding. Significant statements and phrases that directly pertained to the study objectives were extracted. Meanings were formulated from these significant statements and phrases. Formulated meanings were organized into themes and sub-themes (Table 3). To maintain the credibility of data analysis, the transcripts were examined repeatedly by each researcher in order to immerse into the data. Two researchers worked independently to identify the major categories of the transcripts. The coding was compared. There were

Table 1 Items used in the semi-structured interviews

1. How did UI affect your life when your symptom was occured at first?
2. How did this illness affect your sexual life?
3. What are sexual difficulties you have experienced UI during your intercourse?
4. How do you cope with these difficulties?

Table 2 The steps in Colaizzi's phenomenological data analysis

1. Read all the participants' description of the phenomenon under study
2. Extract significant statements that pertain directly to the phenomena
3. Formulate the meaning of the significant statements
4. Categorize the formulated meaning into themes and sub-themes
5. Integrate findings into an exhaustive description of the phenomenon being studied
6. Validate the exhaustive description by returning to some of the participants to ask them how it compares to their experiences
7. Incorporate any changes offered by the participants into the final description of the essence of the phenomena

Table 3 Themes and sub-themes resulting from interviews

Theme 1: Experiences of women when the symptoms first occurred
Theme 2: Feelings about UI symptoms during having an intercourse
Sub-theme 2.1: Shame
Sub-theme 2.2: Blame and guilt
Sub-theme 2.3: Fear that UI symptoms could occur during intercourse
Theme 3: Negative effects on sexual functioning
Theme 4: Behaviors for coping with UI
Sub-theme 4.1: Individual coping behaviors
Sub-theme 4.2: Sharing with the husbands

minor differences between the coding of the two researchers which mainly related to the choice of words. Differences were discussed and finally agreement was reached. To achieve final validation, three paticipants were selected randomly and contacted again to read the descriptions, they agreed that the analyses had accurately represented their personal experiences.

Results

The mean age of the 12 women participating voluntarily in the study was 47.08 ± 6.12 (39–58) years. The participants were from various provinces of Turkey. Four of the women had graduated from elementary school, one from middle school, six from high school, and one had a university degree. Eight of the women were housewives, three civil servants, and one retired. One of the women had no child, two had one child, eight had two children, and one had three children. Of the women with children, two had undergone cesarean section, eight normal births and two had experienced difficult vaginal delivery. Five of the women had undergone hysterectomy and four were in the postmenopausal period.

The findings that attempt to describe how women with UI live their sexuality were presented under the following categories:

Theme 1: Experiences of Women When the Symptoms First Occurred

Most women did not remember when they experienced UI for the first time but stated that they had experienced it with coughing and sneezing from time to time. Five of them stated

they experienced UI for the first time during pregnancy or delivery and after hysterectomy surgery. Women stated not minding when they experienced UI for the first time and perceived it as normal, using phrases such as “I did not really care much”, “I did not notice it much,” “I thought it might be a temporary thing,” and “I did not think it was a problem”. However, in time, they thought this situation they experienced was not normal, and stated that they had difficulties in social life, became anxious and afraid, and felt powerless.

> Since I was 40, I cannot hold my urine while coughing and sneezing. I did not mind this situation at first; I thought it as a temporary thing. Then I thought that everything would return to normal but it did not … it did not improve. Sometimes, I felt powerless. (Case 5, Age: 52)

> I had UI first when my uterus was removed. Naturally, I felt a little anxious. Later, this situation gradually increased… (Case 8, Age: 46)

Theme 2: Feelings About UI Symptoms During Having an Intercourse

This category reflects the feelings of the patients due to UI during sexual intercourse. Ten women participating in the study stated the incontinence condition they experienced affected their sexual lives and described various emotions.

Sub-theme 2.1: Shame

Seven of these women described the feeling that the involuntary urinary inconsistence caused during sexual intercourse mostly as “shame”. One of the participants said that:

> I’m sorry to say but it happens also during intercourse with my spouse. Our intercourse is not very often but it still continues. This is so hard… My God, maybe it does not kill but makes me very ashamed. God helps me that I am not embarrassed from now on… (Case 1, Age: 46)

> I spent about three years ashamed from my husband at home with this big problem. These times were the worst experience in my life. (Case 2, Age: 52)

Sub-theme 2.2: Blame and Guilt

Four of the women expressed that their sexual desire decreased with age and the factor accelerating this process was UI. Women used expressions such as “my intercourse with my husband decreased we got older”, “menopause and my situation caused a decrease in our intercourse” and “we had regular intercourse but now it has decreased” about this situation.

> In fact, menopause, and my situation caused a decrease in our intercourse. Although your husband helps you, you feel bad yourself while in bed, you don’t want to do it. It is a very difficult situation. (Case 7, age 44)

> We had regular intercourse, but it decreased with age, I think … Also, once I got the bed wet, everything got dirty and I felt very bad. (Case 8, age 46)

Some of them expressed that their issue was a result of not receiving treatment on time, and therefore they felt “guilty” (n = 3). One patient stated like this:

> If I went to the bathroom before intercourse it did not happen much. But now it happens too much during the intercourse. Then it feels like my world is falling down. I feel guilty for not going to the doctor on time. (Case 10, age 39)

Sub-theme 2.3: Fear that UI Symptoms Could Occur During Intercourse

Two women who had not yet had problems in their sexual lives stated that they had fear and anxiety of experiencing UI, and that they would be ashamed if they would have UI during sexual intercourse and would restrict sexual relations. In this regard, one of the participants provided the following explanation:

> It does not affect the sexual relationship with my husband at this moment; however, I'm afraid I would if I am forced. Of course, this situation has begun to affect my psychology. Sometimes I'm worried if it might happen. I guess it would be shameful. (Case 3, age 41)

Theme 3: Negative Effects on Sexual Functioning

The women reported that UI or the feeling of embarrassment during sexual intercourse has led to an inability to enjoy sexual intercourse by causing loss of sexual desire (5 women), not having sexual intercourse (3 women), and distraction (2 women). Two patients explained their difficulties in this regard as follows:

> I wish I did not have a UI because it is causing me to feel bad at home. Thank god I have a good marriage, but now I'm so ashamed towards my husband during intercourse … It just takes all my desire away… (Case 5, age 52)

> When I have incontinence during the intercourse, it hurts, the bed gets wet, and I have to clean it. My husband and I therefore do not have intercourse anymore. (Case 12, age 58)

In addition, five women that participated in the study stated that they experienced "pain and burning" due to squeezing themselves in order not to have UI during sexual intercourse. In this regard, one of the participants provided the following explanation:

> I feel distracted because I struggle to keep my urine during intercourse with my husband, I do not feel comfortable. This puts me in a difficult situation. I have pain and it hurts. My world turns upside down… (Case 2, age 44)

Theme 4: Behaviors for Coping with UI

Patients' ways of coping vary in this study. This category is about the strategies women try to cope with UI ranging from individual behaviors to husbands' supports.

Sub-theme 4.1: Individual Coping Behaviors

The women stated that they have developed solutions to decrease the effect of involuntary UI on their sexuality. Most women stated that they try to prevent UI by going to the toilet frequently before sexual intercourse (4 women), others stated that they try to avoid this situation by suggestion during sexual intercourse, positive thinking and relaxing (2 women) or by squeezing the pelvic muscles (2 women). The remaining women (2 women)

stated that they could not effectively cope with the involuntary UI in their sexual life and the situation was very difficult.

> I go to the bathroom twice before the intercourse in order not to have UI. I try not to think about this too much as well. I try to relax. However, this situation is causing us not to live a comfortable sexual relationship. (Case 7, age 44)

> I try to squeeze myself in order not to have UI. I live this situation almost every time. I am sick of it… (Case 1, age 46)

Sub-theme 4.2: Sharing with the Husbands

Within the context of the study, five women expressed that they shared sexual problems easily with their husbands and their husband supported them on every issue. Three women stated that their partner knew about their UI problems, but they could not openly discuss them. Another four women expressed that their husbands did not care about this issue, and they could not talk on this subject. These women stated that they expected support from their husbands, but could not find it.

> My husband is very sensitive and helpful. He too wanted me to see a physician. Perhaps my UI recently increased and it sometimes even happened during sexual intercourse. We were both afraid. What would I do without him. (Case 7, age 44)

> My husband does not say anything about it to me. But even this makes me uncomfortable. Because it is a difficult thing to experience alone… (Case 1, age 46)

> We could not talk about this situation from the beginning with my husband: but I told him that I had such a problem before I went to a physician. He did not think about it much, he ignored it. I would have wanted my husband to share this issue with me and support me before I talked to him about it. I'd have behaved like this. (Case 3, age 41)

Discussion

In this study, the sexual life experiences of women with UI were summarized under four main themes. Although each story was unique, it was seen that UI had important effects on womens' lives. The effects of UI on women's sexuality were investigated by in-depth interviews in this qualitative study.

Most of the women in our study did not remember how and when they had first began experiencing incontinence but had begun to perceive it as a major health problem when its influence on their social and sexual lives increased. This finding is important in terms of the delay of most women in going to healthcare facilities due to UI symptoms. Relevant studies were reported that help seeking behaviors and psychocultural meanings of UI in women may be affected by their health beliefs, cultural, race and ethnic differences [4, 28, 29]. Furthermore, sexuality and UI in Turkey as well as in many cultures are issues ignored by women who are not used to asking questions. They are seen as taboo due to the influence of social and cultural factors and not taken into account by health care professionals [30]. It is therefore important that healthcare providers should evaluate incontinence in every respect according to every culture.

Most of the women in the study reported experiencing shame due to the effect of UI on sexuality and even women who had not experienced sexual problems yet in their lives said they would be ashamed if they experienced UI. In addition, women who participated in the study stated that they experienced decreased sexual desire due to UI during sexual intercourse or had ended having sexual intercourse altogether. Two different studies reported that women who experience UI even at least once during sexual activity to be ashamed of their husbands and to end their sexual life due to the recurrent UI in later periods in parallel with this study [31, 32]. Thus, important contributions will be gathered so that healthcare professionals can improve their psychological focus and the interest in further knowledge about this topic, and may direct women and their husbands' experiencing UI to family therapy in order to help them arrange their sexual lives.

Sexual function is affected by the individual's psychological status [33]. In this study, we found from the expressions of the women that they could not concentrate and enjoy sexual intercourse due to the fear of UI. This result was in parallel to Hartman's study [34]. Another study conducted in Turkey reported a 78.1 % decrease in sexual satisfaction and a 77.7 % decrease in the incidence of orgasms in women with UI, while 45.3 % experienced dyspareunia [35]. We found that some women had experienced dyspareunia due to squeezing themselves to hold the urine during sexual intercourse. The results of two previous studies correlated with our results with incontinence experienced during sexual intercourse often causing pain and leading to sexual intercourse becoming unbearable [36, 37]. It is important for nurses to provide suggestions and act as consultants by discussing concerns about pain, sex role, desirability as a sexual partner and identifying acceptable sexual practices and some alternative ways for sexual satisfaction.

We found that it is difficult for women to deal with UI effectively and they come up with a variety of individual coping behaviors to control UI during sexual intercourse. Reese in his study emphasized that patients always develop coping behaviors and strategies regarding the effects they experience due to UI [38]. UI seriously affects a woman's sexuality. Women therefore try to find a variety of solutions to control their UI. Healthcare staff and particularly nurses are responsible for planning effective coping strategies together with the patient for this problem [39]. No matter what sexual problem the patient is experiencing, it is important to make the patient feel being listened to and taken seriously. When discussing effective coping methods with the patient, medical staff should not judge the individual and should not reflect their own value judgments [14].

When one of the couples have any problem related to sexuality, "partner participation" is important in the problem-solving process [40]. Less than half of women with UI in our study reported sharing this problem with their husband. Communication between the spouses plays an important role in maintaining a positive and healthy marriage relationship. When a sexual problem is being evaluated by healthcare staff, the spouse's responses, opinions and any support he may provide to his wife in this regard, and what they do for the problem should be handled especially carefully. A study on the subject has reported women do not know where to start even when they want to share the UI status and its effect on their life. When experiencing UI for the first time, they were shy to talk with their husbands and tried to hide it but had to talk to them later on with the progression of symptoms [41]. Women whose sexuality was affected by UI in our study chose to share this problem only with their husbands. Andersson [42] reported that women stated they ignored UI at first but became afraid with the progression of symptoms; the support of healthcare staff towards the source of the problem of UI provided a "guiding light" for them.

In conclusion, sexuality is an integral part of general women health. UI is an extremely private, disturbing health issue with negative physical, social and sexual effects for women, decreases the quality of life in women and affects their psychological status negatively. We conclude that UI affects sexuality of women by describing the meanings of UI as a shameful, guilty and fearful situation, has led to an inability to enjoy sexual intercourse by causing loss of sexual desire, not having sexual intercourse, and distraction. The results showed that women's ways of coping may vary from the individual coping techniques to husband's support.

Implications for Practice

In line with the results of the study, it is recommended that the health care staff with their important roles in protecting, increasing and developing women's health with a holistic approach, should ensure an environment for women to discuss their sexual problems easily without ignoring the effect of UI on a woman's sexual life, evaluate the sexual functions, and devote more time to providing knowledge related to maintaining sexuality during patient education. There should be a high degree of UI awareness, not only by women but also by the healthcare staff. This study has essential implications for health care staffs (particularly nurses) about the sexual life experiences of women with UI. Sexuality assessment and counseling are parts of the nurse's professional role, but few nurses integrate these roles into their practice. This study addresses four related implications for nurses:

1. Nurses should evaluate incontinence and its management according to every culture.
2. Nurses may direct women and their husbands who are experiencing the negative impacts of UI to family therapy in order to help them manage their sexual lives.
3. Nurses may discuss women's sexual problems easily without ignoring the effect of UI on a woman's sexual life and may provide suggestions and act as consultants by discussing concerns about pain, sex roles, and desirability as a sexual partner, and by identifying acceptable sexual practices and alternative ways to have sexual satisfaction.
4. Nurses are responsible for discussing effective coping methods with women with UI without any judgments. It is important to make the patient feel that she is being listened to and taken seriously.

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