

Original Article

Knowledge, Attitude, Perception and Stigma Surrounding Female Urinary Incontinence in Urban Populations of India

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Abstract - Urinary incontinence (UI) affects men and women globally, with a higher incidence in women. About 35% of women in India are affected by female urinary incontinence. However, despite its common occurrence in women, studies have shown a lack of awareness and treatment-seeking behaviors due to stigma and little discussion about the topic. This research aims to examine the existing knowledge, attitude and perception of urban-dwelling women with respect to female urinary incontinence and implement an awareness module that effectively improves awareness and clears the stigma surrounding the disease. Using pre-post survey questionnaires with a sample of 24 women aged 30-70 years from urban neighborhoods of New Delhi, India, and data has been collected on awareness, perceptions, and treatment-seeking tendencies towards female urinary incontinence. It has been found that there is a significant lack of awareness, alongside the prevalence of stigma and consequent aversion to treatment. After conducting the designed workshop, awareness levels have increased by large margins alongside more openness towards addressing and treating urinary issues. Stigma and lack of discussion severely impact women's tendency to seek treatment for their urinary and gynecological issues, resulting in a hampered quality of life. Awareness intervention can be done using modules like the one created and implemented in this study.

Keywords - Awareness, Female urinary incontinence (UI), Questionnaire, Stigma, Treatment.

1. Introduction

The International Continence Society defines Urinary Incontinence (UI) as “the complaint of any involuntary loss (leakage) of urine” (*ICS Glossary*, n.d.). Urinary incontinence is a commonly occurring issue globally, with a greater incidence in women. Urinary incontinence is of three types: stress urinary incontinence (SUI), urge urinary incontinence (UUI), and mixed urinary incontinence. [1] The International Urogynecology Association and International Continence Society joint report defines the types of urinary incontinence: SUI is defined as “observation of involuntary leakage from the urethra synchronous with effort or physical exertion, or on sneezing or coughing.” UUI is defined as a “complaint of involuntary loss of urine associated with urgency” and is commonly described in the context of overactive bladder (OAB) syndrome. Lastly, mixed UI is defined as a “complaint of involuntary loss of urine associated with urgency and also with effort or physical exertion or on sneezing or coughing.” [2]

The primary cause of UI in women is the weakening of the pelvic floor muscles, caused primarily due to childbirth, aging, pelvic organ prolapses, menopause, gynecological surgeries, and pelvic injuries, among other factors. [3] Furthermore, some factors may increase the

incidence of UI symptoms for someone with a weakened pelvic floor. These factors include caffeine consumption, over-intake of fluids, chronic respiratory diseases, constipation, diabetes, diuretic medicines (blood pressure medicine, water pills, etc.), genetic predisposition, etc. [1]

Nearly 40% of all adult women worldwide are affected by urinary incontinence at different degrees. [4] In the United States of America, 32.4% of women showed consistently occurring symptoms of UI. [5] Prevalence in Europe and Asia is also at 35-45%. [6,7] studies have shown that about 35% of women suffer from urinary incontinence in India. Stress UI is the most common in Indian women, followed by mixed and finally, urge incontinence. [8]

Despite the high prevalence and adverse effect on quality of life (QoL) in social, physiological and psychological aspects [9], many women do not seek help for UI due to lack of awareness, shame and stigma surrounding the issue. Several studies indicate that stigma is the primary reason women do not seek UI treatment. Stigmatization of physical or mental diseases involves the public stereotyping (i.e., social rejection, exclusion, or discrimination) of these patients as well as the internalization (i.e., shame, humiliation, or embarrassment)



of these stereotypes by the patients. In the existing patriarchal society in India, women also feel the obligation to be sacrificial and leave their problems unaddressed. UI also brings shame and humiliation to individuals suffering from it due to the societal association of incontinence with incompetence, thus resulting in hesitance towards raising the issue with family or with a healthcare provider. [10] In urban Indian populations, the severe lack of awareness results in people having many misconceptions regarding UI, including the belief that it is a normal aspect of aging and that there is no treatment available for it.

Knowledge of women regarding urinary incontinence, its causes, risk factors, and treatments has been shown by previous research to be insufficient, alongside the prevalence of reluctant attitudes towards addressing the issue. In a recent systemic review exploring studies on knowledge, attitude and perception regarding urinary incontinence, 19 studies were selected which met the inclusion criteria, and it was concluded that there is a significant gap in knowledge, attitude and perception regarding UI and help-seeking behavior for the same. This behavior can be attributed to heavy stigma content, shame, embarrassment, feelings of incompetence and inability to participate in daily social and religious activities. To facilitate the increase of treatment-seeking behaviors and daily practices for good bladder health in women in India, it is important to understand and improve the knowledge (comprehension and understanding of all facts pertinent to all types of UI in women), attitude (predisposed perspectives influencing behaviors towards UI and individuals with UI) and perception (individual interpretation of all aspects of UI and its treatment) of people towards urinary incontinence. Studies assessing these criteria have been conducted in many countries globally, but there are no existing studies that explore knowledge, attitude and perception of female urinary incontinence in an urban Indian demographic, specifically. Women who have not sought treatment for urinary incontinence and pelvic organ prolapse are often not exposed to educational training modules for awareness and attitude towards these issues, as existing studies have primarily focused on awareness for diagnosed patients. Furthermore, while some studies have evaluated the improvement in the knowledge gap after implementing educational sessions on pelvic floor training and found improvement in bridging the knowledge gap [11], existing studies associated with the topic in India have not explored interventional methods thus far. In a cluster-randomized trial in Shanghai by Zhang et al., among 2100 participants, 1400 women with stress urinary incontinence showed a significant improvement in the intervention group who were provided with a reproductive health intervention model containing self-designed handbooks, health lectures, and free medical consultations over a period of 6 months. [12] Such a study has not been conducted in calibration to the urban Indian demographic.

Hence, this research study aims to assess pre-existing awareness and beliefs surrounding female urinary

incontinence in urban Indian populations and to effectively improve the knowledge and positively alter attitudes and perceptions towards the prevention and mitigation of UI, seeking to bring about long-lasting behavioral change through information resources, preventive training, and discussion on destigmatizing female urinary issues.

2. Materials and Methods

2.1. Aim of the Study

The study explores the level of knowledge, attitude, perception and stigma surrounding female urinary incontinence in urban populations of India. It assesses the effectiveness of a self-devised workshop module to create awareness and encourage treatment-seeking behavior and preventive habits.

2.2. Research Design

This prospective, observational study was conducted through a pre- and post-questionnaire for two months, from April 2023 to June 2023. A presentation was conducted by the researcher, accompanied by an expert in the field of urogynecology, Dr. Payal Chaudhary. Participants were asked to fill out a survey questionnaire before the presentation and after to gauge existing knowledge, attitude, perception, and stigma, as well as the effectiveness of the presentation module in improving the aforementioned. The dependent variables were knowledge, attitude and perception, with the independent variable being the presentation module.

2.3. Consent and Ethical Issues

All ethical considerations were followed for the study. Informed consent was taken from participants for data collection. Confidentiality and privacy of the respondents were maintained; no data would be disclosed to a third party. No identifiers, such as names or pictures, were disclosed in the article or while conducting the study. Ethical guidelines of research were followed.

2.4. Sample

All women from urban upper-middle-class neighborhoods of Delhi NCR, a metropolitan North Indian city, between the age group of 30-70 years who volunteered to participate in the workshop and fill out both questionnaires were included in the study.

2.5. Workshop Module

The workshop module was a 2-hour session which included a detailed PowerPoint presentation highlighting the prevalence, causes, types, prevention and treatment of urinary incontinence. Using a bony pelvis model, women were taught to identify their pelvic floor and how to exercise effectively. A handout on good bladder practices was also distributed for future reference.

2.6. Tools Used

The questionnaires used for data collection were in simple English, with 24 questions in the pre-questionnaire (Table 1) and 16 questions in the post-questionnaire (Table 2). These were pen-and-paper questionnaires created with

accessibility taken into consideration. The pre-questionnaire contained the following categories of questions: personal details (age, socioeconomic status, health history, urinary habits, experiences), knowledge (causes, preventive measures, treatments), attitude (treatment-seeking tendency, emotions), and perception (“is this a problem?”, treatability). The post-questionnaire contained questions of the latter 3 categories, with additional questions to check for detailed knowledge about causes, risk factors, treatments, and prevention. Questions were all multiple-choice, checkbox, or short answer type.

2.7. Data Collection Procedure

Pre-questionnaires were handed out to attendees upon arrival to be filled and submitted prior to the commencement of the presentation. Following the presentation given by the researcher and urogynecology specialist, a question-answer session was conducted for clarification alongside a detailed description of at-home prevention and treatment measures. Attendees were then given the post-questionnaire to fill out before the session closed. Participant responses were collected and organized by participant-assigned number so that responses in pre- and post-questionnaires could be compared.

2.8. Scoring

An answer key was generated with the questionnaires (Tables 1 and 2), and answers were marked as 1 for every correct answer and 0 for every wrong answer. This was carried out for all participants’ pre- and post-questionnaires. Total score and mean scores were calculated for each category (knowledge, attitude, perception), and mean scores were compared for each question.

2.9. Statistical Analysis

Data were entered into an MS Excel sheet, and statistical analysis was performed using paired t-tests to calculate p-values for comparing mean scores in each category of the questionnaires and overall p-values to compare mean scores for the complete questionnaire.

3. Results

3.1. Sociodemographic Details

A total of 24 women participated in the study, with an age range from 30 years to 70 years. These women were all bilingual, with complete Hindi fluency and basic English fluency. The sociodemographic profile of the participants has been given in Table 3.

3.2. Knowledge

Participants had good knowledge of frequent (hourly urination) being abnormal. There was a good level of awareness of activities during which urine leakage may occur. 70% of participants were aware that leakage often occurs during exercise, laughing, sneezing and coughing. However, participants had poor knowledge of the causal factors of urinary incontinence and lifestyle changes and exercises to combat it. The knowledge that urine leakage is abnormal was 45% before the workshop.

Following the educational module, knowledge levels associated with abnormal urinary functions showed a steep increase, alongside awareness of causal factors, lifestyle changes and exercises. After the workshop, 95% of the participants were aware that urine leakage is abnormal. 100% awareness was displayed with respect to knowledge about activities in which urine leakage occurs, exercises to combat UI, and knowing that hourly urination is not normal. (Figure 1) Mean scores for all knowledge questions showed an increase after the workshop. The knowledge mean score for the pre-workshop questionnaire was 0.511, which increased to 0.942 for the post-workshop questionnaire, yielding an extremely statistically significant paired t-test p-value of 0.0004.

3.3. Attitude

Attitude towards viewing urinary incontinence as a problem was good. 79% of the participants believed that it was an issue. Overall, attitude with respect to urinary incontinence was found to be satisfactory prior to the workshop. 87% of the participants believed in consulting a doctor for female urinary incontinence, and 70% of the participants displayed openness to discussion about the issue with loved ones and doctors as well.

Following the educational module, an ideal score was obtained across all attitude questions, with all participants acknowledging that female UI is a problem, alongside showing complete openness to discussing their urinary issues and seeking treatment for them. (Figure 2) The mean score increased from 0.786 to 1.000, yielding a significant p-value of 0.0491.

3.4. Perception

Participants displayed a poor perception of the association between UI and age. Only 29% of the participants believed other factors could be responsible for UI, which is not solely age-dependent. There was a good perception of the treatability of UI. Participants had a satisfactory perception of sadness and embarrassment caused by UI. 66% of the participants perceived that UI might cause anger and annoyance to those experiencing it.

Perceptions significantly improved ($p=0.0420$) following the educational module, with 100% of the participants perceiving that UI is treatable. Perceptions across all questions improved, resulting in the mean score increasing from 0.6125 (pre-workshop) to 0.9025 (post-workshop). 83% of participants acknowledged that UI is not purely age-associated and may depend on other factors, primarily the weakening of pelvic muscles. Participants’ perception of sadness and embarrassment caused by UI also improved to 100%, and 83% of the participants perceived that UI often causes anger and annoyance. (Figure 3)

3.5. Overall Effect of Educational Module

All categories of the questionnaire showed significant or greater improvement in mean scores. Mean scores for each question increased after the workshop. The overall

mean score increased from 0.5993 to 0.9436. While knowledge, attitude and perception were variable (poor to decent) before the workshop, levels significantly improved to highly satisfactory after the workshop. On conducting an overall paired t-test, an extremely significant p-value of 0.0001 was obtained, indicating a stark improvement of KAP in the participants. (Figure 4)

4. Discussion

Female urinary incontinence is a highly prevalent disease that significantly affects quality of life. It is poorly acknowledged not just by society at large but also by women themselves due to the stigma and sense of shame attached to it. There have been studies in different countries over time which have assessed the prevalence, knowledge, attitude and perception regarding female urinary incontinence. Some studies have also assessed the role of intervention in the form of pelvic floor physiotherapy or imparting educational lectures and materials and the improvement in KAP scores after that. The present study is the first of its kind in an urban Indian population. It also studies the effect of intervention in the form of workshops and its impact on knowledge, attitude and perception associated with female UI. This study was conducted in women aged 30-70 years, similar to a study conducted by Singh et al. [8], whose participant age group was 18 and above. However, the majority of the women suffering from incontinence were aged over 30 years. In a study conducted in a rural area of West Bengal, India, women aged 50 years and older found that 27.7% of the participants suffered from urinary incontinence, with only 30.6% seeking treatment for the same. This differs from the current study, wherein 70% of participants thought that UI is treatable, and 87.5% said that they would consult a doctor about it. [13] This implies that a higher literacy level could translate to more knowledge and treatment-seeking behavior.

This pre-post survey experiment showed significant stigma and lack of awareness in the participating group and, consequently, a lack of treatment-seeking behavior towards female urinary incontinence. This aligns with existing studies emphasising lack of awareness and stigma being the cause for low treatment-seeking behaviors in other populations. In a systematic review by Siddiqui et al., perceptions regarding UI in women of different racial and ethnic populations were assessed, and 23 studies met the inclusion criteria. It showed the differences in perception about UI across different ethnic groups, which can help in strategizing educational intervention in UI. [14] In another systematic review of women's knowledge, attitudes and practice related to urinary incontinence, it was observed that misinformation about UI was prevalent. All the 19 articles reviewed showed low rates of seeking care. [15] In a recent study on the effect of health literacy on help-seeking behavior comparing patients accepting surgery and refusing surgery for urinary incontinence, it was seen that the patients who accepted surgery had higher health literacy as compared to patients refusing surgery (p=0.001). [16] The workshop module could

efficiently and effectively clear many existing misconceptions and encourage open conversation and treatment-seeking behavior for female urinary incontinence. This echoes the outcomes of the aforementioned study, which showed that health education improves treatment-seeking behavior.

The all-women setting also created a sense of security for the attendees, encouraging them to address their issues with the uro-gynecologist present. A similar observation was seen across multiple studies in the systematic review. The results show that the bilingual workshop module was successful in destigmatizing female urinary issues for the attending women. Further research can enhance this module and explore its effectiveness for other demographics and larger groups.

5. Conclusion

Female urinary incontinence is a fairly common issue, yet less heard of, and despite the abundance of treatments, few women seek treatment for it. Evidence from previous studies indicates that social stigma and lack of awareness are the core causes of the lack of treatment-seeking behaviors. This study conducted a pre-post survey experiment to gauge the existing level of knowledge, attitudes toward treatment, and social perception of female urinary incontinence, followed by the effectiveness of a workshop module curated by the researcher in improving the knowledge, attitude and perception of women in urban Indian populations. Thus, a new workshop module was designed to spread awareness and enhance treatment-seeking behaviors concerning female urological issues. The study reflected that while there is a significant lack of awareness, alongside a number of misconceptions surrounding female urinary issues, it is very mitigable through the awareness module structure utilized in this study, which is being further implemented in similar workshops.

To further solidify these findings, a number of future studies should be carried out. These include Preparing a module using the native languages of the area. To conduct the pre-post survey experiment with large groups—knowledge, attitude and perception study in rural populations.

The module created can be implemented in female health awareness programs conducted in society, schools and workplaces. Female urinary incontinence holds pertinence to women of all ages; hence, all biological females must be aware of it. The findings of this study may be used as a reference for future studies on knowledge, attitude and perception towards female urinary incontinence.

Limitations

The module and study were conducted with a small group of 24 women, so there is a need to check the reliability of the module with larger groups. With English

being the second language for most attendees, there was a potential for misunderstanding parts of the questionnaire despite using simple, comprehensible English. This study extended to urban populations only, so the results and effectiveness of the module may not be applicable to populations outside of this demographic.

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Table 1. Questionnaire used for survey in the study, pre-workshop

1. Age (mutually exclusive options)
<ul style="list-style-type: none"> • 30 and below • 31-50 • 51-70 • 70 and above
2. Education level
<ul style="list-style-type: none"> • Matriculate • 12th class • Graduate • Post-graduate • Doctorate
3. Occupation: _____
4. Do you have children?
<ul style="list-style-type: none"> • Yes • No
5. How many glasses of water do you drink per day?
<ul style="list-style-type: none"> • Less than 5 • 5-10 • 10-15 • More than 15
6. How many cups of tea/coffee do you drink in a day?
<ul style="list-style-type: none"> • 0 • 1-2 • 3-4 • 4+
7. How many times per day do you typically urinate?
<ul style="list-style-type: none"> • Less than 5 times • 6-10 times • 11-15 times • More than 15 times
8. How many times per night do you typically urinate?
<ul style="list-style-type: none"> • Not at all • 1-2 time • 1-2 time • 3-4 time • 5+ time
9. When a person has the urge to urinate, do you think that it is normal for them to need to immediately pass urine?
<ul style="list-style-type: none"> • Yes • No
10. Do you think a person typically needs to urinate every hour?
<ul style="list-style-type: none"> • Yes • No
11. Do you think women normally experience urine leakage?
<ul style="list-style-type: none"> • Yes • No
12. If yes, what could be the possible activities during which they experience it?
<ul style="list-style-type: none"> • Physical activity (exercise) • Laughing • Sneezing/coughing • Sleeping • Other: _____
13. Do you believe that urine leakage is just something that happens with age?
<ul style="list-style-type: none"> • Yes • No

14. Do you believe that urine leakage is a problem?
<ul style="list-style-type: none"> • Yes • No
15. If yes, do you think it is treatable?
<ul style="list-style-type: none"> • Yes • No • I don't think it is a problem
16. Should women consult a doctor for urine leakage?
<ul style="list-style-type: none"> • Yes • No
17. If you experience urine leakage, please select the box (or boxes) that you agree with
<ul style="list-style-type: none"> • It has affected my ability to carry out daily tasks • It has affected my ability to participate in social activities • It has affected my ability to participate in religious activities • I do not experience urine leakage
18. Do you think urine leakage causes feelings of embarrassment and sadness?
<ul style="list-style-type: none"> • Yes • No
19. Do you think urine leakage causes feelings of anger and annoyance?
<ul style="list-style-type: none"> • Yes • No
20. Are you aware of the causes for urine leakage? If so, what do you believe is the cause for urine leakage?
<ul style="list-style-type: none"> • Weakening of pelvic muscles • Digestive problems • Sounds of flowing water / rain / rivers • I am not aware of the causes
21. When a person has the urge to urinate, do you think that it is normal for them to need to immediately pass urine?
<ul style="list-style-type: none"> • Yes • No
22. Are you aware of exercises to prevent and control urine leakage?
<ul style="list-style-type: none"> • Yes • No
23. If you experience urine leakage, do you feel like you could openly discuss the issue with your loved ones or with a
<ul style="list-style-type: none"> • Yes • No
24. Do you believe that there is sufficient awareness regarding urinary leakage?
<ul style="list-style-type: none"> • Yes • No

Table 2. Questionnaire used for survey in the study, post-workshop

1. When a person has the urge to urinate, do you think that it is normal for them to need to immediately pass urine?
<ul style="list-style-type: none"> • Yes • No
2. Do you think a person typically needs to urinate every hour?
<ul style="list-style-type: none"> • Yes • No

3. Do you think leakage of urine can occur for women normally?
<ul style="list-style-type: none"> • Yes • No
4. If yes, what could be the possible activities during which they experience it?
<ul style="list-style-type: none"> • Physical activity (exercise) • Laughing • Sneezing/coughing • Sleeping • Other: _____
5. Do you believe that urine leakage is just something that happens with age?
<ul style="list-style-type: none"> • Yes • No
6. Do you believe that urine leakage is a problem?
<ul style="list-style-type: none"> • Yes • No
7. If yes, do you think it is treatable?
<ul style="list-style-type: none"> • Yes • No
8. Should women consult a doctor for urine leakage?
<ul style="list-style-type: none"> • Yes • No
9. Do you think urine leakage causes feelings of embarrassment and sadness?
<ul style="list-style-type: none"> • Yes • No
10. Do you think urine leakage causes feelings of anger and annoyance?
<ul style="list-style-type: none"> • Yes • No
11. Are you aware of lifestyle changes that can prevent urine leakage?
<ul style="list-style-type: none"> • Yes • No
12. Are you aware of the causes for urine leakage? If so, what do you believe is the cause for urine leakage?
<ul style="list-style-type: none"> • Weakening of Pelvic Muscles • Digestive Problems • Sounds of Water Flowing • I Am Not Aware Of The Causes
13. Are you aware of exercises to prevent and control urine leakage?
<ul style="list-style-type: none"> • Yes • No
14. If you experience urine leakage, do you feel like you could openly discuss the issue with your loved ones or with a doctor?
<ul style="list-style-type: none"> • Yes • No
15. Which of these factors do you think increase urine leakage?
<ul style="list-style-type: none"> • Childbirth • Menopause • Gynecological surgeries • Frequent coughing • Diabetes • Urinary infections • Pelvic injuries • Caffeine intake • All of these • None of these

16. Do you believe that there is sufficient awareness regarding urinary leakage?
 • Yes
 • No

Table 3. Sociodemographic details of workshop participants

Variables	Number (n)	Percentage (%)
Age (Years)		
30-50 years	5	20.83
50-70 years	11	45.83
>70 years	8	33.33
Educational Status		
Matriculate	2	8.33
Senior Secondary	4	16.66
Graduate	7	29.16
Post-graduate	11	45.83
Parity		
Have children	22	91.66
Do not have children	2	8.33

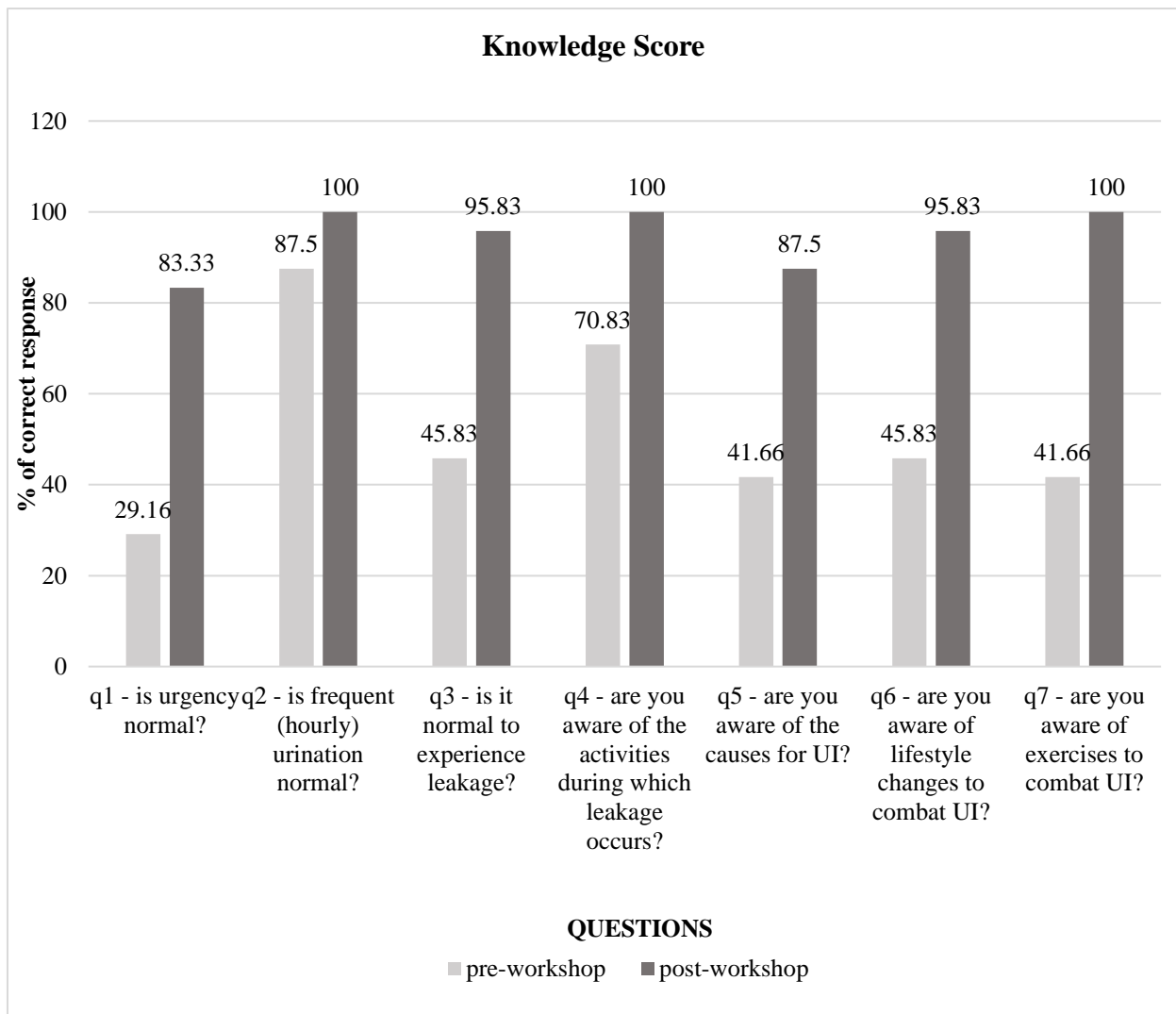


Fig. 1 Graphical representation of a comparison of mean scores for knowledge questions in the pre-and post-questionnaires

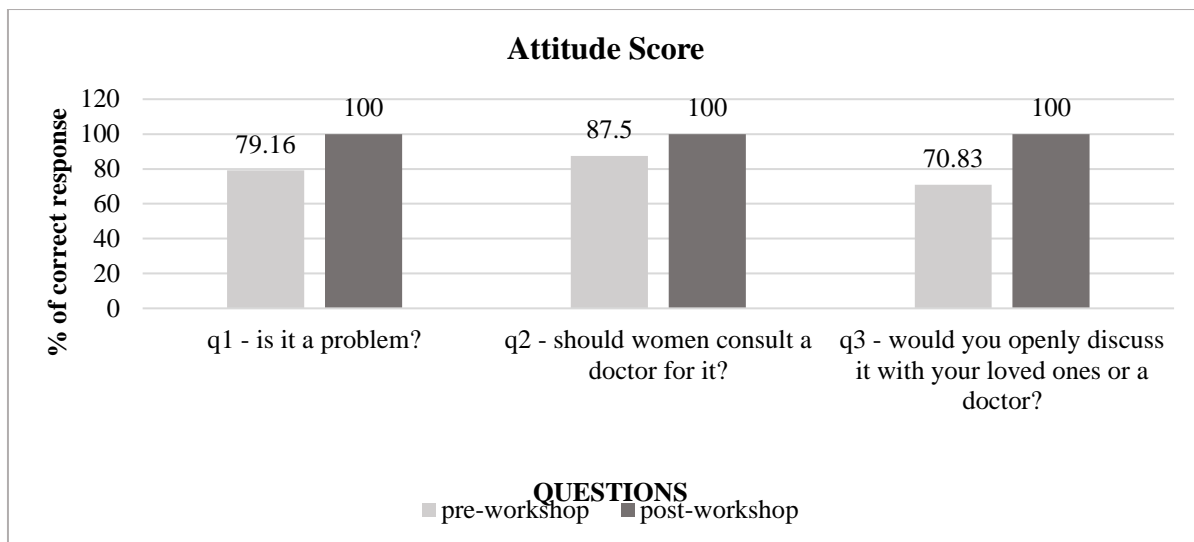


Fig. 2 Graphical representation of a comparison of mean scores for attitude questions in the pre-and post-questionnaires

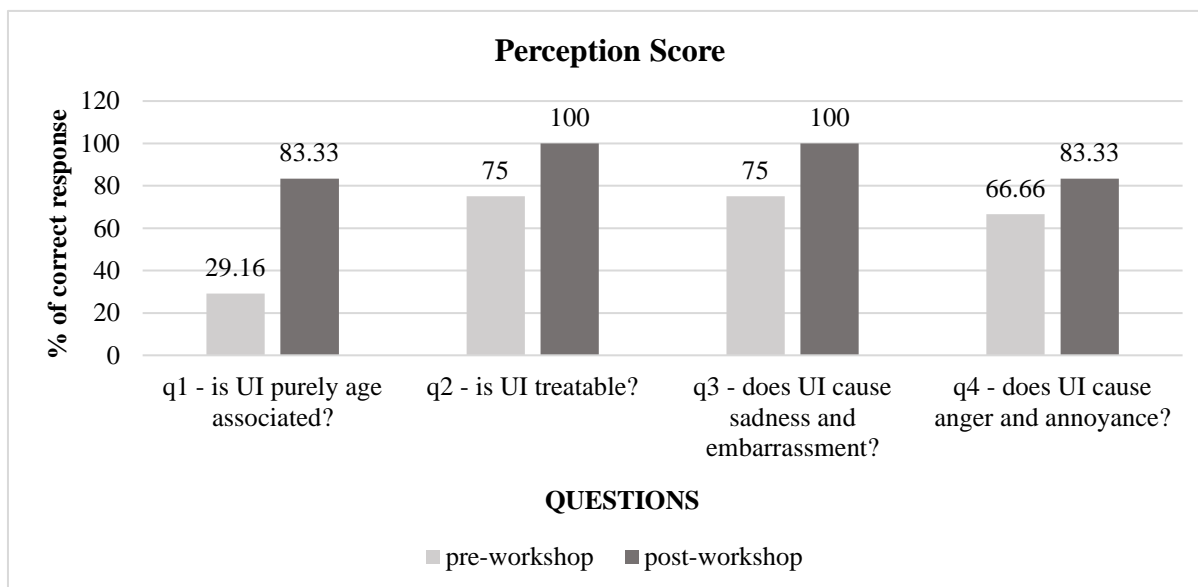


Fig. 3 Graphical representation of a comparison of mean scores for perception questions in the pre-and post-questionnaires

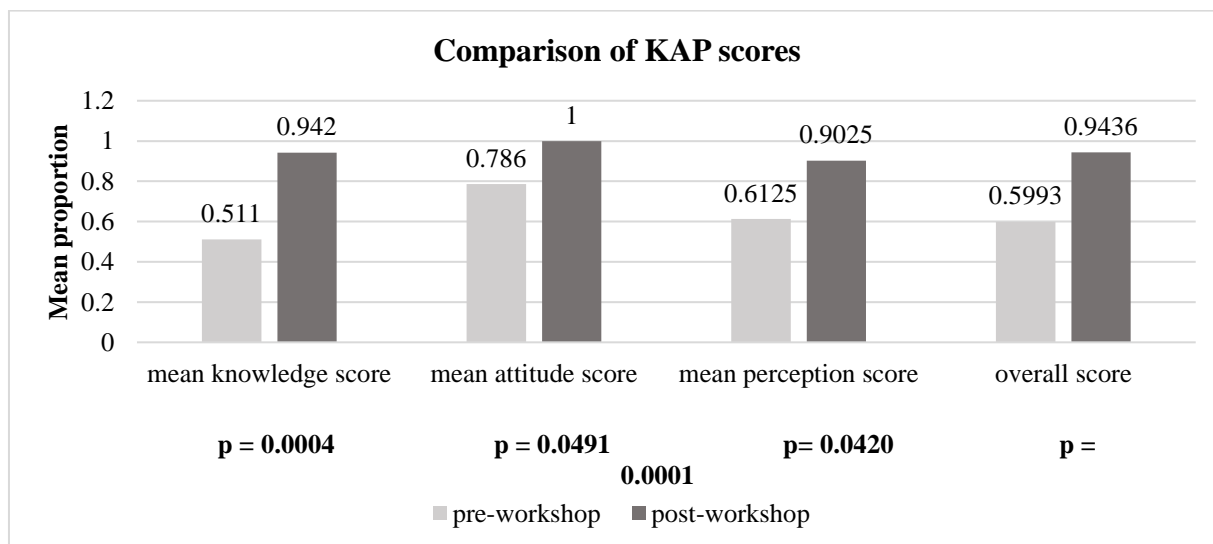


Fig. 4 Graphical representation of a comparison of mean scores for all categories in pre- and post-questionnaires