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Social barriers to the uptake of and participation in urinary incontinence exercise groups in Jordanian women: A cross-sectional exploratory study

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Abstract

Considering the high prevalence of urinary incontinence (UI) in men and women, and its negative impacts specifically on women, UI affects women's quality of life, which might have a subsequent impact on their physical, emotional, and social well-being. There is a lack of healthcare management, specifically physiotherapy for UI in women living in Jordan. The aim of this study was to explore Jordanian women's experiences of UI physiotherapy management and the social barriers that may restrict participation in UI physiotherapy management among Jordanian women. An exploratory qualitative study was conducted. Semi-structured interviews were used to explore the experiences of and barriers to participation in UI physiotherapy management among women who attended gynecology clinics during or after pregnancy in Jordan. Data were analyzed using thematic analysis. A total of 16 women, between 6-10 months postpartum, completed the interviews. Two themes were identified from the interview data: social barriers to participation in physiotherapy treatment and poor quality of life due to incontinence. Examples of social barriers identified include shame in declaring UI, intimate sexual relationships, and a sense of low self-esteem. Examples of poor quality of life include the inability to work, poor household management, and limited physical activities and exercises. In conclusion, UI might affect different aspects of quality of life in Jordanian women who suffer from UI. This includes work restrictions, household responsibilities, driving, and exercise. In addition, this study reported that Jordanian women with UI are socially restricted from participating in UI physiotherapy management. Therefore, suggested action points were proposed to overcome these restrictions.

Keywords: Physiotherapy, Social barriers, Urinary incontinence, Women health.

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1. Background

Urinary incontinence (UI) is a widespread and distressing condition that affects individuals of all ages and genders [1, 2]. It is characterized by the involuntary leakage of urine, and it can have a significant impact on an individual's physical, emotional, and social well-being [2]. The prevalence rate of UI is reported to be between 5% to 70% [1].

According to the World Health Organization (WHO), urinary incontinence (UI) affects approximately 200 million people worldwide, with women being more commonly affected than men [3]. The prevalence increases with age, with estimates suggesting that up to 30% of women aged 60 and oldesr experience some form of urinary incontinence [3].

UI can be categorized into several types, including stress incontinence, urge incontinence, mixed incontinence, and overflow incontinence [4]. Stress incontinence, characterized by leakage during physical activities, such as sneezing or laughing, and urge incontinence, characterized by a sudden and uncontrollable urge to urinate, are among the most common types [4]. UI can have a profound impact on an individual's quality of life across physical, psychological, and social domains [5]. Physically, UI can increase the risk of skin irritation and infection due to constant moisture [6], decrease the level of independence and mobility due to the fear of leakage [7], and increase sleep disturbances and fatigue due to nighttime incontinence [8].

The psychological effects of UI include anxiety, depression, stigma, embarrassment, reduced self-esteem and self-confidence, and social isolation [9]. The social and personal effects of UI include: daily planning of activities around restroom access; limitations on travel, work, and leisure activities [10]. Additionally, society's misconceptions and negative stereotypes surrounding incontinence can lead to feelings of shame and isolation [10].

Effective management of UI is crucial to improving an individual's quality of life [11]. Treatment options may include medication, and surgical interventions, depending on the underlying cause and severity of the condition, and physiotherapy treatment [11]. Physiotherapy treatment for UI typically involves the following: pelvic floor muscle training; biofeedback; bladder retraining; electrical stimulation; lifestyle modifications; and education [11, 12].

However, there remains a lack of appropriate healthcare, particularly for pregnant women in developing countries, such as Jordan, which contributes to the widespread prevalence of urinary incontinence after pregnancy and birth [13]. In southern Asia, it is suggested that a complex network of social issues contributes to the poor quality of healthcare provided to women during and after pregnancy; these include the social status of women, the distribution and availability of healthcare resources, perceptions about the nature and importance of maternal health problems, and the social, economic, and political infrastructures [13]. Developing effective self-management strategies, such as pelvic floor exercises, bladder training, and dietary modifications, can improve an individual's sense of control and confidence [14, 15].

In Jordan, the prevalence of UI was reported to be 67.6% of women postpartum, of whom 23.1% had stress UI, 26.4% had urge UI, and 18.1% had the mixed type of UI [16]. Furthermore, it was reported that UI affects the quality of life for Jordanian women in terms of low self-esteem, work inefficiency, social life restrictions, and negative effects on sexual life [16]. Although it is clear that effective management of UI improves quality of life, there is a lack of healthcare management, specifically physiotherapy, for UI in women. Current development of new trials relating to physiotherapy management of UI in Jordan has revealed that there may be social restrictions on the participation of Jordanian women in physiotherapy management of UI. Thus, this study aimed to explore the social barriers restricting Jordanian women from participating in UI physiotherapy management.

2. Method

2.1. Study Design

An exploratory qualitative study was conducted using semi-structured interviews. Ethical approval was obtained from the institutional review board at Applied Science Private University (2022-2023-4-10). Signed consent forms were obtained from all participants prior to the interviews.

2.2. Population, Sample, and Recruitment

Jordanian women, aged over 18 years, attending gynecology clinics for regular pregnancy or postnatal visits, were recruited over a 16-month period. Participants were included if they were: women attending the gynecology clinics during or after pregnancy; experiencing urinary incontinence; not participating already in physiotherapy management for UI. Participants were excluded if they were: not Arabic speakers; not living in Jordan; under 18 years old; or if they were healthcare providers who were working in hospitals, clinics, or care homes.

Participants were purposefully sampled to provide insights into the experience of urinary incontinence (UI) physiotherapy management, social barriers, and limitations to participating in pelvic floor exercises for the treatment and management of UI [17]. A sample size of 16 was deemed large enough to ensure sufficient breadth to allow for in-depth data analysis and data saturation [18].

2.3. Development of Questions

The interview included two main domains: 1) UI prevalence, symptoms, and management; and 2) participation in physiotherapy treatment for UI. The interview questions were developed by a physiotherapist (AA) and checked and revised by a second physiotherapist (MZD). After that, the questions were sent to three postnatal women in the community for revision and comment. The questions were developed in Arabic and then translated into English (Table 1). The questions were subsequently sent to three women in the community. An advertisement for the study was posted on social media, and the first three women who reported that they were happy to review the questions and provide their feedback in terms of any comments about the questions were included. The same inclusion and exclusion criteria mentioned above were applied to these three women. The three women reported that no further revisions were necessary. The final version of the interview questions can be seen in Table 1.

Table 1.
Questions of the interviews.

Questions
How do you prescribe urinary incontinence?
What are the non-pharmaceutical management of urinary incontinence that you are receiving?
Did you receive any education about pelvic floor muscle exercise?
Tell me what you know about Kegel exercises.
If you are not doing physiotherapy treatment for urinary incontinence, please tell me why?
Are there any social restrictions behind not participating in urinary incontinence physiotherapy sessions? Please tell me about it

2.4. Data Collection

Semi-structured face-to-face interviews [19] were conducted at the Applied Science Private University by the lead author (AA), a female physiotherapist researcher. Interviews were conducted between the 15th of July and the 27th of August 2023 and were audio-recorded. Interviews lasted between 30 and 60 minutes. The audio data were then transcribed verbatim and checked for accuracy by two researchers to assure the trustworthiness of the data and avoid the selective reporting of information [20].

2.5. Data Analysis

Data analysis followed a thematic analysis approach [21]. This involves six steps: 1) Familiarization with data; 2) generation of initial codes; 3) searching for themes by sorting relevant data together; 4) combining, refining, separating, or discarding initial themes where needed; 5) refining and defining themes and naming the themes; and 6) producing the report. The coding and the themes were developed by two researchers independently, and then the final themes were discussed and agreed upon. Themes and their corresponding quotations were translated from Arabic into English by an independent native English-speaking translator at Applied Science Private University. To avoid cross-cultural methodological issues, the back-translation procedure (from English to Arabic and back to English) was used to ensure consistency between the Arabic and English versions of the questionnaire [22] as the majority of the respondents were Arabic-speaking.

3. Results

A total of 16 women, all between 6-10 months post-partum, completed the interviews. Table 2 summarizes the characteristics of the interviewees.

Table 2.
Characteristics of mothers who participated in the interviews.

Participants' code	Age (years)	Working status	Marital status	Place of living (city, town, village)	Number of siblings
P1	22	Working (teacher)	Married	City	1
P2	32	Unemployed	Married	City	2
P3	34	Working (office work)	Married	City	1
P4	31	Unemployed	Married	Town	4
P5	27	Working (teaching)	Married	City	1
P6	28	Working (teacher)	Married	City	3
P7	31	Working (office work)	Married	City	7
P8	33	Working (lab technician)	Married	City	1
P9	19	Working	Divorced	Village	2
P10	22	Unemployed	Married	Town	1
P11	25	Unemployed	Married	City	1
P12	32	Unemployed	Married	City	5
P13	21	Working (office work)	Divorced	City	3
P14	27	Working (office work)	Married	City	3
P15	24	Working (teacher)	Married	Village	2
P16	23	Working (office work)	Married	Town	3

Two themes were identified from the interview data: social barriers to participation in physiotherapy treatment, and poor quality of life due to incontinence.

Theme 1: Social barriers to participation in physiotherapy treatment

Participants reported that there are social barriers to participating in UI treatment. For example, they reported feelings of shame and embarrassment about declaring UI and the desire to keep this information private, shared only with the clinic:

> *"I feel shame! I cannot say that I have incontinence! This is something that makes me embarrassed. I feel that participating in physiotherapy sessions would let people know about my case. I would prefer to keep my treatment within the gynecology routine clinic only." (P12).*

Additionally, participants reported the fear of others, specifically their partners, knowing that they have UI, in case it affects their relationship and intimacy:

> *"I do not want my husband to know that I have incontinence. I feel that knowing this point might affect our relationship in a negative way." (P3).*

> *"I think my husband might not like the fact that I have incontinence. I think he might avoid sexual intimacy if he knew. This will worsen our relationship." (P10).*

One participant reported a sense of low self-esteem and feeling ashamed when trying to teach her son to sit on a potty, because of her own incontinence:

> *"On that day, I was crying. Because how can I teach my son to use the potty if I cannot control myself? How can I teach a three-year-old boy to control his urine if his mother cannot do so? It is a shame." (P4).*

Other participants were concerned that society might reject them, and one reported experiencing family members no longer wanting to be close to her when they knew that she was experiencing urinary incontinence (UI), as they felt this was repulsive. Furthermore, living in a small village meant that if she attended physiotherapy for UI, then this would be common knowledge, and this deterred her from attending physiotherapy for her UI:

> *"No one would accept me. When my sister knew that I had incontinence, she started to sit away, stand away, and feel disgusted. I do not like the feeling that people would reject me if I had incontinence. This is why I do not think I will participate in physiotherapy sessions about incontinence. We live in a small village. The world is small. Everyone will know." (P19).*

Theme 2: Poor quality of life due to incontinence.

Participants reported that UI led to a poor quality of life in many ways. For some, UI caused them to leave their jobs and stop working, or to feel uncomfortable while working because of having to manage their UI during working hours and in challenging working environments:

> *"I do not feel confident at work. I keep checking my sanitary pad from time to time." (P 7)*

> *"Incontinence led me to resign. I couldn't continue working as a field engineer while having incontinence. I cannot ask for a ladies' toilet while in the field. There are even no ladies' toilets while you build a house; it's all for men." (P4).*

Furthermore, participants reported that UI affected their ability to manage household activities such as vacuuming, cooking, cleaning, and gardening because of the need to take frequent breaks to manage their UI:

> *"I keep taking breaks while doing housework tasks. I always take breaks while cooking to run to the toilet. It often interrupts the cooking recipe as I need to be strict in time. Especially while cooking with yogurt and milk." (P11).*
>
> *"I feel I cannot continue vacuuming, gardening, or general house cleaning as I was doing before. This is because incontinence has led me to take many breaks. I feel that the tasks are taking more time and effort." (P12).*

Participants also reported that the UI affected their usual physical activity, exercise, and ability to travel long distances, which stopped them from wanting to visit family members who lived some distance away:

> *"I stopped going to the gym. I was walking and running on the treadmill, cycling on a stationary bike, and rowing on a rowing machine. Now I have stopped doing that because of urinary incontinence." (P6)*
>
> *"Well, I used to drive between Amman and Al-Karak, which is around a two-hour drive. I cannot do so now. There are no toilets available everywhere, and if they are found, they wouldn't be clean. I started to minimize visiting my family as I cannot tolerate it." (P1).*

4. Discussion

This study aimed to explore Jordanian women's experience of urinary incontinence (UI) physiotherapy management and the social barriers that may restrict participation in UI physiotherapy management among Jordanian women. This study has found that Jordanian women with UI are socially restricted from participating in UI physiotherapy management. These restrictions are due to feelings of shame and embarrassment about having UI, fear of poor relationships with their partners as a consequence of having UI, and the loss of privacy and confidentiality for patients who live in rural areas and villages. This study also reported that UI may lead to a poor quality of life, which affects the ability to work, manage household chores, drive, and exercise.

These findings are similar to Grimby et al. [10], who reported that UI could affect social-related quality of life, including daily planning of activities around restroom access, limitations on travel, work, and leisure activities. The restrictions on work, in particular, should be considered in Jordan. This is because women in Jordan have many other non-health-related factors that affect their participation in work. For example, being a married woman, being a mother, and being a mother of infants and toddlers [23]. Participants in this study reported that their work is affected due to UI, and one participant even resigned because of UI. Therefore, serious actions are required to reduce such factors that might lead to a decrease in the participation of Jordanian women in the workforce.

The suggested actions might include: spreading the word about the importance of physiotherapy in treating UI to increase the awareness of women with UI; educating the community about treatable causes of UI in women, particularly postpartum; considering work-related adjustments for women with UI; and providing a practical way to assure confidentiality and privacy for women who are attending UI physiotherapy sessions. To limit the decrease in participation in exercise and physical activity, it is suggested that an Arabic version of exercises that do not provoke UI should be provided, to include the most suitable exercises for women with UI.

Previous research reported that UI had a negative effect on partner relationships and the partner's life [24]. Similarly, building on this study, participants reported that they fear poor relationships developing due to UI and that they did not want their partners to know they have UI. In a previous study among men with UI due to prostate cancer, it was reported that men and their partners needed educational support and other assistance throughout the prostate cancer journey, which required attention and tailored management [25]. Furthermore, Hyder et al. [26] it was reported that there is a need to have a "bond of trust" between the person with UI and their partner, which is considered an essential factor for the success of UI management. Subsequently, in Jordan, there will be a need to raise awareness of the importance of women's partners' support in this matter.

In conclusion, this study found that urinary incontinence (UI) in Jordanian women affected their quality of life negatively, including work restrictions, household management, driving, and exercise. Additionally, this study showed that Jordanian women with UI are also socially restricted from participating in UI physiotherapy management. These restrictions are due to feelings of shame and embarrassment because they have UI, fear of poor relationships with their partners as a result of having UI, and the loss of privacy and confidentiality for patients who live in rural areas and villages. Therefore, this study has provided suggested action points to overcome these restrictions.

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