

Research Article

“I really thought nothing could be done”: help-seeking behaviour among women with urinary incontinence

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ABSTRACT

Background: This study explores help-seeking behaviour among women with Urinary Incontinence (UI). Help-seeking behaviour is interpreted as the result of a process which is influenced by several factors, such as the appraisal of symptoms, individual characteristics, experiences within the health-care system, especially with regard to health professionals' reactions to personal needs, social norms, and information about health issues.

Methods: The study was carried out between 2012 and 2014 in Northern Germany and followed an exploratory qualitative study design. Four semi-structured focus group interviews were undertaken with women affected by involuntary loss of urine. 49 women, aged 41 to 86 years old, participated in the focus groups. Thorough sampling of study participants was carried out to warrant demographic and cultural variation and, resultantly, the completeness of perspectives relevant to this field. The verbatim transcripts of the interviews were analyzed following the content analysis method of Mayring. The analysis combined deductive and inductive approaches.

Results: Important barriers to seeking medical help were identified: women's interpretation of UI as a non-medical problem, the lack of knowledge about the causes and treatment of UI, shame and taboo, and the problem of naming "it". Also, the study results showed factors which supported women's decision to seek medical help, notably the severity of symptoms or the women's feeling of losing control of her bodily functions and significant parts of everyday life.

Conclusion: The results of the study allow recommendations about measures that can be taken to improve the situation of women affected with UI.

Keywords: Qualitative research, Help-seeking behaviour, Urinary incontinence, Appraisal of symptoms

INTRODUCTION

Urinary Incontinence (UI) is a common, but often unreported, symptom experienced by women of all ages. Prevalence rates given in the literature vary between 10% and more than 50%,¹⁻⁵ depending on study designs,

included age groups, and definitions of UI.^{6,7} UI is known to cause psychosocial effects, such as impairment of quality of life, social isolation, anxiety disorders, and depression.⁸⁻¹³ Nevertheless, only a minority of women affected by UI seek medical help.^{3,14,15} Former studies have identified a range of reasons why women do or do

not seek medical help. Frequently, these studies found that the severity of UI and its impact on everyday life and self-esteem are major factors influencing the decision to seek help.^{9,14,16-18} It is known that many women do not seek medical help, although the perceived severity of problems regarding UI is high.^{14,19-21} A reason for this might be that women's knowledge about treatment options and, in general, their appraisal of UI symptoms are also crucial factors regarding help-seeking behaviour, or lack thereof.^{15,18,22,23} The individual's appraisal of symptoms is influenced by many factors, such as personal traits and experiences, social norms and stigma, and, last but not least, the structure of the health system and women's knowledge about possible contact partners.

Apart from general factors which may influence help-seeking behaviour in women with UI, knowledge on the factual reasons why and which women with urinary problems in Germany seek medical help is scarce.

The present study was undertaken between 2012 and 2014 in the Fehmarnbelt region, which covers the region Zealand in Denmark and the communities of Plön, Ostholstein and Lübeck in Northern Germany. The study included a qualitative section followed by a survey involving 8000 women and all GPs practicing in the region (929). One of the aims of the whole project was to assess the prevalence of UI in the region and to evaluate different types and the severity of UI symptoms. Another aim of the study was to describe the help-seeking behaviour of affected women as well as GPs' attitudes towards UI and the barriers to the assessment and treatment of female urinary problems. This article focuses on the results of the qualitative interviews we conducted with women in Germany.

METHODS

Recruitment and sampling

Included in the study were women aged 18 years or older living in the German part of the Fehmarnbelt-Region, who were affected by involuntary loss of urine. Information and recruitment was achieved by an advertisement in the local press. Women were asked to call the study team at Lübeck, which then conducted a short telephone interview to obtain basic information about the women's demographic data and their history of urinary symptoms. These data included age, place of residence (rural or urban), duration and severity of UI symptoms and information about existing medical advice on or treatment of UI.

The information collected in these interviews was used for sampling. The aim was to include women in the focus groups who reflect the largest possible variation in demographic aspects, experiences and handling of UI.

Each participant gave written informed consent and received a reimbursement of 25€.

Data collection and analysis

The study followed a qualitative exploratory design based on semi-structured focus group interviews. Each interview was conducted by two of the authors using an interview guideline. The interviewers were social scientists (MJ and SE) and - in one interview - a gynecologist together with a social scientist (EF, MJ). The interviews lasted approximately one and a half hours.

The interview guideline was based on a comprehensive review of the literature and was discussed among the study team. It covered the following main topics:

- Women's individual UI "history"
- Women's individual appraisal of impairments due to UI
- Handling of UI symptoms, coping strategies
- Help-seeking behaviour (triggers and barriers, reasons for seeking medical help or not)
- Experiences of the health system/physicians regarding urinary problems
- Knowledge about UI

Interviews were audio recorded and transcribed verbatim into MAXQDA software. Names, addresses and other individual attributes which could be used to identify the participating women were anonymized. Consistent pseudonyms were used to identify quotes: each quotation includes the number of the focus group (FG1 to FG4), the number assigned to the woman (W1 to W13) and, as additional information, the age of the woman.

As group interactions play an important role in focus group interviews by influencing data,²⁴ each focus group interview was analyzed with regard to interactive processes among participants, including dominant views, statements that evoke conflict, emphasizing of common experiences, and domineering or quiet group members. For each focus group, study memos about group interactions were made and included in the further content analysis.

Analysis was conducted according to the content analysis method of Mayring²⁵ and combined deductive and inductive approaches. In the first step, a basic system of categories, which included all topics seen as relevant for answering our research question (deductive approach), was developed by two of the authors (MJ, SE). For the next step, the same two scientists independently analyzed two focus group interviews with this system of categories and added new categories as required. Within this inductive approach, we enhanced the basic system of categories. During the third step, we compared and

discussed the coding trees of both scientists and developed a common version. This version was used for the repeated analysis of all focus group interviews. The common version of the coding tree was discussed and reviewed in a team workshop with five team members (social scientists, epidemiologist, medical documentarist, and gynecologist).

The coding of interviews was done iteratively again by MJ. In cases where new codes were identified, interviews which had already been analyzed were reviewed again.

RESULTS

Sample

Advertisements in local newspapers achieved an overwhelming response. It was obvious that lots of women affected by UI felt the need to talk about their problems and to exchange information.

Altogether, we conducted four focus group interviews with 49 participants (age range 41 to 86 years). Nearly 50% of women lived in rural areas and lived in the city of Lübeck, respectively.

A significant majority of women had experienced UI for many years. It became obvious that UI in this group was not only a problem for elderly women: Some women said that they had always had problems with urinary leakage, or a “nervous bladder”. Many other women had been affected following childbirth in their 20s or 30s, and others reported that UI appeared with the onset of menopause. Only a minority of the study participants said that their UI started after the age of 60.

Barriers to seeking medical help

So far, nearly half of the women had not talked to a physician about their UI. The women mentioned a broad range of reasons for not seeking medical help:

Necessity to become active by themselves

On barrier was that physicians very seldom ask about UI. Therefore, most women had to take responsibility and raise the topic themselves if they wanted to speak about it.

It is always up to you. They never ask about it. (FG2, W7, 58 years.)

Women had different views regarding the question of whether physicians should ask patients about UI. Some women were expecting the physician to raise the question:

Well, I think, for women or female patients of a certain age it should be included in the query canon when visiting the GP, for example. (FG4, W9, 66 years.)

It would take away the sense of shame if they asked directly. Because once they have (asked) then one begins to talk. (FG2, W4, 65 years.)

Others pointed out those physicians cannot ask about everything; as such, it is up to women themselves to talk about their problem:

The doctor can't always think about everything, that's impossible with (all) the patients he is serving and the small amount of time. (FG1, W6, 73 years.)

But how should the GP, how should he know if you don't tell? (FG1, W2, 72 years.)

No (responsible) physician available

Some women participating in the study, especially younger women and those who had changed residence in recent years, claimed that they did not have a GP or a gynecologist at all. These women did not know, or have, a physician to whom they could address their questions, about UI.

Gender and age of the physician

Women reported several physician-related factors that kept them away from addressing their problem in the consultation hour. Some women stated that the gender of their physician has played an important role in their decision about medical help-seeking. Many women believed that it is easier to talk to female physicians about UI and that female physicians are more capable of understanding their problems:

I have talked to a female doctor. Since I express myself differently - from woman to woman than from woman to man - it is sometimes easier to address this -. From woman to man, I have to think about what I say, well, for a long time. How I tell it to him in simple words. Among women that's easier. (FG1, W6, 73 years.)

Furthermore, women suspected that male physicians would not take urinary problems seriously.

Anyway, these problems are not taken seriously by men, neither by bosses nor by gynecologists. I find that very sad. (FG4, W10, 59 years.)

Well, my experience is that once one has talked to a man about it - I once had a male gynecologist - then, somehow, one is treated as being stupid. (FG4, W10, 59 years.)

Also, women pointed out that they feel more ashamed when talking to a male physician about UI compared to when talking to a female physician:

And maybe I am to be partly blamed, but they are almost always men - and I am also very, I would not say vain,

but I was then a little bit ashamed to mention it. (FG3, W3, 48 years.)

For other women gender did not matter - they pointed out that the professional skills of the physician and the confidence between her and the physician are more important.

The age of the physician seemed to play no relevant role for the participating women.

Previous experiences with physician(s)

Women mentioned previous experiences with physicians in general, or with their physician in particular, which had hindered them from asking for help regarding their UI. Several women reported that they attempted to speak with a physician about their UI but the physicians were not responsive and so the women did not try again:

I have also mentioned it to my GP in a subordinate clause, that I'm having problems with it. He then brushed it aside nicely and I did not get into it any further. (FG3, W1, 46 years.)

But it is so tersely dismissed and then you're told: 'Well, you have to live with it.' (FG2, W9, 62 years.)

I have told my doctor and he replied: 'Well, you do drink a lot, thus you have to go to the bathroom a lot.' (FG3, W2, 77 years.)

Beyond this, nearly all women participating in the study reported that their physician was always in a hurry and so there was not sufficient time to raise the topic of UI.

Nobody has any time for this. (FG1, W10, 80 years.)

When I notice somebody lacks time and the waiting room is full then I think: 'Well, it is not so pronounced yet, my involuntary bladder weakness.' (FG4, W6, 67 yrs.)

There has been no need for medical help (until now)

The last citation alludes to another important reason why women did not seek medical help. Women developed a broad range of strategies to cope with the situation of urinary leakage and in many cases they thought they should be able to manage the problem by themselves and therefore did not need medical help:

One can still find such loopholes. And as long as that is possible, you go with the flow. (FG2, W10, 64 years.)

I now try to live like I do, but maybe someday I will see an urologist. (FG2, W9, 62 years.)

Some women pointed out that they expected the UI to vanish on its own.

One sometimes thinks it will be definitely got better by it, but it does not seem to be that way. (FG2, W13, 41 years.)

I have not yet talked about it because, yes, at first I thought: 'Oh, this could also be a coincidence, yes, and one must not exaggerate. And what comes all of a sudden will certainly leave all of a sudden.' (FG2, W2, 48 years.)

Several women had other physical diseases or complaints in addition to UI. They weighted their different problems and, in most cases, UI was rated as a minor problem – another reason not to address this topic during consultation hours:

I am now in the process where I say each and every day: 'So, now I'm one day older and now I have a blemish more.' So, you have so much, what is suddenly in need of a repair, right? Knees and back, and when one goes to a doctor because of this, that's enough. Then you cannot add the bladder on top of that. (FG1, W3, 71 yrs.)

UI is not seen as a medical problem

Also, the idea that UI is not a medical problem but rather a "natural" fact that women - especially of older ages or after giving birth - have to live with was very common:

I did not come up with the idea to talk to a doctor. (...) I thought: 'So now I just have to suck it up and live with it.' (FG2, W13, 41 yrs.)

It wasn't shock or fear to talk about it, but somehow I accepted it as a given fact. (FG2, W10, 64 years.)

The idea of UI as a "natural fact" was supported by the friends to whom they have talked about their UI:

And I have been talking with my girlfriends, who also accept it all as it is. No one said: 'I went to the doctor.' All shared the same opinion that one has to get used to it and that's about it. (FG2, W13, 41 yrs.)

Some women drew an analogy between UI and menstruation and interpreted UI as another kind of "female trouble".²⁶ Through dealing with menstruation, women developed skills, such as handling pads and tampons without attracting attention and avoiding public "accidents", that also helped them to cope with UI.

But I also think that it's due to the fact that one, as a woman, has had bleedings and that is an issue which is likely ... not a deep secret ... But you tell yourself: 'Oh, I've got my monthlies and I feel really shitty and I would love if you could leave me all alone.' (...) And I think that (UI) is exactly the same (as menstruation). Something's running out of a body opening where it does not belong or you feel left high and dry, while you are far away from being dry, and that's kind of embarrassing! (FG2, W2, 48 years.)

Maybe this comparison between menstruation and UI supports the opinion that UI is a problem of practice rather than a medical problem.

Conviction and/or experience that there is no effective or acceptable medical treatment

Also, the interviews showed that many women thought that there were no suitable medical interventions available. In some cases, this conviction is a kind of prejudice because the women have not talked to a physician at all to ascertain what treatment he or she may offer. In other cases women had sought medical help previously but the treatments administered had not helped.

He (the doctor) won't help me anyway. (FG2, W8, 46 years.)

But I thought nothing could be done. (FG2, W13, 41 years.)

Other women who sought help from a physician judged the suggested treatment options as unacceptable for themselves. In this case, they chose not to undergo the suggested therapy and UI became a "non-topic" in physician-patient-communication.

Shame and taboo

The topic of shame and taboo very often emerged in the interviews and were described as the main barriers to seeking help in the case of UI. Nearly all the women said that they felt inhibited and ashamed about their urinary problems and that they needed a lot of courage to address the problem during the consultation hour.

It was so bad. Still, I could not say anything. So I have not talked to a doctor, it just was not possible. (FG2, W8, 46 years.)

But to say: 'I pee my pants', to phrase it in easy words, that is the pure essence of shame, right? For me, definitely. (FG2, W9, 62 years.)

This is really a taboo. I have quite a few friends who also have it, but do not talk about it, and certainly not to their doctor. (FG4, W9, 66 years.)

Problems in naming "it"

The interviews showed another aspect which sometimes may keep women from seeking medical help for UI. It became obvious that many women found it difficult to name the problems they have.

And I have endured it for a quite long time, but without giving it any name. (FG1, W6, 73 years.)

The terminology they used in the interviews was predominantly vague ("the problem", "these mishaps") and often a description of "what happened": "that I lose something when doing some things", "that it pours out", "that it cannot be stopped".

During the focus group interviews, some women adopted the terms we used on our information sheets ("involuntary loss of urine") but, in using them, they often misspoke or stumbled over the words. This may be seen as an indicator that they usually did not use these terms.

The difficulties in giving the problem a "name" also make it difficult to communicate with others about it. Several study participants pointed out that they did not know how to address their UI during the consultation hour in a way that made physicians aware of the severity of the problem:

We say: 'we drop water', or such like; we would not say: 'it runs like crazy'. (FG2, W7, 58 years.)

This is another thing like that, where one (...) what should I say? 'I pee in my pants'? (FG3, W3, 48 years.)

Lack of knowledge

Many of the topics discussed above as barriers preventing women from seeking medical advice or treatment include a topic which can be seen as "superior": women's lack of knowledge with regard to causes, prognosis, and treatment options of UI.

When we directly asked if they feel sufficiently and adequately informed about UI, most women said they did.

In contrast to their own estimation of being well-informed, the questions women asked in the interviews and their comments and signs of astonishment at the contributions of the other women allowed the assumption that, on average, women's knowledge about UI was rather scarce. Most of them knew giving birth or gynecological surgeries could cause UI but they only speculated about the possible reasons for their urinary problems and possible treatment options:

Can it be diagnosed then? If there is a weakness of the connective tissue? (FG1, W10, 80 years.)

I do not know: are younger women also affected? (FG4, W5, 67 years.)

Does weight play also a major role, too? (...) But the weight is here and here and there [points to her hips and belly] and not inside. (FG3, W3, 48 years.)

W4: I have a question for everybody here: Does anyone have experience with prescription drugs?

W5: Nope

W9: Not at all ...

W5: I don't know about such things.

W1: I never ever have.

W7: I don't know any pills for that.

W5: There are pills for it? (FG4)

It is comprehensible that women who do not know the reasons for their urinary problems, who interpret UI as a normal part of the aging process, who are unaware of the existence of treatment options, and, above all, feel ashamed to experience and talk about it, are unlikely to seek medical help.

Reasons for medical help-seeking

About half of the women participating in the study had talked to a physician about their UI. In some cases it was a singular attempt (see above), but in other cases it resulted in continuing medical treatment.

In some cases, women did not have to become active themselves because their physician asked them about urinary problems. In general, women stated that they found it very helpful and facilitative if the physician raised the topic.

Women who were not asked by their physician mentioned various reasons and situations which supported their decision to seek medical help.

Impairments due to UI

All women reported impairments due to UI in several areas of life, particularly with regard to social and sporting activities, sexuality/partnership, and self-esteem. Most women felt able to cope with these impairments, at least for a time and if the symptoms did not worsen (see above).

In the interviews, women declared having their own, very individual, "threshold of tolerability". When they exceeded this threshold, the women decided to seek a remedy and asked a physician for help.

But you reach the point that you say to yourself: 'No, not anymore. Someone has to help you now. You do not want to live like this anymore, because it's so annoying'. (FG2, W1, 42 years.)

For me, a point was reached where the suffering was so intense and I now had to find a way to talk about it. I wanted to get rid of this problem, no matter what. But one has to reach this point first. (FG2, W8, 46 years.)

Working women discussed the impairments of UI interfering with work as a crucial factor in seeking medical help:

My job was the trigger for this decision. I was at the court and participated in lengthy hearings, and then it began ... it was not too bad, but it was already there. When the hearing took three hours, then I thought: 'Oh my God, before this somehow gets worse, I would rather go to the doctor.' (FG1, W4, 75 years.)

Special triggers

Some women named special situations which triggered their decision to seek medical help. Typical triggers are public "accidents" with urinary leakage:

For me there was as a point like that, where I was really so wet, I just did lunch break, toilet break, shopping. So just getting from A to B and back I was so wet! And this happened in the office. So, I had nothing to change into. I then said: 'So now it works no longer. You went to the toilet beforehand. It just does not work anymore.' (FG2, W7, 58 years.)

Once I got a gastroscopy, went to the toilet before, you know, I peed and did everything and so on, I even wore a pad. Awoke a little afterwards, still a bit dazed and thought: 'What's that?' I was soaking wet down there! And I thought: 'No! That's enough!' (...). And that was somehow the point for me where I said: 'Stop it now!' (FG2, W1, 42 years.)

Another typical situation which induced the decision to seek help was the beginning of a new love relationship:

When I met my second husband and we were newly in love and, yes, I constantly had problems during sex. I was always afraid that I would miss something and I could not enjoy anything, but I loved this man so much and I wanted it to be perfect. So, then, yes, the point for me was reached that the suffering was too great, and I now had to find a way to talk about it. I wanted to get rid of this problem, no matter what. (FG2, W8, 46 years.)

Fear that UI will become worse

The decision to ask for medical help was in some cases supported by the fear that UI may become worse, and that the "right" moment for medical treatment may be missed:

I did talk to the doctor early about it because I worried whether I would be in a very bad situation later, and then would regret, perhaps, not to have talked about it earlier. That someone says: 'Yes, if you would have said that three years ago, then we could have managed this and that would have been quite simple. But now it's too progressed.' (FG4, W10, 59 years.)

Family/friends insisted on seeking medical help

Another trigger for women to seek medical help was the influence of relatives and friends. The estimation by other persons that their symptoms of UI are not “normal” induced the decision to ask for help:

My kids say to me: ‘Tell me, that can’t be real. You can’t just not drink anymore, or you can’t simply say now: No, I’m not doing it. You have to face it and do, change something.’ And I myself had already thought of it as being normal, or like that. But now I have been thinking, if other people mention this, as my children do, that is a real annoyance which I did not notice before. But the others already have brought this to my attention. And then I also said to myself: ‘You have to take care of it. It can’t be alright like this.’ (FG2, W5, 58 years.)

Crucial aspects: Maintenance, loss and regain of control

One “superior” topic which was noticeable throughout the women’s narratives concerning reasons for whether or not they sought medical help was their feeling of losing control and the wish to regain control, respectively.

In most cases, women tried to self-manage their symptoms of urinary incontinence as long as possible. For this, they used and developed a broad range of everyday strategies to handle the problem. This could include management of drinking behaviour, creation of city maps including sanitary facilities or taking a set of clothes for changing.

Even if these self-management strategies were successful, women described them as very exhausting and wearing. Moreover, mostly all the women in the interviews expressed an impression of losing control, or voiced their concern that this may happen in the future if symptoms became worse.

The feeling of losing control includes different aspects:

First, it is the aspect of losing control of bodily functions. Women realize that a part of their body, which has been subject to their intentional control before, “disobeys” more or less often. The formerly obedient body becomes a body which seems to have “its own” will. This impression of a body which acts according to its own rules, which are not understood by the woman herself, arises, especially if the symptoms of UI occur only occasionally and unexpectedly.

Altogether, the situation of losing control over bodily functions may cause much grief and anxiety.

It makes one feel like ... I don’t know, handicapped that you can’t control it. (FG2, W12, 45 years.)

As you sit in the theater, nicely dressed, looking beautiful, and down there it trickles! So, it was kind of depressing! And terrible! (FG1, W7, 71 years.)

When we dance and somebody wants to really rock the dance floor with me, and I am wearing high-heeled shoes, then I have to (pee) and at some point ‘oh shit!’. I can’t control that. (FG3, W3, 48 years.)

The second aspect included in the topic “losing control” is the feeling or fear that the urinary problems influence and control a significant portion of everyday life. Many women stated that decisions about what could and should be done are more influenced by UI-given requirements than by their “real” wishes or other requirements such as familial or vocational duties.

You really have to adjust your life and your whole day to it. (FG3, W9, 52 years.)

Then they were saying ‘we do a canoe trip’ - actually, I would love to do this - and then I think: ‘Oh no, we will be on the water for two to three hours and I can’t get out of there! That’s not gonna work.’ And I always felt I was isolating myself more and more. And no matter where I had to go, I imagined the way beforehand, and, yes, sometimes stopped drinking in the evening in order to survive for two hours. (FG2, W6, 52 years.)

A third aspect related to the topic “losing control” that women mentioned was the question of which image others have, or may have, about them or things others might know. Women with UI aimed to control whether, and to what extent, others know about their condition. They tried to manage this by using strategies to avoid public “accidents”, “conspicuous” waste or odor and by informing only those persons they want to know about their urinary problems.

Now when I get home, I unlock the door and I sniff immediately to see whether it smells like pee in my home ... I’ve already put out scented candles. (FG2, W9, 62 years.)

Being at a friend’s house, you can’t put it in the corner of the bathroom. This is not a hotel where they have those buckets. (FG1, W7, 71 years.)

Why should I disclose a weakness or anything to someone, because in today’s society you have to fear that someday it will - err - that it will be laid out on the table, where you do not want this, because you cannot control it. (FG3, W6, 59 years.)

DISCUSSION

Help-seeking must be seen not as a singular fact but as the result of a - sometimes long lasting-process which is influenced by several factors, such as appraisal of symptoms, individual characteristics and experiences,

social norms, and information. Sometimes, this process leads to seeking medical help and sometimes not.

Results of the interviews showed that there are huge differences in women's interpretations of the "meaning" of UI. The way the symptoms of UI are perceived and interpreted strongly influences help-seeking behaviour - a relation which is well-known from other studies (e.g.²²). Women who see UI as a medical/health problem will be much more apt to seek medical help than those who interpret UI as a normal consequence of aging which has to be accepted and for which no adequate medical help is available.

Literature about coping with chronic conditions gives evidence that individuals usually experience the loss of control and/or feelings of helplessness as very stressful.^{27,28} Perceived control influences coping behaviours and, vice versa, the outcomes of coping strategies effect perceived control.²⁸ In general, the feeling of having control about the central aspects of one's own life has a strongly positive effect on physical and mental well-being.²⁹⁻³³ In our interviews with women with UI, the feeling of losing control was a central aspect. Women tried to self-manage urinary problems as long as possible.

Many of those women who have not (yet) sought help pointed out that they feel able to cope with the situation by themselves - a feeling which fosters self-esteem and a good quality of life. For these women the costs of help-seeking, for example embarrassment, shame, financial costs and time spent²³, are higher cost than the anticipated benefit.

The results of our study showed that most women lacked knowledge about the causes and treatment options of UI. For this, they stick to lay knowledge which regards UI as a normal part of the aging process. This interpretation "may have a protective effect on self-esteem by normalizing incontinence in old age".²⁶ On the other hand, it might lead to a "therapeutic nihilism"³⁴ and keeps women from informing themselves so that they lack a valid basis to make a well-informed decision about whether or not to seek help.

Another striking result of our study was that communication with a physician about urinary problems seems to be very difficult: Women often do not raise the topic because of shame. They wish for the physicians to ask about UI problems, but often experienced that physicians rarely do. Moreover, many women reported that they had the impression that physicians trivialized their problem if they had talked to them. Often this leads to resignation and a life as "silent sufferers". Melville and colleagues¹¹ pointed out that UI is associated with a "lack of recognition by physicians" - a view which was confirmed by the results of our study. The education of and information given to physicians about UI, its effects on women's lives and adequate UI management, which

should include the teaching of communication skills, will be an important step in improving the situation of women affected by UI.

In contrast to other studies,^{15,35} the concern that UI may be a symptom of a more serious medical condition and, therefore, a reason to seek medical help was not reported by our study participants.

CONCLUSION

Study results enable recommendations to improve the situation of women affected with UI. First of all, an increase in knowledge about the frequency and causes of, treatment opportunities for and impairments surrounding UI is important for both affected women and physicians. Knowledge can form the basis on which affected women are able to make an informed decision about whether or not they want to seek medical help. Furthermore, knowledge will help to overcome shame and break the taboo around UI.

Knowledge will also change physicians' appraisal of UI symptoms and their effects on women's quality of life and social well-being, thus preventing them from interpreting UI as a minor problem which does not demand serious attention. A precise recommendation for GPs, resulting from our study, is to ask women routinely about urinary problems during consultation hours, in the same way as they ask about sleeping problems, blood pressure, defecation and so on. The question may function as a "door-opener" for those women who feel too ashamed to address the problem on their own.

Strengths and limitations of the study

The study gives a detailed and so far nonexistent insight into the help-seeking behaviour of women living in Northern Germany. The results of the study enable recommendations about measures that can be taken to improve the situation of affected women.

The recruitment strategy and the large number of women who wanted to participate permitted an accurate sampling. In this way it was possible to include women with huge variations regarding socio-demographic aspects, severity and duration of UI symptoms, handling of UI and experiences with physicians. However, a recruitment bias cannot be completely ruled out.

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