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Barriers in entering treatment among women with urinary incontinence

Bariery w podejmowaniu leczenia przez kobiety z nietrzymaniem moczu

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Abstract

Objective: *The aim of the study was to identify barriers in help seeking behaviors among women with urinary incontinence UI .*

Materials and methods: *The study was performed using the method of diagnostic enquiry by means of questionnaire and interview among two groups of patients. The first group of women aged 47-79 years consisted of 80 members of the Association of People with Urinary Incontinence „Uroconti". The second group included 61 females aged 26-81 years admitted to the Urodynamic Laboratory of Gynecology and Oncology Clinic at the University Hospital in Krakow.*

Results: *Patients with stress urinary incontinence (SUI) reported to the doctor on average after 4 years, patients with urgency urinary incontinence (UUI), after 3 years, patients with a mixed form of urinary incontinence (MUI), after 6 years, and with overflow incontinence, after 10 years from the appearance of first symptoms. Anxiety, shame, the conviction that symptoms of UI are a normal age related state, as well as the conviction that the symptoms are temporary, significantly affected the delay in seeking medical consultation. Most of the surveyed women made the decision to undertake treatment themselves, and their main motive was the escalation of symptoms. The majority (89.4%) of women surveyed alleviated the symptoms of urinary incontinence without the help of a doctor, sometimes using methods detrimental to their health.*

Conclusion: *The identification of help seeking barriers and reaching out to risk groups is essential for early diagnose and effective treatment of women with urinary incontinence.*

Key words: **urinary incontinence** / **help seeking barriers** / **education** /

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Streszczenie

Cel: *Celem pracy była identyfikacja barier w szukaniu pomocy przez kobiety z nietrzymaniem moczu (NM).*

Materiał i metody: *Badania przeprowadzono metodą sondażu diagnostycznego, techniką ankiety i wywiadu wśród dwóch grup pacjentek. Pierwszą (gr. I) stanowiło 80 kobiet w wieku 47-79 lat, należących do Stowarzyszenia Osób z Nietrzymaniem Moczu "Uroconti". Druga grupa (gr. II) obejmowała 61 pacjentek w wieku 26-81 lat, które zgłosiły się do Pracowni Urodynamicznej Kliniki Ginekologii i Onkologii Szpitala Uniwersyteckiego w Krakowie.*

Wyniki: *Pacjentki z wysiłkowym nietrzymaniem moczu (WNM) zgłaszały się do lekarza średnio po 4 latach, z naglącym nietrzymaniem moczu (NNM) po 3 latach, z mieszaną postacią nietrzymania moczu (MNM) po 6 latach, a z nietrzymaniem moczu z przepełnienia po 10 latach od wystąpienia pierwszych objawów. Lęk, wstyd, przekonanie, że objawy NM są stanem normalnym związanym z wiekiem, a także uznanie go za sytuację przejściową miały znaczący wpływ na długość czasu, jaki upłynął od wystąpienia objawów do zgłoszenia się do lekarza. Najczęściej badane kobiety podejmowały decyzję o leczeniu samodzielnie, a głównym motywem było nasilenie objawów. Większość (89,4%) ankietowanych kobiet łagodziła objawy nietrzymania moczu bez pomocy lekarza, niekiedy stosując metody niekorzystne dla zdrowia.*

Wnioski: *Pacjentki z NM zgłaszały się późno do lekarza z powodu braku wiedzy i błędnych przekonań na temat choroby. Konieczne jest opracowanie metod wczesnego dotarcia do grup ryzyka i systemu pomocy dla kobiet z tym problemem.*

Słowa kluczowe: **nietrzymanie moczu** / **bariery w szukaniu pomocy** / **edukacja** /

Introduction

Urinary incontinence (UI) is a common problem affecting 17% to 60% of women [1, 2, 3, 4]. Estimated data regarding the frequency of the occurrence of this disorder are divergent, which makes the recognition of the extent of this phenomenon much more difficult. The discrepancies in study results caused by the use of different methodologies and models of research by different scientists, and the small quantity of surveyed women make extrapolation of their results very difficult.

The lack of wide-scale epidemiological studies regarding the frequency of UI in Poland results in the scale of this problem not being fully known [5]. An important factor which impacts better recognition of the disorder is the improvement in reaching those at risk of UI (risk group) and conducting wide scale population research.

In some countries, due to many years of research, it was possible to better understand the medical and social aspects of this disorder. Moreover, actions were taken to improve the efficiency in which information regarding UI reaches the risk group, as well as, overcoming the barriers in reporting complaints and starting treatment by the people affected by this problem. This research also contributed to the popularization and development of urogynecology, engaging a wide spectrum of specialists from a variety of medical milieus (doctors, nurses, physiotherapists, etc.).

Research indicates that most women are convinced that urinary incontinence is a natural consequence of aging, which cannot be treated [6, 7]. These convictions, which are the result of the help system's neglect, the social stigma and shame related to having this problem all impact help seeking motivation. Reasons given by women for not seeking help include: not regarding symptoms of incontinence as abnormal or serious, considering incontinence to be a normal part of ageing and having low expectations of treatment [8]. There are reports which confirm the notion that embarrassment may be an important reason for not seeking help [9].

The late onset of treatment causes the inevitable exacerbation of symptoms as well as socio-economic costs, which have been detailed in the 2012 report done in Poland by the World Federation of Incontinent Patients *(Światowa Federacja Pacjentów z Inkontynencją)* [10].

The lack of Polish publications concerning the phenomenon of seeking help by people with UI became the inspiration for this research study; the aim of which is the identification of barriers in initiating treatment among the women with urinary incontinence.

Materials and methods

The study was conducted in the group of 141 women aged 26-81 (average 59.88 ± 9.66) years during the period from December 2011 to May 2012. The study group consisted of two subgroups. The first (group I) consisted of 80 women aged 47-79 years (ave. 61.8 ± 6.5 years) who were part of the Association of People with Urinary Incontinence "Uroconti" in Lublin, Warszawa and Wrocław second group (group II) contained 61 patients aged 26-81 years (ave. 57.4 ± 12.3 years), who were admitted to the Urodynamic Laboratory of Gynecology and Oncology Clinic at the University Hospital in Krakow to undergo urodynamic testing or the procedure of electro stimulation.

The studies were conducted by method of diagnostic survey. A questionnaire technique, interview, and analysis of medical documentation were used. The studies utilized the Polish version the Guadenz incontinence questionnaire, as well as the standardized questionnaire score, of recognized reliability and relevancy [11], upon which the type of UI was determined. The surveys were anonymous. Consent was obtained from all surveyed women.

Data was analyzed with the help of the SAS program, version 9.3. The Pearson correlation factor, chi-squared test and ANOVA were used to assess the dependence between variables. Significance factor of $p<0.05$ was employed.

Results

Most surveyed women (n=108, 76.59%) were in the age range of 50-69 years, the least were in the range of 20-49 years (n=17, 12.05%) and 70- 81 years (n=16, 11.34%). It was observed that the number of women aged 40-49 years seeking help in regards to UI was twice as large compared to the number studied in the range of 30-39 years (0% vs. 3.75% in those studied in group I and 6.55% vs. 11.5% in group II respectively).

It seems that the women most interested in seeking help were those aged 50 to 59 years, since this range saw a radical increase in the number of people seeking help when compared to the group of women in the 40 to 49 years range (3.75% vs. 38.75% as well as 11.5% vs. 32.8% respectively). This trend was maintained on a similarly high level in the group of women aged 60-69 years (47.5% and 31.1%). The number of women seeking help decreased significantly in the range of 70-81 years (10% and 11.5% respectively) when compared to the group in the 60-69 year range.. There was no significant dependence between the age of women and the type of UI ($p>0.05$). Table I.

The majority (88.65%, n=125) of those surveyed were in the perimenopausal or postmenopause period. Around half (44.68%, n=63) claimed that they observed the symptoms of UI after menopause. The vast majority of the respondents gave birth at least once (93.6%, n=132). In 26.2% (n=37) UI occurred after giving birth. Less than half (44.7%, n=63) had abdominal surgery. It caused disturbance of urinary incontinence in 19.85% (n=28). Aggravating physical work contributed to the formation of UI in 9.2% (n=13). Figure 1. Giving birth impacted the occurrence of stress and mixed type of UI ($p <0.05$). Figure 2.

Women's knowledge about incontinence

The women were asked if they knew the issues concerning urinary incontinence before they developed symptoms of this disorder. General lack of knowledge about incontinence was declared by 70.2% of women in the research group.

The responses of women who claimed to have knowledge about UI showed that it was incorrect or incomplete and it did not influence their decision to seek treatment. Both women who claimed they had knowlage of urinary incontinence before they experienced first symptoms, and those who did not have this knowledge sought treatment after more than 3 years from the onset of symptoms. Analysis of the data from the respondents of both subgroups showed that older women were often characterized by less knowledge of the disease ($p<0.001$).

Time from the onset of symptoms to the initiation of treatment

The time which elapsed from the onset of first symptoms of UI to the report to a doctor was found to be long. About one third (31.9%) of women active in the "Uroconti" Association and up to 68.9% of those treated in the urodynamic clinic reported to the doctor after over 3 years time (ave. 3.24 ± 0.9 years) since the onset of symptoms.

Patients with stress urinary incontinence reported after an average of 4 years (ave. 4.41 ± 6.75 years), those with mixed urinary incontinence after about 6 years (ave. 6.26 ± 8 years), those with urge urinary incontinence after 3 years (ave. 3.15 ± 4.6 years), and those with overflow UI after close to 11 years (ave. 10.8 ± 7.3 years) after the onset of first symptoms until the start of treatment.

Age did not play a role in the time, which elapsed from the onset of first symptoms to the issue being brought to the attention of a doctor ($p <0.05$).

Patients active in the association definitely started the diagnostic work-up earlier than those from the urodynamic clinic (ave. 3.4 ± 6.20 years and 7.85 ± 0.84 years after the onset of symptoms, $p<0.05$ respectively). It is important to note, however, that 10% of the women from the association did not report to the doctor to seek treatment at all. The longest period from the onset of symptoms to signaling of the problem was 34 years, the shortest about a month.

Motives behind the decision to seek treatment

The surveyed women from both subgroups usually claimed that they independently decided to seek treatment (80% in group I and 74% in group II respectively). It turned out, however, that women who were motivated to seek treatment due to the exacerbation of symptoms were reporting to the doctor after more than 3 years since the beginning of the problem, which is later than the rest ($p<0.05$). (Table II).

The barriers in seeking help

More than half of those surveyed in the first, as well as the second group (55% and 68.85% respectively) regarded urinary incontinence as a transitional state, which "will pass on its own". The majority (70.5%) of patients reporting to the urodynamic laboratory claimed that they reported to the doctor late due to the conviction that urinary incontinence is a normal phenomenon, related to aging and thus cannot be cured. Additionally 11.5% of them responded that a doctor confirmed this conviction. Table III.

Fear ($p<0.0001$), shame ($p<0.0001$), the conviction that UI is a normal state related to age ($p<0.01$), and also considering it as a transitional condition ($p<0.001$) had a significant impact on the length of time which passed from the onset of symptoms to the report to a doctor.

At the time of the interview the majority of patients in group II (n=46; 75.4%) reported that their problem was belittled by the doctor and hence wasn't treated promptly. The majority of those surveyed visited two (n=28; 45.9%), three (n=12; 19.7%) or even more doctors (n=6; 9.83%).

Self-treatment methods for symptoms of urinary incontinence

The majority, up to 89.4% of the surveyed women, alleviated the symptoms of urinary incontinence without the help of a doctor (Table IV). Some of the methods used, such as the reduction of fluid intake or limiting physical activity, could have had a negative impact on their health and on the aggravation of symptoms.

Discussion

The results of this study show that the women most interested in seeking help were those aged 50 to 59 years. Other Polish authors obtained similar data, which showed that regardless of the type of UI, women between the age of 50 and 60 years (on average 55 years-old) are the ones most often reporting to the doctor [12].

According to studies on postmenopausal women, urinary incontinence occurs in up to half of those over 60 years of age [13, 14]. Studies conducted by Jędrzejczyk (et.al) show that 30% of studied women after obstetric-gynecological surgery procedures have urinary incontinence [15].

Table I. Types of urinary incontinence—data from the Gaudenz questionnaire.

Types of UI	Group I		Group II		Total	
	n	%	n	%	n	%
Stress UI	35	**43.75**	16	**26.2**	51	**36.2**
Urgent UI	10	**12.5**	11	**18**	21	**14.9**
Mixed UI	34	**42.5**	29	**45.5**	63	**44.7**
Overflow UI	1	**1.25**	5	**8.2**	6	**4.25**

Table II. Patients' reasons to initiate treatment.

Who or what influenced the decision to initiate treatment?	Group I		Group II		Total	
	n	%	n	%	n	%
Independent decision	64	**80**	46	**75,4**	110	**78,1**
Exacerbation of symptoms	49	**61,25**	48	**78,7**	97	**68,8**
Refundable medication	0	**0**	14	**23**	14	**9,9**
Family/Friends	6	**7,5**	6	**9,8**	12	**8,5**
Gynecologist	1	**1,25**	8	**13,1**	9	**6,4**
"Uroconti" Association	6	**7,4**	0	**0**	6	**4,25**
Nurse	0	**0**	2	**3,3**	2	**1,4**
Urologist	0	**0**	1	**1,6**	1	**0,7**
Media: press, television, internet	0	**0**	1	**1,6**	1	**0,7**

* % does not total 100 because patients were allowed multiple responses

Table III. Barriers in seeking treatment by patients.

Barriers in seeking treatment	Group I		Group II		Total	
	n	**%**	**n**	**%**	**n**	**%**
Fear	13	16,25	28	45,9	41	29,1
Shame	32	40	43	70,5	75	53,2
Considering UI a transient condition, which "will pass on its own".	44	55	42	68,85	86	61
Conviction that UI is not treated as it is a normal part of aging	37	46,25	43	70,5	80	56,7
Anxiety of surgical procedure	1	1,25	1	1,6	2	1,4
Lack of burdensome symptoms	5	6,25	3	4,9	8	5,6
Unwillingness to see a doctor	1	1,25	1	1,6	2	1,4

*****% does not total 100 because patients were allowed multiple responses

Table IV. Patients' methods of self-treatment.

Methods of alleviating symptoms of UI	Gr.I		Gr.II		Razem	
	n	%	n	%	n	%
Inserts	67	**83,75**	53	**87**	120	**85,1**
Reduction of fluid intake	51	**63,75**	30	**49,2**	81	**57,4**
Mapping out toilets	28	**35**	27	**44,3**	55	**39**
Wearing dark clothing	12	**15**	23	**37,7**	35	**24,8**
Limiting physical activity	11	**13,75**	11	**18**	22	**15,6**
Exercises	11	**13,75**	6	**9,83**	17	**12**
Medications: Urospet, Furagin	0	**0**	12	**19,7**	12	**8,5**
Herbs, sitz baths	1	**1,25**	10	**16,4**	11	**7,8**
Setting breaks in work for voiding	7	**8,75**	12	**19,7%**	19	**16,7**

*****% does not total 100 because patients were allowed multiple responses

The small representation of women aged 20-39 years in the study (which is reflected in other national and international data), is either caused by the absence of symptoms in this age group or by their low severity which combined with the embarrassing nature of the problem affects their motivation to seek treatment. The lack of adequate information and effective awareness campaigns aimed at this age group regarding the consequences of neglecting early symptoms results in the delay of undertaking treatment. According to this study 26% of all surveyed women declared experiencing first symptoms of UI after childbirth. It is estimated that approximately 4.4% of women with urinary incontinence are aged 20-39 years [16]. Disturbing is the fact that the disease affects also younger women [1].

The presented research showed that the majority of women did not have any knowledge regarding urinary incontinence before they developed this problem. This is confirmed by many authors who describe a low awareness of women from different populations regarding the problem of UI.

For example Kang [6] conducted an analysis of the knowledge of 182 American women of Korean heritage who are suffering from UI, which showed not only the limited knowledge of UI but also demonstrated a negative attitude towards treatment of the disease. The author also pointed to the important role of education of women in the early diagnosis of UI. She believes that nurses, who are closer to patients and who may be the first to provide information, should carry out education. However, according to Albers-Heitne *et al* the role of the nurses should focus on instructing and helping women with pelvic floor exercises [17]. There are reports of doctors not responding, either by ignoring the statement of symptoms or by providing a dismissive explanation, and women interpreting a lack of response from the doctor as an indication that no treatment is available [18].

Knowledge of UI among Canadian women also proved to be inadequate, as shown in a survey study by Swanson et al [19]. Only half of the 600-person study group responded to the survey and 65% though that UI is not a disease but the effect of aging. In 30% UI occurred for at least a year, 40% from 1 to 4 years, and 30% suffered from UI for over 5 years. All respondents claimed that the disease limits their daily functioning, but only 40% sought help from a doctor.

As early as 1992 [20] studies around the world have been conducted with the aim to identify the barriers of early initiation of treatment in women with UI. Meanwhile, in Poland, there is a lack of research studies dedicated to the barriers in seeking help by those with UI. Understanding them would be essential to effectively reach people with this problem. It could also be a starting point for the development of educational programs for these women.

The Shaw study showed that only 20% of people with UI symptoms seek help [21]. Around 3 million women in Great Britain suffer from urinary incontinence. However, very few of these women report to the doctor [22]. Our own studies showed that the majority of women make the decision to self-treat and starts looking for help when there is an exacerbation of symptoms. Howard study [22] also showed the significant relationship between the exacerbation of UI and seeking help. The author stresses that the fact of reporting to the doctor often depends on knowledge and understanding of how the disease may be treated.

A study of Japanese women aged 40-75 years showed that

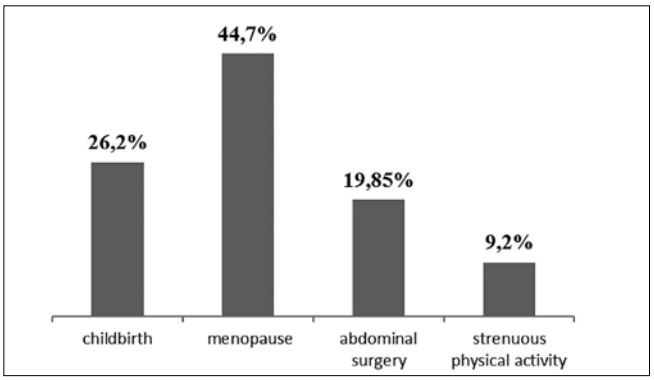

Figure 1. Presence of risk factors and the occurrence of urinary incontinence.

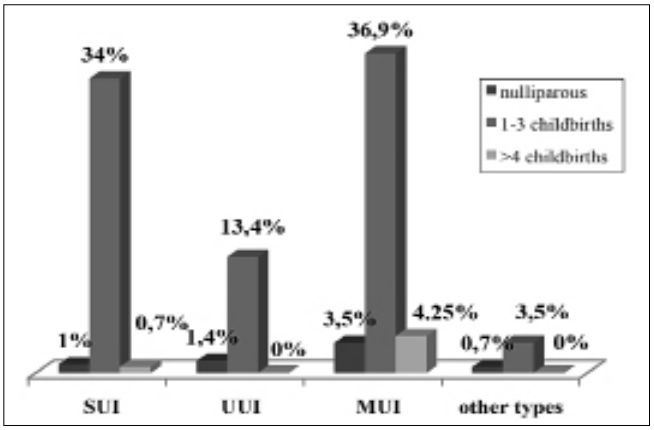

Figure 2. Number of childbirths and the occurrence of UI.

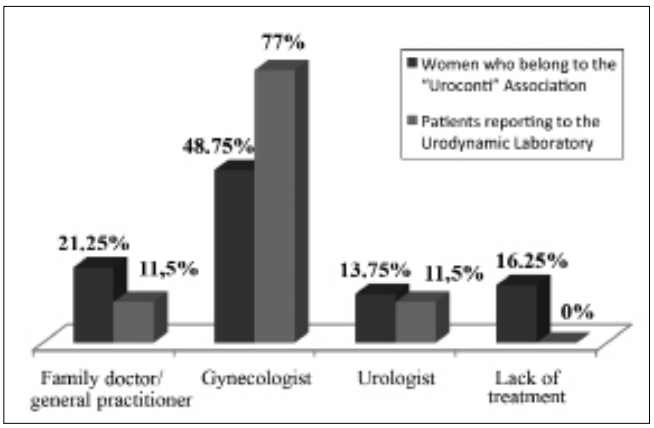

Figure 3. Physician to whom the women reported urinary incontinence.

only 3% of them, with symptoms of UI, consulted this problem with a doctor. What's more, among the women reporting symptoms of UI only 25% regarded it as a disease. Most of the surveyed women believed that this is a consequence of old age and thus they never tried to diagnose or treat the disorder. In addition they had a negative attitude towards treatment [23].

The Goldstein study showed that the most often declared reason for not seeking treatment was the conviction that UI is a normal element of aging or the aftermath of labor, as well as the lack of knowledge regarding the possibility and method of treatment [20]. Other authors also reported that a large part of

women treat UI as an inseparable element of the aging process [24, 25].

A similar study of 1718 women aged 15-49 years (9.8% of whom reported problems with stress urinary incontinence) showed that although UI causes sexual dysfunction and worsening of mood, women do not recognize it as a health problem, they rarely discuss this with others and rarely seek treatment because of embarrassment [26].

Our study confirms global reports on barriers in seeking help for women with UI.The reluctance of women to seek help of their own initiative regarding the treatment of UI indicates the necessity of the health care system to pay greater attention to this condition and to initiate appropriate preventative measures. Future work should also examine the knowledge of the experts in this field.

Goldstein recommends that in order to overcome barriers in diagnosing urinary incontinence and initiating treatment early medical professionals should routinely ask questions directly regarding UI [20]. In our own studies only 13.5% of the respondents claimed that the doctor asked about the occurrence of this problem. Urinary incontinence is not a normal condition. It undoubtedly causes a decrease in the quality of life. At the same time actions of the medical society as well as government authorities are very limited at every level. The problem is belittled, UI is not considered a disease, there is a lack of efficient tests as well as lack of knowledge among medical professionals regarding the management of people suffering of incontinence. It deepens the suffering of people with UI, who are left to their own devices the majority of time.

In summary, it should be stated that early diagnostics of UI among women in Poland is not sufficient and should be the main priority of future policy. Development of reach out programs aimed at risk groups, putting emphasis on the study and evaluation of their effectiveness, improvement of early health education, can limit the occurrence of UI, as well as influence early detection and application of noninvasive methods of treatment. In the long run it can decrease the financial burden associated with treatment and improve the quality of life of these people.

Conclusions

1. The majority of women surveyed did not have knowledge of the problem of UI before the occurrence of their own symptoms, which had an impact on the delay in initiating treatment.
2. When it came to urinary incontinence, most women initiated treatment between the age of 50 and 69 years.
3. The time from the onset of symptoms of urinary incontinence to the initiation of treatment was long and on average: 4 years with stress UI, 6 years with mixed type, 3 years with urge UI, and even as much as 10 years with overflow UI.
4. Reasons of the delay in reporting to the doctor were the women's incorrect convictions regarding UI (considering UI as a normal condition related to aging, one which is not treated, or considering it as transient), as well as fear, shame, and the initial lack of bothersome symptoms.
5. The women in the study often alleviated their own symptoms of urinary incontinence by adverse methods, which further intensified the problem.

Oświadczenie autorów

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