

Explaining Factors Affecting Help-Seeking Behaviors in Women with Urinary Incontinence for Early Diagnosis by Healthcare Providers: A Qualitative Study

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Abstract

Background: Urinary incontinence is widely accepted to be among the most important issues in the global health system. However, only a limited number of women refer for treatment as different factors make help-seeking behaviors more complicated than they initially seem to be. The aim of this study was to explain the factors affecting help-seeking behaviors in women suffering from urinary incontinence.

Methods: The present study used a qualitative method, the conventional content analysis approach, and in-depth semi-structured interviews. The study was conducted between December 2018 and August 2019 in Tehran, Iran. The participants of the study included 34 women with urinary incontinence selected using purposive sampling method. The content analysis approach was based on the Graneheim and Lundman method, and qualitative data management software was used to analyze data.

Results: Data analysis illustrates two facilitating and deterring themes; the categories "not perceiving disease", "shame", "negative influence of important others", and "the health care system" were among the deterrents and the categories "weakening the quality of life" and "positive effect of important others" were found to be facilitators.

Conclusions: The findings of the present study highlight the need for understanding the underlying facilitators and obstacles to help-seeking behaviors in women with urinary incontinence and suggest that healthcare providers consider an open dialogue with patients taking into account their subjective beliefs and life context during routine referrals so as to facilitate early diagnosis of the disease and ultimately lead to an improvement in the woman's quality of life.

Plain English Summary

Urinary incontinence is a social and hygienic problem that affects women's quality of life but women with urinary incontinence usually do not seek treatment or delay treatment. The present study used a qualitative method, because to discover a problem, it is more appropriate to use a qualitative study to examine it in depth. The participants of the study included 34 women with urinary incontinence selected using purposive sampling method. Data collection methods included in-depth semi-structured interviews with women with urinary incontinence and data management software was used to analyze data. This study determined the factors affecting referral for the treatment utilization in women with urinary incontinence in the form of two facilitating and deterrent themes and which were discussed in this study. The findings suggested that introducing the extracted effective factors helps healthcare providers to consider those factors in dealing with women who refer to the healthcare centers for any reason, that is, recognizing the effective factors on referral helps to early diagnosis disease.

Background

According to the International Continence Society, any complaint of the involuntary leakage of urine is called urinary incontinence (1). Urinary incontinence (UI) is currently one of the most important and

significant global health system issues (2).

Involuntary leakage of urine occurs in both genders, but women are more susceptible than men due to their urinary system anatomy. In addition, researchers believe different factors may cause involuntary leakage of urine in women. Therefore, there have been a number of studies considering the relationship between demographic and midwifery factors such as age, parity and delivery method and urinary incontinence, and some studies have incriminated hysterectomy, diabetes, obesity and depression in relation to UI (3–7).

Although studies have been conducted on the prevalence of urinary incontinence, its exact prevalence is difficult to identify due to the difference in different diagnostic definitions, instruments, and methods (8). One of the studies reported an average urinary incontinence prevalence of 27.6% in women (ranging between 4.8%-58.4%) (2). A study also demonstrated that one in five women experience incontinence during their lifetime (9). Overall prevalence of urinary incontinence in the Iranian women has been reported to be 46% (10).

The physical effects of incontinence on the body include rash, persistent skin irritation, and bacterial and fungal infections. Anxiety, stress, and depression are said to be the psychological consequences of incontinence. Moreover, UI disrupts normal daily activities and the social presence of the patient. In addition, involuntary leakage of urine also disrupts sexual intercourse (11–13). Consequently, urinary incontinence has an undeniable detrimental effect on patient quality of life, pointing to the important role treatments may play in the improvement of patient quality of life (11, 13–15).

There are various and effective treatments for urinary incontinence. Behavioral treatments, pelvic floor muscle exercises, various medications, and surgery are the most common treatment strategies for urinary incontinence (16). Moreover, reports have indicated that 70% of urinary incontinence cases can be treated (17). However, a limited number of women -merely 25%, according to one study seek help for treatment (18). In addition, most women with urinary incontinence try to manage it themselves rather than seeing a physician for treatment, which is itself among the reasons for the development of chronic conditions (19).

There are a number of studies dealing with the reasons for non-referral or delay in women's referral for treatment (20, 21). For example, a study found that one reason for non-referral was the attribution of incontinence to natural changes such as those caused by aging or vaginal childbirth (21). Another study reported that help-seeking behaviors depended on the intensity of the complications caused by incontinence (22).

The experiences of women with urinary incontinence in Iran have been investigated, revealing a tendency among Iranian women to tolerate the inconvenient conditions caused by incontinence without seeking help (23). However, with regard to the relatively high prevalence of urinary incontinence in Iranian women (10), no study has been conducted on this society to discover the factors affecting treatment.

The concept of help-seeking behaviors in the field of health refers to planned behavior aimed at getting help from professional healthcare providers on detection of changes in health status. Help-seeking behaviors are complex behaviors influenced by a variety of factors and are consequently subject to change in different contexts (24). Therefore, it is possible to reduce the time between the onset of the problem and receiving professional help by determining the effective factors at play. In other words, early diagnosis and timely treatment could be achieved by identifying the factors affecting referral for treatment and then training and informing healthcare providers. Hence, the present study was designed to explain the factors affecting help-seeking behaviors in women with urinary incontinence in Iran.

Methods

Study design

The present qualitative research is the first study conducted exclusively in the Iranian population to determine the factors affecting referral to treatment from December 2018 to August 2019.

Settings, sample and recruitment

The research context was the urology clinics of teaching hospitals of Shahid Beheshti University of Medical Sciences, and also, public places (parks, mosques, etc.) or in other parts of the city on interviewee request. Purposeful sampling was performed. The participants of the study included women with urinary incontinence who met the inclusion criteria, i.e. they were willing to be interviewed, were not pregnant, were suffering from urinary incontinence (any kind of incontinence (for at least 6 months or more, had been treated (admission and treatment) or had avoided referral for treatment, did not suffer from of any acute mental disorders or disease that could interfere with the interview, and were able to communicate verbally with the researcher in Persian. On the other hand, if the interviewee was not willing to continue participation at any time during the interview or if she was unwilling to disclose her experiences, she was excluded from the study.

Data collection

Data collection methods included in-depth semi-structured interviews with women with urinary incontinence. The samples were taken in the research context, after the evaluation of the inclusion criteria, and approval of the diagnosis of UI by Bradley's Questionnaire for Urinary Incontinence Diagnosis (QUID) (25). As participants of this study were women with urinary incontinence, screening tools needed to be used to confirm incontinence; therefore, Bradley's Questionnaire was used to quickly diagnose stress, urge, and mixed urinary incontinence with the least number of questions (6 items). The interviews were conducted individually and recorded using a digital voice recorder with the permission of the participants. All interviews were conducted in person by the same interviewer. The interviews began with an open-ended question (What are the reasons for your referral or non-referral for the treatment of your

urinary incontinence?) and continued with in-depth semi-structured questions provided by the interview guide. Also, the probing questions (Please explain more. What do you mean? etc.) or clarification statements (What you said means, You meant that) were used during the interviews. This process of interviews continued until data saturation was achieved with maximum diversity (achieved by selecting people from different places, levels of education, employment, and income). The duration of the interviews was determined by the participants and their willingness to continue the interview, but the sessions took on average 30–60 minutes. At the end of each interview, the researcher listened to the recorded interviews several times and then transcribed them into a Microsoft Word file.

Data analysis

We conducted conventional content analysis approach based on principles recommended by Graneheim and Lundman (2004), which included implementing the entire interview immediately after it ended, reading the entire text to fully understand its contents, determining meaning units and initial codes, classifying similar initial codes into more comprehensive classes, and determining the main theme (latent content). In this method, classes and their names were created from data (26). Data management software was used to analyze data.

Rigor and trustworthiness

Lincoln and Guba's (1985) trustworthiness criteria, which include credibility, dependability, conformability, and transferability, were used to increase the rigor of the collected data (27). Credibility included prolonged engagement, reviewing by participants and feedback, and requesting a review by the members of the research team. Two external researchers were asked to review the data to ensure its dependability. Moreover, code-recode method was used for at least two weeks. In addition, the confirmability of the findings was verified by two auditors familiar with qualitative research. The transferability of the findings was confirmed by selecting participants with the highest ability to communicate and by maintaining diversity in the selection of participants. Moreover, the authors strived to provide thick descriptions for those who seek to transfer the results.

Ethical considerations

The research protocol and sampling has been approved by the ethics committee at Shahid Beheshti University of Medical Sciences (the code: IR.SBMU.PHNM. 1397.33) in the Tehran (Iran). Informed consent was obtained from each woman included in the study.

Results

The participants of the study included 34 women with urinary incontinence with an average age of 54.50 years (range: 29–75 years) (Table 1 Sociodemographic characteristics of participants). The

minimum and maximum duration of urinary incontinence in the participants was 1 year and 25 years; also, the lowest and highest number of childbirths were zero (0) and 11 times, respectively.

Table 1
Demographic characteristics of participants

| Variable | Mean(SD) | |
|---------------------------|---------------|---------|
| Age (in years) | 54.50 (11.31) | |
| Education | Number | Percent |
| Illiterate | 8 | 23.5 |
| Diploma and under diploma | 22 | 64.7 |
| Higher education | 4 | 11.8 |
| Occupation | | |
| Housewife | 28 | 82.4 |
| Employed | 6 | 17.6 |
| Type of incontinence | | |
| Stress | 7 | 20.6 |
| Urgency | 14 | 41.2 |
| Mixed | 13 | 38.2 |

After reviewing the participants' perspective on the factors affecting their help-seeking behaviors, two themes were obtained. In the process of analyzing and comparing data after categorization codes and eliminating similar codes, 60 codes, 36 sub-sub-categories, 17 sub-categories, 6 main categories, and 2 themes (deterrents and facilitators) were extracted (Table 2 and Fig. 1 Classification of themes). The deterring themes included the main categories of "not perceiving disease", "shame", "negative influence of important others", and "the health care system" and the facilitating themes included "weakening the quality of life" and "positive effect of important others".

Table 2
Classification of Theme, main categories and subcategories

| Sub-Subcategories | Subcategories | Main categories | Theme |
|---|---|---------------------------|-----------|
| Attributing to natural processes | Non-acceptance incontinence as a disease | Not perceiving disease | Deterrent |
| Non-warning nature of incontinence | | | |
| Adaptation to symptoms | Self-control | | |
| Changing eating habits | | | |
| Unawareness of the nature of the disease | Unawareness | | |
| Unawareness of treatment | | | |
| Fear and worry investigation of the disease | Fear- worry | | |
| Fear of invasive treatments | | | |
| Concealment of the disease | Shame related to the nature of incontinence | Shame | |
| Shame of expressing to caregivers | | | |
| Shame of talking about genital area | Shame related to the genital area | | |
| Shame of observation of genital area | | | |
| Cost of diagnostic | Enormous costs | Health care system | |
| Cost of therapeutic | | | |
| Inaccessibility | Poor quality of care | | |
| Unavailability | | | |
| Defective reference system | | | |
| Inappropriate behavior of caregivers | | | |
| Providing incorrect information | Negative effect on decision-making | Negative effect of others | |
| Dissuade from visiting | | | |
| Reverse therapeutic experiences | Creating doubts about treatment outcomes | | |

| Sub-Subcategories | Subcategories | Main categories | Theme |
|--|---|---------------------------|-------------|
| Treatment as ineffective | | | |
| Misconceptions in the family | Role of family deterrence | | |
| Numerous expectations from a woman | | | |
| Lack of perception of the spouse's problem | Role of husband deterrence | | |
| Lack of spouse support | | | |
| Encouragement to refer | Positive effect on decision-making | Positive effect of others | Facilitator |
| Recommend treatment places | | | |
| Expressing experiences of improving | Transfer positive therapeutic experiences | | |
| Confirm of non-invasive treatments | | | |
| Emotional support | Support | | |
| Financial support | | | |
| Intensity increase of symptoms | Exacerbation of the disease | Weakening quality of life | |
| Symptoms of accompanying weakening | | | |
| Limitations | Pervasiveness of the disease | | |
| Exhausted | | | |

Not perceiving disease

The reason why some participants did not seek help, was not perceiving incontinence that it resulted from not accepting incontinence as a disease, unawareness, fear, or worry. In addition, this not perceiving led to self-care, resulting in avoidance of referral to treatment.

Not accepting incontinence as a disease was related to its attribution to natural processes, as well as the absence of warning signs. In this regard, one participant said, "*Incontinence is normal for those who are getting older*" (Participant 5, age 64, under diploma, housewife, 21 years of incontinence, 2 parturitions, mixed type).

"*Anyway, we have given birth many times; eventually, incontinence relates to many pregnancies and deliveries ...*" (Participant 13, age 75, illiterate, housewife, 10 years of incontinence, 9 parturitions, mixed

type).

"I have urinary incontinence, but I don't have any pain or bleeding at all..." (Participant 31, age 44, diploma, housewife, 1 year of incontinence, 2 parturitions, mixed type).

Some participants controlled the disease by adapting to the symptoms of incontinence and changing their eating habits. One participant said, *"I follow a diet of fruits, vegetables, and herbs"* (Participant 2, age 75, higher education, employed, 25 years of incontinence, 2 parturitions, urgency type).

"I try not to drink water or tea" (Participant 1, age 31, under diploma, employed, 4 years of incontinence, 1 parturition, mixed type).

Unawareness of the nature of the disease (as the cause of disease genesis) and unawareness of its treatment prevents people from making the right decision in dealing with it. As one participant stated:

"Where I worked, I used the well water; it was near a gas station, and people said the gasoline was leaking into the well. When we used water, it had a bad smell, and after that, I developed this urinary problem" (Participant 1, age 31, under diploma, employed, 4 years of incontinence, 1 parturition, mixed type).

"Women with the disease don't pursue treatment because it has no treatment. I don't know if there is a cure" (Participant 2, age 75, higher education, housewife, 25 years of incontinence, 2 parturitions, urgency type).

Fear and worry about the consequences of the disease investigate, as well as fear of invasive treatments was effective on referral.

"I think women are afraid that go to a physician for their disease because of being diagnosed with a dangerous disease" (Participant 28, age 54, under diploma, housewife, 1 year of incontinence, 4 parturitions, urgency type).

"If a doctor tells me to have a surgery, I won't do it; why should I put myself at the mercy of the surgeon's knife?" (Participant 13, age 75, illiterate, housewife, 10 years of incontinence, 9 parturitions, mixed type).

Shame

In some participants, the shame of having incontinence led to hiding the disease and not telling the problem to healthcare professionals.

"I didn't tell anyone about my problem; it's not a matter to be talked about ..." (Participant 3, age 67, diploma, housewife, 2 years of incontinence, 4 parturitions, mixed type).

"I'm embarrassed it's so hard to go to the doctor and say I'm incontinent; that I can't hold it ..." (Participant 17, age 50, diploma, housewife, 7 years of incontinence, 4 parturitions, stress type).

Another part of the shame was shame of exposing the genital area. Participants were ashamed of being examined by their caregivers and even of talking about it. This embarrassment became more apparent in relation to male healthcare specialists, so they preferred same-sex caregiver.

"I told myself that if I went to the doctor, he might want to examine me; he would look down there (the genital area), which I wouldn't allow" (Participant 13, age 75, illiterate, housewife, 10 years of incontinence, 9 parturitions, mixed type).

"I didn't go to see the doctor; I took medicine myself; I'm embarrassed to talk about a problem in the genital area..." (Participant 24, age 48, under diploma, housewife, 1 year of incontinence, 5 parturitions, urgency type).

A participant who was upset after realizing the presence of male students in the doctor's room said *"I came here to be examined by a female doctor, but the men examined me; her students were male; they're the ones examining the patients"* (Participant 21, age 69, under diploma, housewife, 5 years of incontinence, 3 parturitions, mixed type).

The health care system

Diagnostic and therapeutic costs have been found to be effective in use of medical services, because many people are unable to afford them.

"The medicine is expensive; my husband told me to, tell the doctor to prescribe medicine covered by insurance. I said, 'What can I do?'" (Participants 23, age 50, under diploma, housewife, 1 year of incontinence, 3 parturitions, mixed type).

"I heard that this hospital is free, so I came here ... I have health insurance. I just paid for the commute" (Participant 9, age 61, illiterate, housewife, 15 years of incontinence, 7 parturitions, urgency type).

"I just came for a check-up, but they gave a lot of tests, an ultrasound; they exhausted me.... I paid a lot of money" (Participant 31, age 44, diploma, housewife, 1 years of incontinence, 2 parturitions, mixed type).

Inaccessibility to services in some areas, unavailability (for example, long waiting time), lack of referral of patients due to the defective referral system, and inappropriate behavior of caregivers were some of the poor quality of services that participants complained about. One participant said in this regard:

.... They [care providers] said that I should do the urodynamic test whose device is not available here; they told me to go to ... [Province center]" (Participant 27, age 55, under diploma, housewife, 2 years of incontinence, 4 parturitions, mixed type).

"If I didn't have the necessary time, I went to private centers; now that I have the time, I have come here (public hospital). You have to wait a long time for your turn" (Participant 14, age 48, diploma, housewife, 1 year of incontinence, 2 parturitions, stress type).

"One says do surgery, another one says no, the other one says go to that clinic, another one says go to this doctor; they give addresses, this is better, that's better; I don't know, where should I go? What can I do?" (Participant 18, age 42, under diploma, housewife, 3 years of incontinence, 3 parturitions, urgency type).

One of the patients, complaining of the disrespectful treatment said, *"Excuse me, but some people insult us; for example, my belly is big, one of them said 'What a big belly,' and 'Why is your belly so big?' They insulted me repeatedly, for this reason. I didn't like that hospital ...; that's why I didn't go to that hospital anymore"* (Participant 23, age 50, under diploma, housewife, 1 year of incontinence, 3 parturitions, mixed type).

"I'm a patient of Dr..., but her students always examine me. She is there too, but she doesn't answer me; she doesn't pay attention to the patient at all" (Participant 4, age 63, illiterate, housewife, 1 year of incontinence, 6 parturitions, urgency type).

Important others

Important others had a dual effect on the patients' life. In the deterrent theme, important others by incorrect information about the disease and dissuade the patient from visiting had a negative effect on a person's decision to seek help. Furthermore, the expression of reverse therapeutic experiences and ineffective can cause doubt about the consequences of treatment and therefore, prevent referral.

"My sister-in-law has been suffering from urinary incontinence for almost 6 years. She says, it's because of the cesarean, and that I will get better; she tells me not to go to the clinic, I'll get better, it's a complication of surgery" (Participant 26, age 42, illiterate, housewife, 1 year of incontinence, 3 parturitions, urgency type).

"My friends say we have the same problem, one of my friends had surgery and says she still has the problem; she tells me not to do it and that it's useless" (Participant 10, age 69, under diploma, housewife, 8 years of incontinence, 3 parturitions, mixed type).

"One of my daughters said that her mother-in-law had this problem, so she had surgery; the doctor pierced her bladder during the operation, and now, instead of a few drops, she has become completely incontinent"... (Participant 23, age 50, under diploma, housewife, 1 year of incontinence, 3 parturitions, mixed type).

In the deterrent theme, the role of the family and spouse in referring to treatment was significant. On the one hand, misconceptions in the family affected on seeking behaviors, and on the other hand, the various expectations and responsibilities of the woman in the family prevented her from paying attention to her own problem. Moreover, her husband's lack of perceiving of the problem, as well as his lack of support, reinforced the lack of seeking help. The women said:

"My children, my daughter-in-law, and my son-in-law shouldn't know about my incontinence problem. If they find out, they think I'm loose. It's ugly for me. If I want to see a doctor, I will have to lie" (Participants 33, age 51, diploma, employed, 25 years of incontinence, 3 parturitions, stress type).

"My family thinks that I'm lax" (Participant 8, age 52, under diploma, employed, 9 years of incontinence, 3 parturitions, urgency type).

"Look, I did the urodynamic test two years ago. I haven't been able to show it to a doctor yet. I have a handicapped child at home and a lot of work to do; I'm so busy" (Participant 15, age 60, under diploma, housewife, 3 years of incontinence, 4 parturitions, mixed type).

"My husband says 'Can't you go to the bathroom sooner?' I'm under a lot of pressure involuntarily, I can't hold myself; I can't control it" (Participant 4, age 63, illiterate, housewife, 1 year of incontinence, 6 parturitions, urgency type).

"At least I don't have financial problems, but what about other women?!! They're financially dependent on their husbands, so they do not have the authority to see a doctor whenever they wanted" (Participant 33, age 51, diploma, employed, 25 years of incontinence, 3 parturitions, stress type).

In the facilitator theme, others encouraged patients to see a doctor, as well as suggesting places to get treatment, that had a positive effect on the decision to refer. Another way in which the others facilitated treatment-seeking behaviors was by providing positive treatment experiences. Therefore, speaking about signs of recovery after receiving treatment, as well as transferring the experience of non-invasive treatments pursued patients to use treatment. The supports were also a stimulus for refer. Participants said:

"My gynecologist told me to follow up for the urinary problems, and my sister confirmed it, she said go visit a doctor, follow up your problem" (Participant 19, age 35, higher education, housewife, 1 year of incontinence, 1 parturition, stress type).

"My mother also has this problem, she went to see a doctor; the doctor prescribed pills for her; she says she's better ...I said to myself, why did I bother myself when I could get better with one pill!!" (Participant 20, age 62, illiterate, housewife, 2 years of incontinence, 11 parturitions, urgency type).

"My husband isn't like some men who don't pay attention to their wives. If I have surgery, I'm not worried because he does everything for me" (Participant 32, age 47, illiterate, housewife, 12 years of incontinence, 5 parturitions, stress type).

Weakening the quality of life

The weakening in quality of life was one of the factors that were extracted as a facilitator from the participants' interviews. As the symptoms worsened, the limitations, and exhaustion from the disease,

increased the chances of seeking help.

"It wasn't so bad before; it's gotten worse for one or two months. When I get out of bed to go to the bathroom in our bedroom, before I take three steps, I lose control of my urine" (Participant 21, age 69, under diploma, housewife, 5 years of incontinence, 3 parturitions, mixed type).

"I go to the bathroom a lot, that's why I get wet all the time, my body is constantly burning".

(Participants 15, age 60, under diploma, housewife, 3 years of incontinence, 4 parturitions, mixed type).

"I couldn't go out much, I didn't go to a party, if that was not possible, I stayed there for just two or three hours, I was tired" (Participant 23, age 50, under diploma, housewife, 1 year of incontinence, 3 parturitions, mixed type).

"I was obsessed with the bathroom, I was tired, I was looking for it everywhere I went ..." (Participant 15, age 60, under diploma, housewife, 3 years of incontinence, 4 parturitions, mixed type).

Discussion

In the present study, the main factors affecting help-seeking behaviors in women with urinary incontinence were studied using a qualitative approach for the first time in Iran. Our findings indicated that there are different facilitating and deterring factors influencing the help-seeking behaviors and successful treatment.

Due to the lack of a proper and real perceiving of urinary incontinence, the participants did not consider it as a disease and attributed incontinence to natural processes (such as aging and vaginal childbirth), so they did not refer to treatment. In addition, incontinence does not come with clear warnings, and this was another reason why women did not accept incontinence as a disease, resulting in delays or lack of help-seeking partly because people usually take action faster in the face of more alarming symptoms such as pain or bleeding. As a result of the unrealistic perception of the nature of this disease, they did not have a correct perception of treatment either, and they assumed urinary incontinence to be incurable. Therefore, they coped with the disease using self-care strategies. Some patients did not go to see a doctor because of the fear and worry caused by the probable outcomes of further investigation of the disease or the fear of invasive treatments which resulted from the lack of perceiving of the disease. These results are consistent with other results reported on help-seeking in patients with urinary incontinence, in which adaptation mechanisms, belief in the naturalness of incontinence as a result of the aging process, and unawareness of the treatment options as the reasons for avoiding treatment (28). Moreover, a study found that more than 50% of patients with urinary incontinence mentioned aging as the cause of the disease (29). Another study also reported that women with urinary incontinence used self-management strategies to control their disease (19). In addition, several studies have reported the low awareness of women with urinary incontinence of anatomy and the causes of incontinence and the misconception of the incurability of incontinence (21, 30, 31), which is consistent with the results of the present study. It is

mentioned in a report that fear of invasive treatments is a cause of delay in treatment (32). In this study, most patients avoided referring for treatment assuming that surgery was the only treatment for urinary incontinence, while many of them may not have had the criteria for surgery at all; this condition also resulted from their low awareness. Those who were more aware of incontinence had more referral to treatment (29). In general, awareness has been introduced as one of the important factors in the management of incontinence (33). On the other hand, it should be noted that care providers may actually have a lower tendency to recommend supportive therapies; examining this possibility would require investigation into the financial motives of physicians, especially in terms of stakeholders-induced demands.

Shame was another main category of the deterrent theme in the study. In general, shame is mostly considered a cultural issue because it, as a barrier to referral to treatment, accounted for only 3% of cases in the United States, and it did not play a significant role in the help-seeking in the Netherlands (30, 34). However, a sense of shame in most women was reported in Turkey (31). In fact, shame has been reported as a barrier for help-seeking of treatment in various studies (28, 32, 35), with one study reporting shame to account for approximately 60% of the cases of help-seeking avoidance (36). Some participants in the study hid their incontinence and did not seek treatment out of shame, it is regarding the nature of incontinence. So that, the person felt shame that others noticed that she had urinary incontinence (19). Some women were even ashamed of mentioning the issue of incontinence with caregivers. Other studies also found that women were ashamed to talk about their urinary incontinence to their doctors (32, 35), which could be because incontinence is considered to be private in nature, to the extent that it may even border on taboo; The sense of shame is even reported to be more than depression (37). Another part of the shame is related to the discomfort of talking about and the examination of the genital area, especially if done by a male doctor, which could be one of the reasons for the unwillingness to be treated by a male care provider. Women with urinary incontinence prefer to receive help from a female physician (31). In one study, while female patients preferred to have a female physician in the field of obstetrics and gynecology, this preference was not reported in the case of choosing a family physician (38), reflecting the fact that gender preferences may be further seen in diseases that necessitate the examination of private areas of the body such as the genital area as in the case of urinary incontinence. However, the most important factor affecting the gender bias towards same-sex healthcare providers was patient religious status (39, 40). It should be noted that shame is not the only factor affecting gender preference; another reason may be that women may feel better understood and more comfortable when speaking about feminine issues to female physicians (38). However, this was not observed in the interviews in this study.

Moreover, the main categories of the health care system included cost and quality of care. Most participants mentioned the enormous costs of diagnostic and therapeutic procedures as one of the factors causing their delay or non-referral due to the lack of basic health insurance or insufficient coverage of diagnostic and treatment costs by the insurance companies. Therefore, they preferred not to refer for treatment or to postpone it as much as possible. In addition, some of diagnostic costs were related to over-diagnosis as the over-diagnosis phenomenon has become common among service

providers, leading to increased financial burden for patients. A study reported that financial problems have been demonstrated to be the essential cause of treatment avoidance in around 70 percent of women with UI in India (36). In addition, lower economic status and lack of medical insurance were related to delaying treatment seeking for urinary incontinence (41). In general, affordability is effective in receiving treatment (42). One study found that the quality of care as well as the costs influenced the participants' choices. Part of the quality of services was related to the structure of the provision of services, including accessibility, service availability, and patient referral. Accessibility and availability were found to be effective in receiving services (43). A number of participants of our study stated that some services were provided only in certain areas (such as the center of the province), and people had to travel to access these services; consequently, inaccessibility caused some people to avoid seeing a doctor or to delay it as much as possible. On the other hand, sometimes services were accessible, but they were provided with delay or had a long waiting list. In other words, availability of services is often poor. As reported in the findings, patient referral in the healthcare system, as another aspect of service quality, influenced the use of services. It was found that some patients were confused by the referrals, and as a result, they deviated from the main treatment path due to the defective service referral system. Lack of adequate links between various levels of service delivery and self-referral cause disorder in the referral system. An efficient referral system would definitely lead to enhanced service quality (44). Inappropriate behavior of caregivers was another aspect of service quality. In fact, how services were provided affected the quality of services, which in turn influenced patient satisfaction (45); one of the important factors of patient satisfaction was respect and dignity from service providers. Although many people had little knowledge of this right, providing services with respect and dignity for patients was accompanied by better treatment outcomes (46–48). Effective and appropriate communication, accountability, empathy, and protection of the patient's privacy led to satisfaction and quality, thereby strengthening the patient's inclination to refer to medical centers. On the other hand, disrespect, discrimination, and poor communication skills of healthcare providers could result in non-referral (46, 49, 50). In other words, the caregivers themselves could be a barrier to access to care. In the interviews of the present study, participants pointed out the care providers' negligence, disrespect, and neglect of their dignity. The overcrowding of patients in health centers, in particular, in teaching and public centers due to their lower costs, reduced the amount of time and attention the patient received for their problem in comparison with what they had experienced in other centers. On the other hand, focus on students' clinical education led to the ignorance of respect and dignity, in particular, in private issues such as urinary incontinence.

The undeniable role of the important others, such as relatives, friends, and spouse, was another finding of the present study; these people played both a deterring and facilitating role in the interviews. In one study, the effect of relatives was one of the factors in referral for urinary incontinence (28). This influence is so great that some people preferred to seek help from non-official sources such as relatives, which could be due to their greater accessibility (51). On other reason may be the private and sensitive nature of the issue. For example, reports indicated that patients further benefited from the help of others for their mental health problems (51, 52). Therefore, it could be stated that patients trusted to important others more than healthcare providers in sensitive issues such as mental health or urinary incontinence. As

mentioned earlier, the important others had both positive and negative roles in the help-seeking behavior. Transfer of positive experiences of relatives and their support acted as a facilitator, and the family (the family was more supportive than the friends) had a special place in the interviews. A study on mental disorders in the United States, which is one of the topics of stigma, showed that the family's social support was more effective than the professional support or even peer support in improving the disease (52). In addition, perceived social support has been shown to be a positive factor in help-seeking behavior for women with UI (53). Similarly, in our study, social support was a facilitator in help-seeking. However, there were concerns about seeking help from relatives, because such help may be harmful, prohibitive, or useless and thus play a negative role in help-seeking (54). According to this study, information, experiences, misconceptions, expectations, and lack of support in relatives had a deterring effect. Therefore, the beliefs of people important to the patient, even misconceptions, affected their thoughts and performance. One of the significant misconceptions of the relatives was giving the "laxity" label to a person with urinary incontinence. It seems that the "laxity" label had a lot of negative connotations in this society; this stigmatizing labeling caused the patient to hide her incontinence from the caregivers rather than referring to them. Also, the transmission of incorrect information and negative therapeutic experiences to some participants by important others had a deterring impact on help-seeking as this information cast doubts upon incontinence treatments, which may have dissuaded them from referring for treatment or follow-up. Additionally, another reason observed in the interviews for delaying referral was the family's expectations of a woman. In general, women have different responsibilities in the family, which could occasionally cause conflicts in women's priorities concerning these roles (55). These concerns led the women to ignore their disease and to delay its treatment. In addition, the husband could have both deterring and facilitating role. Therefore, the spouse could be a deterring factor by not understanding the woman's problem and not supporting her due to lack of intimacy. On the other hand, the husband's sincere support for his wife played a facilitating role in some patients' help-seeking behaviors. However, the spouse's deterring role was more prominent in the interviews, which could be due to the financial dependence of women, which means that spouses, as the only sources of income in the family, had to pay all treatment costs; however, it is more likely which related to men's authority in this society.

Another major facilitating category of this study was the weakened quality of life. Exacerbation of the disease and its pervasiveness fell in this category, i.e. as the symptoms of disease worsened and invaded more dimensions of the patient's life, the likelihood of help-seeking behavior increased. In other words, the weakened quality of life is accompanied by an increase in referral. It should be noted that the patients' quality of life changed from the onset of the disease, but they seek treatment only when these changes were tangible and intolerable. Various studies have reported the effect of urinary incontinence on quality of life (11, 12, 20). There was a reverse relationship between the quality of life and help-seeking behavior. For instance, a study showed that people with poorer quality of life had more referral to treatment (35), In other words, poor quality of life positively influences help-seeking behaviors (20). Intensity of symptoms was also directly related to these behaviors. Indeed, patients with more severe symptoms sought more

help (30). Anyway, extracting the weakened quality of life category as a stimulus to referrals indicates the importance of screening and diagnosis in the early stages of the disease.

Strengths

One of the strengths and innovations of the study was the co-extraction of the factors affecting referral for the treatment in both forms of facilitating and deterring factors. In addition, sampling was not limited only to those referring for treatment or those who had not referred or only to a specific age group; therefore, the results would be more applicable to healthcare providers.

Moreover, this study was the first to use women's perspective of the effective causes in the treatment of urinary incontinence in this society.

Limitations

As in other qualitative studies, generalizability, which is typically higher in quantitative research, was one of the limitations of this study. However, we strived for maximum diversity in recruiting the participants, and various strategies were used to increase the study acceptability and objectivity. Hence, our findings seem to have acceptable reliability

Conclusions

This study determined the factors affecting referral for the treatment utilization in women with urinary incontinence in the form of two facilitating and deterrent themes.

Diagnosis and screening would be accelerated by introducing the effective factors extracted in this study to healthcare providers so that they may be considered in dealing with and treatment of women who refer to clinics or healthcare centers. For example, since urinary incontinence is a private issue and care providers are aware of the women's shame to express it, they can be the pioneers to examine the symptoms and perform the initial screening by respecting and maintaining one's dignity with simple diagnostic methods (such as questionnaires), which do not require them to examine the patients. Furthermore, education the factors affecting referral to healthcare providers, in particular, at the first level of the referral system, at in-service training and regular retraining programs, with an emphasis on maintaining patients' dignity, could have a fundamental and significant effect on the changes in the attitudes and awareness, modify misconceptions and the health literacy level of society. The care providers should consider the support of relatives, in particular, the family, in designing therapeutic interventions to reduce both the negative burden of the disease and enable women to adjust their roles and more easily follow up on the treatment of urinary incontinence with the comprehensive support.

The final result, it is better to pay attention to people's subjective beliefs and life context in routine care in an open dialogue with patients for early diagnosis disease.

Abbreviations

UI: Urinary incontinence

Declarations

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Authors' contributions

FRF, SH, SD and HAM participated in study design, data collection and analyze the data. FRF, SH and HAM analyzed the data and helped with study design. FRF and SH assisted with writing and editing. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

This work was approved by the Ethics Committee of the Shahid Beheshti University of Medical Sciences receiving the code: IR.SBMU.PHNM. 1397.33. Informed consent was obtained from each woman included in the study.

Consent for publication

Consent for publication was obtained from each woman included in the study.

Competing interests

The authors declare that they have no conflict of interest

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Figures

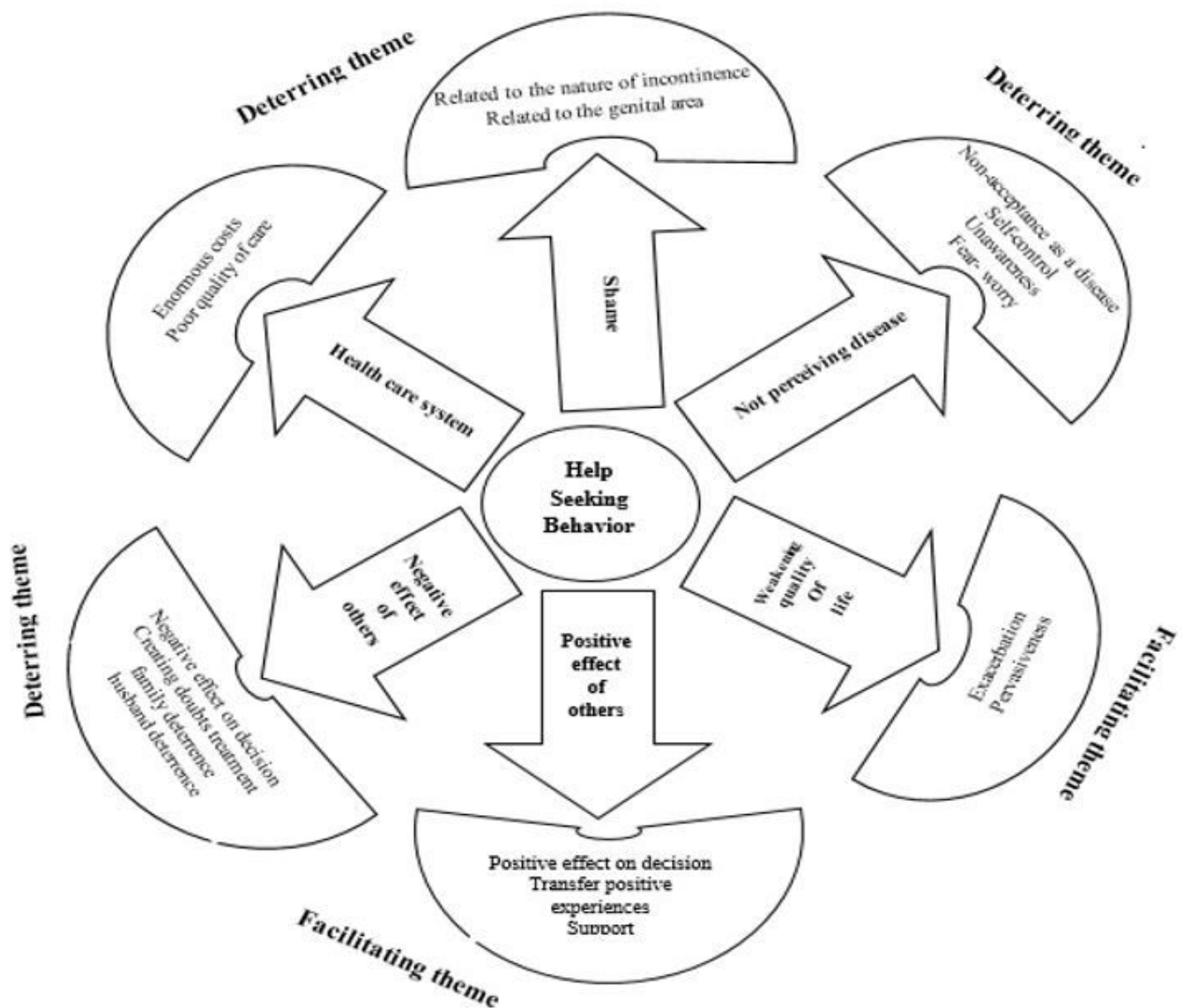


Figure 1

The schematic form of the factors affecting the help-seeking behaviors of women with urinary incontinence, which includes two facilitating and deterring themes, main categories.