

Urinary incontinence in older people living in the community: examining help-seeking behaviour

Doreth Teunissen, Chris van Weel and Toine Lagro-Janssen

ABSTRACT

Background

Only a small proportion of older people with urinary incontinence seek help, despite the availability of adequate treatment.

Aim

To ascertain the patient- and disease-specific factors that determine whether medical care for urinary incontinence is sought by independently living older people with urinary incontinence.

Design of study

Qualitative and quantitative analyses of interview data.

Setting

All independently-living older patients aged 60 years or over from nine family practices involved in the Nijmegen Monitoring Project.

Method

All the independently-living patients aged 60 years or over with uncomplicated urinary incontinence were interviewed at home using the Protection, Amount, Frequency, Adjustment, Body image (PRAFAB) assessment tool, the Incontinence Impact Questionnaire, and the Urogenital Distress Inventory (UDI).

Results

In total, 56 men and 314 women were interviewed. Half of the patients had sought help from a GP. Help-seeking was related to the duration of symptoms, the severity of incontinence, the impact experienced emotionally and/or physically, and the presence of concomitant symptoms, particularly of urinary obstruction. Only the presence of incontinence-related complaints as listed on the UDI (odds ratio = 2.74, 95% confidence interval = 1.42 to 5.29) was a significant predictor of help-seeking. Most of the patients who had not sought help did not do so because they considered incontinence as not very serious, or because of a lack of knowledge about cause and treatment options — comments such as 'incontinence is age-related', and 'there is nothing that can be done about incontinence', were reported. Major reasons for seeking help were perceived increase in severity or distress and the need for incontinence materials.

Conclusions

Seeking help is particularly determined by the impact experienced and presence of concomitant symptoms. When patients perceive their incontinence as not very serious or distressing and have a lack of knowledge about cause and treatment options, they usually do not seek help. When they perceive an increase in severity or distress or require incontinence materials, they usually do seek help.

Keywords

help-seeking behaviour; older people; urinary incontinence.

INTRODUCTION

Urinary incontinence is a common problem among older people. Its prevalence varies between 20% and 40% depending on the research populations and definitions used.¹ Urinary incontinence affects general wellbeing, self-esteem, and social functioning.^{2–4} Conservative therapies such as bladder retraining, pelvic floor exercises, and medication prove very successful in the treatment of involuntary loss of urine.

Over the last few years, it has become increasingly clear that urinary incontinence is not only a common problem for middle-aged women, but also for older men and women.⁵ Although adequate treatment is available, few older people seem to take advantage of it. Most studies on help-seeking for urinary incontinence, however, concentrated on middle-aged women: it appears that 14–33% of this population consult their GP;^{6–12} for older people, this percentage varies between 20% and 80%.^{13–18}

It is well known in medical care that only a minority of all health problems are presented to GPs and, as such, are not specific to patients with urinary incontinence.¹⁹ This phenomenon can be related to disease-specific, as well as patient-specific, factors; Burgio *et al*,¹⁴ Dugan *et al*,¹⁶ Stoddart *et al*,¹⁷ and Peters *et al*,¹⁸ investigated these factors among older people with urinary incontinence, but their findings were not equivocal.

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Considerations regarding why patients do or do not present health problems may explain the discrepancy between the availability of adequate treatment and the low percentage of older people with urinary incontinence that take advantage of them. Understanding these factors may help to better identify older patients with urinary incontinence who wish to receive treatment.

This article analyses reasons for older patients to present or not present urinary incontinence to their GP. It addresses patient-specific and disease-specific factors.

METHOD

Study sample

This study is part of a longer study on urinary incontinence that we conducted in the eastern part of the Netherlands between January 1999 and January 2002.¹ The subjects in this study were recruited from the practice population of the nine practices of the Nijmegen Monitoring Project, the academic registration network of the Department of General Practice of University Medical Centre Nijmegen, the Netherlands.²⁰ These nine practices with 28 GPs are fully computerised and provide medical care to a total of 46 500 patients. According to the structure of the Dutch healthcare system, patients can only access health care through the GP practice at which they are registered. Consequently, the GP has a full overview of medical care provided; particularly relevant to this study was the professional support for incontinence.

Patients considered for this study were those who had reported presence of urinary incontinence in a survey of the entire practice population aged 60 years and older (Figure 1). With a response rate of 88%, this survey had yielded incontinence in 18% and 61% indicated that they were prepared to participate in this study.

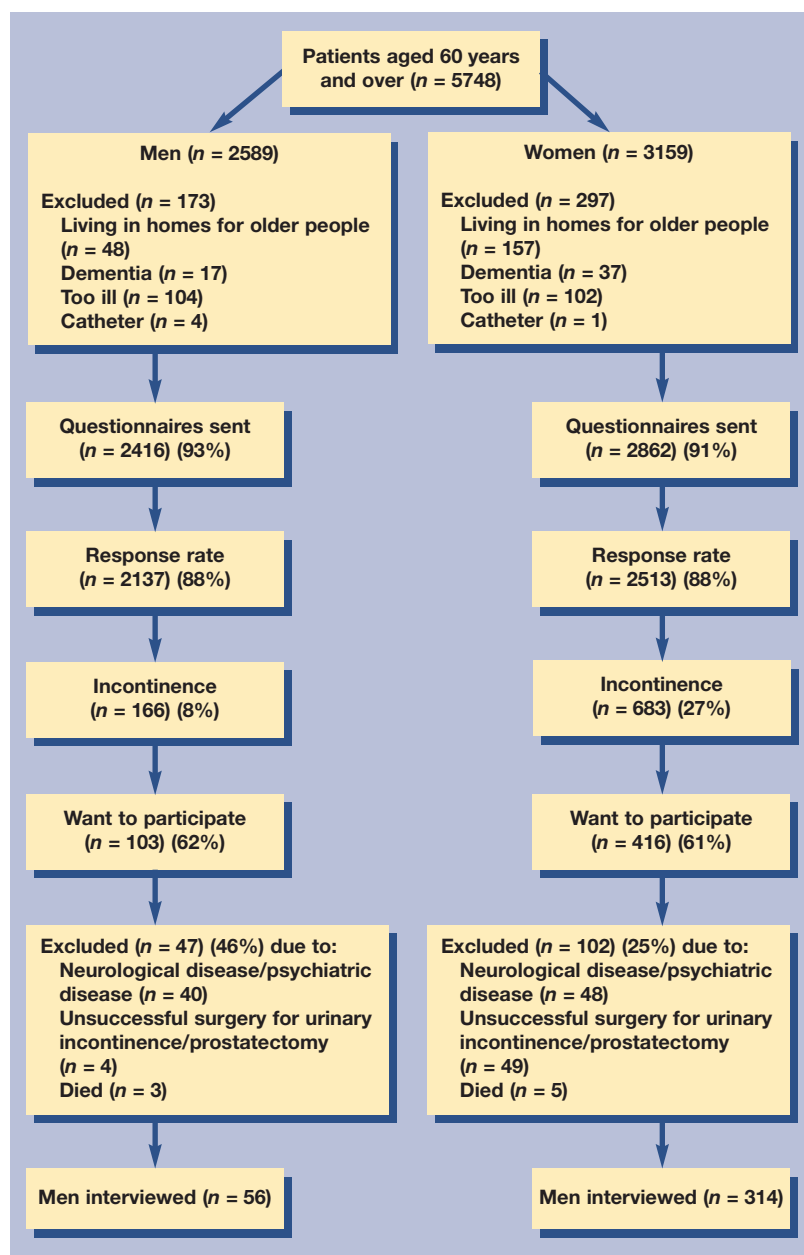


Figure 1. Flow chart of the study population.

Data collection

Urinary incontinence has been defined according to the Dutch guidelines for GPs as involuntary loss of urine at least twice a month.²¹ Post-micturition dribbling in men was not considered a symptom of incontinence. The study focused on uncomplicated urinary incontinence in older people living in the community. Patients with a neurological or psychiatric disorder, patients who had previously undergone unsuccessful surgery for urinary incontinence, and patients living in homes for older people were therefore excluded (as outlined in Figure 1). The interviews were conducted at home and lasted up to 1 hour. During the interviews, quantitative data were collected on:

How this fits in

Urinary incontinence is a common problem in older people. Conservative therapy is effective, but only a small proportion of older people actually seek help. Help seeking is dependent upon how it affects everyday life and the presence of concomitant symptoms. Patients do not seek help because they perceive that their incontinence is not serious enough and because they lack knowledge about the cause and the treatment options.

- background characteristics;
- incontinence type; and
- disease-specific quality of life, disease-specific impact on daily life, and the severity of the incontinence.

Background characteristics comprised age, sex, civil status, and level of education. The type of incontinence was determined on the basis of the following questions:²² 'does loss of urine occur at moments of increased pressure, for example, when sneezing, jumping or straining at stool?' and 'do you experience such strong urge that you fail to reach the toilet in time?'. According to these questions, urge incontinence was defined as 'involuntary loss of urine during strong urge' and stress incontinence was defined as 'involuntary loss of urine during increased abdominal pressure'. Disease-specific quality of life, disease specific impact on daily life, and the severity of the incontinence was measured with three standardised instruments, namely the Protection, Amount, Frequency, Adjustment, Body image (PRAFAB) score,²³ the Incontinence Impact Questionnaire (IIQ),²⁴ and the Urogenital Distress Inventory (UDI).²⁴

The PRAFAB score gives an indication of the severity of incontinence. It involves questions on the involuntary loss of urine frequency, the amount of urine that is lost each time, the use of incontinence material, the limitation of activities of daily living, and the effects on self-image. According to the PRAFAB guidelines the following categories were distinguished: mild (1–7 points), mild-to-moderate (8–10 points), moderate (10–13 points), and severe (14–20 points).

The IIQ determines the impact of involuntary loss of urine on four domains in daily life, namely daily physical activities (six questions), social functioning (10 questions), emotional wellbeing (eight questions), and travel (six questions). The subjects were asked to tick one answer for each multiple choice question; the possible answers were: none (0 points), some (1 point), moderate (2 points), and severe (3 points).

The UDI determines the presence of symptoms often concomitant with urinary incontinence such as prolapse complaints in women, urgency, and voiding problems. The subjects were asked 19 questions divided into three subscales: stress symptoms (two questions), irritative symptoms (seven questions), and obstruction symptoms (10 questions). If subjects answered affirmatively they also had to indicate the degree of distress, none (0 points), some (1 point), moderate (2 points), and severe (3 points).

To assess help-seeking behaviour we also collected qualitative data on help seeking. We adopted a qualitative approach because such methods tend to be the most appropriate way to explore attitudes and behaviour. All interviews were conducted by the same interviewer, who did not know the patients. After the interviewer had collected the quantitative data she introduced the qualitative part of the interview. She told the patients that this part would concentrate on help seeking and that all answers were recorded on tape. This part of the interview consisted of asking if the patient had ever sought help from their GP. If the patient's answer was negative they were asked for their reasons for not seeking help. In the last four practices, patients were asked about their reasons for seeking help from their GP to get a better insight into help-seeking behaviour.

Statistical analysis

Quantitative data were analysed with the help of SPSS for Windows. Statistical differences between patients who had sought help and patients who had not sought help were analysed by the χ^2 test for categorical variables and the *t*-test for continuous variables. To calculate the mean of the various domains and subscales of the IIQ (impact score) and UDI (distress score), the total score of each domain and subscale was divided by the total number of questions less the number of questions that were not applicable. If 50% of the questions or more in the domain or subscale were not applicable, the data were not included in the analysis.

Of each disease- or patient-specific factor for which a significant difference was found between those who did and those who did not seek help, the odds ratio was determined and subsequently a multiple regression analysis was performed. We used $P < 0.01$ to indicate statistical significance.

Qualitative data on the reasons to seek or not seek help were fully typed out and analysed with the help of the ATLAS computer program. The analysis began with open coding of episodes using the patients' own words (in vivo codes) such as 'not bad enough' and 'I can take care of it myself'. Subsequently, these episodes were placed in different categories. The entire analysis was performed by two researchers. There was a large degree of correspondence between the two researchers in coding the categories.

RESULTS

In total, the research population comprised 370 patients with uncomplicated urinary incontinence, of which 56 were male and 314 female. The

analysis involved data of 348 patients (55 male patients and 293 female patients). Twenty-two patients dropped out because of a technical error that occurred during the recording of the qualitative part of the interviews.

Results showed that 54% of the male subjects and 50% of the female subjects with involuntary loss of urine had never sought any help from their GP (Table 1).

Whether or not help was sought also correlated with the effects of involuntary loss of urine on daily life: the more impact patients experienced, the more often they sought help of their GP. This also applied to the separate subdomains of 'emotional impact' (which may include anxiety, fear, frustration and anger) and 'limitations experienced during physical activities'.

Furthermore, patients who sought help also proved to have more incontinence-related symptoms (the distress score). The total score for patients who sought help was significantly higher than that for patients who did not seek help (odds ratio = 2.49, 95% confidence interval = 1.51 to 4.13). This was also found for the domain of obstruction symptoms (such as pressure or pain in the lower abdomen, a feeling of constant vaginal pressure, and voiding problems; these usually indicate prostatic hyperplasia in male patients and prolapse in female patients). Seeking help was not related to age, sex, civil status, level of education, nocturnal micturition frequency, type of incontinence, severity, or the duration of the incontinence. In a multiple regression analysis with all bivariate factors, the presence of incontinence-related symptoms proved the only significant predictor for seeking help (Table 2).

The reasons for seeking or not seeking help were further explored in the qualitative part of the study. Again, we found a relationship between seeking help and severity and distress. For 80% of the patients, mild-to-moderate severity of incontinence was the reason for not presenting their problems to their GP. Most of them did not find the symptoms serious enough to seek help; patients made comments such as: '... it's not so bad ...'; '... it wasn't yet so serious that I needed help ...'; and '... it doesn't really bother me ...'. In other cases, patients had no difficulties in dealing with the disorder or did not find it troublesome: '... I can take care of it myself ...'; '... I use sanitary towels to solve the problem ...'; '... I've got other complaints that are much more serious ...'. As soon as the complaints got worse or distress increased, they did seek help from their GP. A quarter of the patients mentioned increase in the frequency of urinary leakage or amount of urine lost as the reason for seeking help after all: '... it

Table 1. The characteristics of patients who did/did not seek help for urinary incontinence.

	Sought help n = 170 (49%)	Have not sought help n = 178 (51%)	P-value
Mean age (years)	71	71	0.643
Sex:			
Men	25 (4)	30 (54)	0.583
Women	145 (50)	148 (50)	
Civil status:			
Married/cohabiting	109 (47)	121 (53)	0.569
Single	7 (64)	4 (36)	
Widow(er)	52 (52)	49 (48)	
Divorced	2 (33)	4 (67)	
Education level:			
Low ^a	114 (52)	104 (48)	0.213
Medium ^b	39 (45)	48 (55)	
High ^c	17 (40)	26 (60)	
Duration of symptoms:			
<6 months	0 (0)	0 (0)	0.043
>6 months–<2 years	13 (33)	27 (67)	
2–5 years	58 (47)	66 (53)	
>5 years	99 (54)	85 (46)	
Type of incontinence:			
Stress	30 (51)	29 (49)	0.337
Urge	45 (47)	51 (53)	
Mixed	90 (52)	84 (48)	
Other	5 (29)	12 (71)	
Severity of incontinence:			
Mild	10 (42)	14 (58)	0.042
Mild to moderate	43 (42)	59 (58)	
Moderate	84 (49)	88 (51)	
Severe	33 (66)	17 (34)	
	Mean score	Mean score	P-value
IIQ total score	0.24	0.17	0.012 ^d
IIQ subscale score:			
Physical activity	0.21	0.14	0.008 ^d
Social functioning	0.06	0.05	0.717
Travelling	0.25	0.23	0.643
Emotional wellbeing	0.45	0.29	0.000 ^d
UDI total score (mean)	0.92	0.83	0.006 ^d
UDI subscale score:			
Obstruction symptoms (mean)	0.50	0.38	0.003 ^d
Irritative symptoms (mean)	1.40	1.32	0.747
Stress symptoms (mean)	1.33	1.29	0.472
Nycturia (mean)	1.53	1.45	0.380

^aNone/basis/lower professional. ^bMedium general preparatory/medium professional. ^cHigher general preparatory/higher professional/university. ^dP<0.01. Statistical analysis by χ^2 test for categorical variables and t-test for continuous variables. IIQ = Incontinence Impact Questionnaire.²⁴ UDI = Urogenital Distress Inventory.

happened more often ...'; '... sanitary towels were no longer sufficient ...'; and '... it also happened when I had to cough ...'.

Table 2. Bivariate and multivariate regression analysis of the characteristics of the study population.

	Bivariate analysis Odds ratio (95% CI)	Multivariate analysis Odds ratio (95% CI)
IIQ total score:		
mean = 0	2.12 (0.89 to 5.05)	ns
mean 0.01–0.25	2.04 (0.95 to 4.43)	ns
mean 0.25–0.5	1.09 (0.46 to 2.63)	ns
(mean >0.5) ^a		
Physical activities:		
mean = 0	1.49 (0.95 to 2.33)	ns
(mean > 0) ^a		
Social functioning:		
mean = 0	1.53 (0.89 to 2.61)	ns
(mean > 0) ^a		
Travel:		
mean = 0	1.15 (0.74 to 1.77)	ns
(mean > 0) ^a		
Emotional wellbeing:		
mean = 0	1.39 (0.88 to 2.19)	ns
(mean > 0) ^a		
UDI total score:		
mean 0–0.5	1.47 (0.79 to 2.71)	1.57 (0.53 to 4.69)
mean 0.5–1.0	2.49 (1.51 to 4.13) ^b	2.74 (1.42 to 5.29) ^b
(mean 1.0–4.0) ^a		
Obstruction symptoms:		
mean = 0	1.19 (0.74 to 1.92)	ns
(mean >0) ^a		
Irritative symptoms:		
mean = 0–1	0.50 (0.32 to 2.48)	ns
mean 1–2	0.51 (0.31 to 2.78)	ns
(mean 2–4) ^a		
Stress symptoms:		
mean = 0	1.18 (0.68 to 2.02)	ns
mean = 0.1–1.0	0.84 (0.51 to 1.41)	ns
(mean ≥1) ^a		

^aThe odds ratio of each characteristic is the difference between the group between brackets and the others. ^bP<0.01. ns = not significant. IIQ = Incontinence Impact Questionnaire.²⁴ UDI = Urogenital Distress Inventory.

As in the questionnaires, the interviews showed that an increase in the number of incontinence-related symptoms was mentioned as the reason for consulting the GP: '... it became more and more troublesome ...'; '... it also caused irritation ...'. Finally, a quarter of the patients went to see their GP in order to obtain incontinence materials: '... sanitary towels no longer helped and I therefore wanted incontinence material[s] ...'.

Apart from severity and distress, cognition appeared to be an important factor and almost half of the patients presented a rationale for not

seeking help. The most important were that incontinence is age-related: '... what do you expect? I'm almost 80!'; '... that's what happens when you get older ...'; and that there is nothing that can be done about incontinence: '... the doctor won't be able to do anything about it ...'.

Other reasons for not seeking help were related to the doctor–patient relationship: '... I'm not one to visit a doctor regularly ...'; '... I only go to the doctor's when there's a reason ...'; '... I don't get along with the doctor ...'; and '... the doctor didn't ask ...'. Reasons for finally consulting GPs include the discovery that treatment was possible: '... I saw a television programme about the treatment options ...'; and fear of an underlying disease '... afraid that something was seriously wrong ...'. These were in addition to an increase in severity and distress.

DISCUSSION

Summary of main findings

The most unexpected finding in this study is the fact that in the qualitative analysis of the interviews, embarrassment did not emerge as a key factor in the decision regarding whether or not to seek help for urinary incontinence.

Another important finding in this study was the large number of the patients who did not experience any problems with incontinence. This may explain the discrepancy between the availability of adequate treatments and the low percentage of patients that sought help from their GP. This may have something to do with the fact that older people accept physical ailments more readily than the younger people.²⁵ Older people also experienced more distress because of the presence of comorbidity, as a result of which loss of urine is not their main concern. Furthermore, the patients in our study often did not know the cause of the disorder and the treatment options.

The major reasons why patients seek help are increased severity of incontinence together with distress, knowledge of treatment options, the need for incontinence material, and fear of an underlying disease.

We found that patients tended to seek help more often if incontinence had a substantial effect on physical activities and on emotional wellbeing, and if more incontinence-related symptoms occurred, especially obstruction symptoms. We also found that only half the older people with uncomplicated urinary incontinence contacted their GP for this problem.

Comparison with existing literature

Embarrassment did not emerge as a key factor in

the decision as to whether to seek help for urinary incontinence or not. This is in contrast with existing literature.^{26–28} A lack of knowledge about cause and treatment also played a role in help-seeking behaviour with regard to other problems such as impotence, breast cancer and heart complaints.^{29–31}

We also found that only half the older people with uncomplicated urinary incontinence contacted their GP for this problem. Burgio *et al*¹⁴ and Dugan *et al*¹⁶ studied independently-living older people with urinary incontinence in the US, Stoddart *et al*¹⁷ and Peters *et al*¹⁸ did so in the UK — all these studies used only a quantitative approach and the percentage of older people who had sought help varied from 15% to 69%. The differences between the studies may well be explained by the variation in the definition of incontinence: the more serious the definition, the more likely patients are to seek help.

In these studies a relationship was found between help seeking and severity and distress experienced. We did not find this relationship in our study. We also did not find any support for Burgio *et al*'s finding that there is a relationship between the type of incontinence, for Dugan *et al*'s finding that there is a relationship with age, or for Peters *et al*'s finding that there is a relationship between being married or having a partner. Contrary to our study, these studies also included patients with complicated urinary incontinence.

Strengths and limitations of the study

This is one of the few studies into help-seeking behaviour among independently-living older people with urinary incontinence in the general population, involving both male and female subjects. Given the structure of health care in the Netherlands, the GP records provide a reliable overview of all professional medical care for incontinence. As far as we know, this is the first study in which interviews with open-ended questions were used to elicit information concerning the patient's reasons for seeking help and not seeking help.

A limitation of this study is that the study population was composed of patients of general practices of an academic network in the eastern part of the Netherlands; this should be taken into account when applying the results to other general practice settings. Academic practices may differ from other practices with regard to the characteristics of the GPs involved. On the other hand, similar to other general practices, academic general practices provide care for unselected patient populations. Given the fact that patient characteristics, by and large, determined our

findings we think the practice setting of this study had little effect on the generalisability of our findings.

Implications for clinical practice and future research

This study emphasises the importance of practices taking a stand against therapeutic nihilism in this area. Given its effectiveness, GPs should be encouraged to pursue conservative therapy in older people. These people must also be informed of the effectiveness of treatment in order to make an informed decision to seek help. Under these conditions GPs can concentrate their care on those older people with urinary incontinence who have made the decision to seek help. This way, patients in whom urinary incontinence is a problem will get optimal treatment and those who do not have problems with their incontinence will not seek help unnecessarily.

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