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ORIGINAL ARTICLE

“It can always happen”: The impact of urinary incontinence on elderly men and women

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Abstract

Objective. To determine the impact of urinary incontinence (UI) on the quality of life of the elderly in the general population and to identify factors with the greatest effect. **Design.** Qualitative and quantitative analyses of interview data. **Setting.** Patients from the nine family practices of the Nijmegen University Research Network. **Subjects.** Independently living patients aged 60 and over. **Main outcome measures.** All independently living patients aged 60 and over with uncomplicated UI were interviewed at home using the Incontinence Impact Questionnaire and open-ended questions. **Results.** In total, 56 men and 314 women were interviewed. A majority do not have such an impact. In the Incontinence Impact Questionnaire (IIQ) emotional well-being was most affected. Half to one-third of the patients felt nervous, embarrassed, or frustrated because of their incontinence. In the social domain “clothing” and “fear of odour” scored the highest impact. The most affected practical consequence in the IIQ was “going to places where you are not sure about the availability of a toilet” followed by “travelling longer than 20 minutes” and “entertainment”. Men reported higher impact scores than women, despite the fact that incontinence was less severe in men. The most important effect of incontinence reported in men was “being out of control” while most women considered “feeling impelled to take several precautions” to be the most important consequence of UI. **Conclusion.** UI affects nearly half of patients, particularly as regards their emotional well-being and in public activities. Men experienced more impact compared with women and experienced loss of control more often than women.

Key Words: *Elderly, family practice, gender differences, quality of life, urinary incontinence*

Introduction

Urinary incontinence (UI) is a common condition in the general population, especially in the elderly [1]. At the same time, there is a recognized discrepancy between the number of women who report UI and the number who seek help [2]. Reluctance to seek treatment may be due to the perception of incontinence as a taboo subject or because urinary leakage does not substantially interfere with an individual’s daily life. Data to support either view are scarce.

The literature presents conflicting information on the importance of UI as a health problem for those afflicted. Some studies have suggested that UI has a major impact on well-being; other studies conclude that the effect is more modest [3–5]. A possible

Urinary incontinence (UI) affects nearly half of elderly patients in their daily life.

- UI in the elderly affects mostly emotional well-being.
- Men report higher impact scores than women, despite the fact that incontinence is less severe in men.
- Men report “being out of control” as the most important effect of UI while most women consider “feeling impelled to take precautions” to be most important.

explanation for these contradictory results could be related to the non-standardized definition of UI and the lack of standardized questionnaires. Health-related quality of life has been a widely used term

with little consensus about what it means and how best to measure it. Generally there is agreement that quality of life is a multidimensional construct that refers to patients' perception of and satisfaction with their well-being. Health-related quality of life includes specific dimensions of physical, psychological, and social health, as well as global perceptions of function and well-being [5].

It is important to know the effect UI has on health-related quality of life because it affects not only the patient's ability and willingness to seek help but also the ability to benefit from treatment. This knowledge is useful in designing the approaches to patients who are affected by UI but do not explicitly ask for help.

The importance of UI as a health problem for those affected has mainly been studied in middle-aged women and/or in clinical settings [7,8]. Relatively little is known about the impact of uncomplicated UI on daily life in the elderly in the general population, especially in men. Because elderly men seek help for less severe UI than women [9] this study also focused on the differences between the sexes in the impact of UI on daily life.

The aim of this study was to determine the impact of uncomplicated UI on quality of life in elderly men and women in the general population and to identify factors with the greatest effect.

Material and methods

This study was part of a large study on UI conducted in the eastern part of the Netherlands between January 1999 and January 2002 [1,2,9]. Subjects were recruited from the practice populations 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 [10].

All the patients considered for this study had reported symptoms of UI in a survey of the entire practice population aged 60 years and older (Figure 1). With a response rate of 88%, this survey revealed incontinence in 920 (20%) patients and 519 (56%) of them indicated that they were prepared to participate in a follow-up study. The response was similar in men and women and in the different age groups.

UI was defined in accordance with the Dutch guidelines for general practitioners as the involuntary loss of urine at least twice a month [11]. Post-micturition dribbling in men was not considered a symptom of UI. The study focused on uncomplicated UI in community-dwelling elderly people because the uncomplicated UI is the most prevalent

type of UI in general practice on which the UI guideline is based. Therefore, patients with a neurological or psychiatric disorder, patients who had previously undergone unsuccessful surgery for UI and patients living in homes for the elderly were excluded (see flow chart, Figure 1). The interviews were conducted at home and lasted up to an hour. During the interviews, the following data were collected:

(a) Background characteristics

- age, gender, civil status, level of education, duration of symptoms;
- the type of incontinence: determined on the basis of the following questions[12]: “does loss of urine occur at moments of increased pressure, for example, when sneezing, jumping or coughing?” and “do you experience such a 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, in the absence of stress symptoms. Stress incontinence was defined as: involuntary loss of urine during increased abdominal pressure, in the absence of urge symptoms.
- the severity of incontinence: assessed by the PRA-FAB score (=Protection, Amount, Frequency, Adjustment, Body image) [13]. The questionnaire involved questions on the use of protective pads, the amount of urine lost each time, the frequency of involuntary loss of urine, the limitation of activities in daily life, and the effects on self-image. According to the PRA-FAB score the following categories were distinguished: mild (1–7 points), moderate (8–13 points), and severe (14–20 points).

(b) Health-related quality of life

We used the Incontinence Impact Questionnaire (IIQ) to determine the impact of UI on daily life [14–17]. The IIQ is a disease specific health-related quality of life instrument and is designed to measure the specific consequences of UI on the quality of life. We opted for a disease-specific questionnaire because it allows a more in-depth assessment of specific concerns pertinent to UI. We opted for the IIQ because it is a widely used and well-tested questionnaire and it contains four domains of daily life. It determines the impact of involuntary loss of urine on daily physical activities (6 questions), social functioning (10 questions); emotional well-being (8 questions), and travel (6 questions). The subjects were asked to tick one answer for each

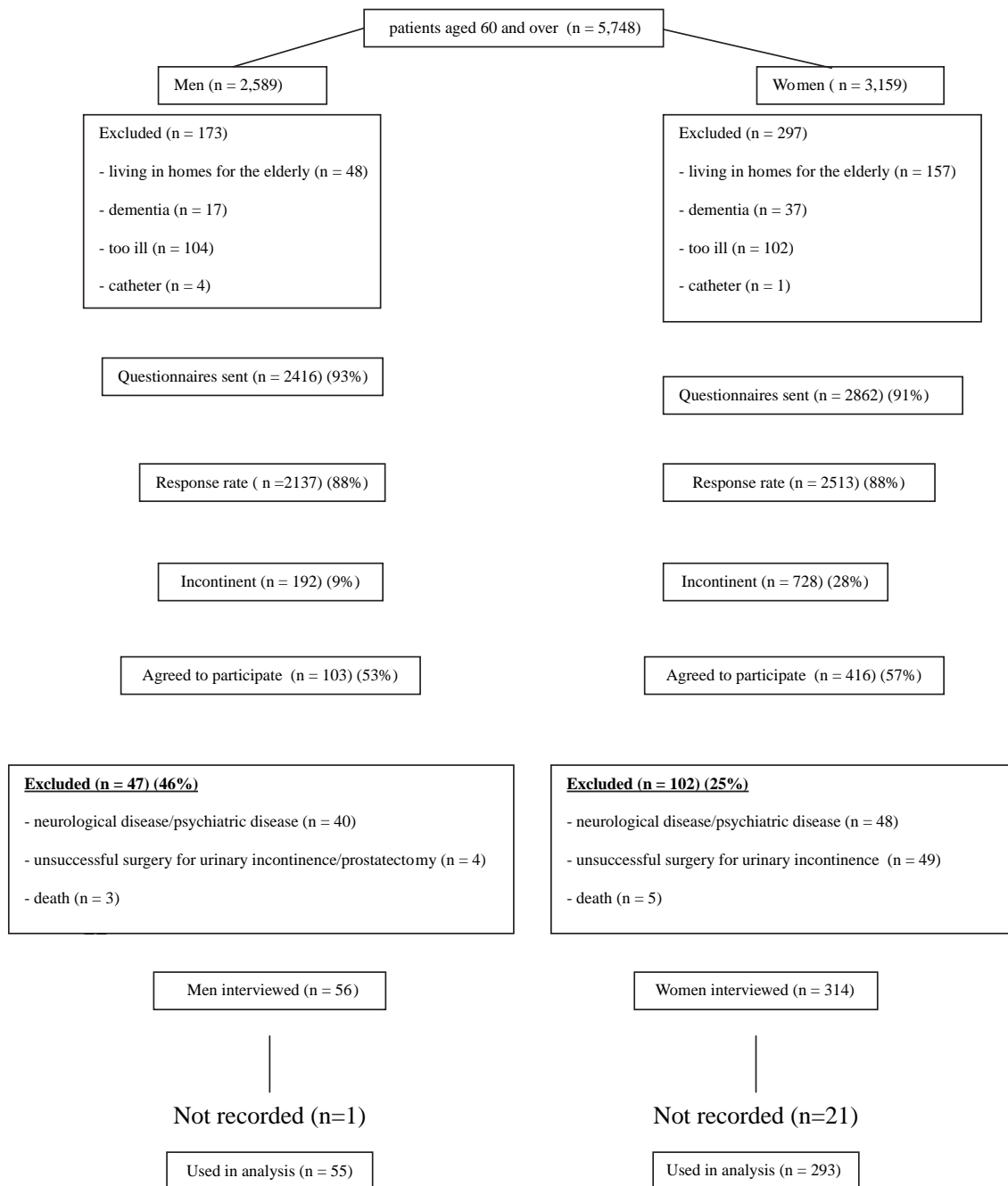


Figure 1. Flowchart of the study population

multiple-choice question; the possible answers were: none (=0 points), some (=1 point), moderate (=2 points) and severe (=3 points).

We also performed in-depth interviews that encouraged patients to tell us about embarrassing aspects and because it could identify hypotheses that were not initially anticipated. The same trained interviewer carried out all interviews. The interview consisted of the following topics: does UI impact on your daily life and if so what are the most troubling aspects? All the answers were recorded on tape.

Statistical analysis

Qualitative data on the impact on daily life were fully typed out and analysed with the help of the ATLAS ti software program (Visual Qualitative Data Management Model Building Version WIN 4.2). The qualitative approach used in this study was based on the categorizing process in grounded theory where categories are derived through open and selective coding [18]. Two researchers did the open coding independently of one another. Quantitative data were analysed with the help of SPSS for Windows.

We calculated the mean of each question, of each domain, and of the total IIQ score. The means were transformed into continuous scales ranging from 0 to 100. Statistical differences between male and female patients were analysed by the chi-squared test between patients who experienced impact and those who did not *and* between the four groups of patients who experienced no impact, some impact, moderate impact, and severe impact. The sex differences between the domains were analysed by the *t*-test. We used $p < 0.01$ to indicate statistical significance. If 50% of the questions or more in the domain were not applicable, the data of these cases were not included in the analysis of the mean of the domain score.

Results

The research population comprised 56 male and 314 female patients with uncomplicated UI. The patients who indicated on the questionnaire that they have UI and who did not want to be interviewed were older in age and had more comorbidity but did not differ in gender. Twenty-two patients dropped out because of a technical error that occurred during the recording of the qualitative part of the interviews (see Figure 1). The analysis consequently involved the data on 55 men and 293 women.

Characteristics and urogenital symptoms in the population

Male and female patients differed significantly in the type and severity of UI (Table I) experienced. In men urge incontinence was the most common type compared with mixed incontinence in women. The incontinence was more severe in women compared with men.

Impact of urinary incontinence

The IIQ indicated that UI affected emotional well-being in particular (Table II). Half to one-third of the patients felt nervous/anxious, embarrassed, or frustrated because of their incontinence. The impact score for the items fear, anger, embarrassment, and sleeping problems were significantly higher in men than in women.

In the social domain, the fear that someone could see the UI, "clothing", scored the highest impact, reported by 20% of the male and 10% of the female patients (see Table II). The impact score was significantly higher in men. Some 13% of the men were also afraid that someone could smell their UI. This item scored a very low impact for women.

Concerning travel, 31–37% of the patients reported feeling restricted going to places where they were not sure about the availability of a toilet, with a high impact score of 26.8 in men and 19.5 in women. Men in particular felt restricted when it came to travelling for longer distances (see Table II).

Finally, about 10% of the patients restricted their physical activities. The impact score for almost all items was higher in men than in women except for three items on the physical activities list: physical recreation, household chores, and repair work in home or garden.

The greatest effect of UI on daily life reported could be divided into "being unable to control the incontinence" and "feeling forced to take several precautions". One in 10 patients did not experience any impact.

Box1: Quotes related to "being out of control"

"I just can't control it."
 "It can always happen despite all of my preparations."
 "I'm afraid that someone can see I'm wet or can smell it."
 "When you feel the urge to go to the toilet I have to run because otherwise I'm too late."
 "Despite the pads I feel always wet and dirty."
 "I'm always afraid of having a fit of coughing, because when that occurs I'm totally wet."
 "Incontinence makes me feel old."

Two-thirds of the men and 4 out of 10 women felt unable to exert control over their incontinence (see Box 1), which resulted in fear of an accident and fear of discovery of the UI, especially in the case of urgency and frequency ($n = 118$).

Box2: Quotes related to "feeling forced to take several precautions"

"Every time it happens I have to change pads or sometimes my clothes. This is especially annoying when I am out. I always have to take clothes and pads with me and I'm always looking for a toilet."
 "I need the security that a toilet is nearby. That's especially a problem when I go to places where I'm not sure if there is a toilet available. This means I avoid leaving home."
 "When I go shopping I plan the route on that way so that there is always toilet nearby."
 "I also have to change pads at night, that is really annoying."
 "I cannot be without pads, the need to wear them is terrible."
 "I'm less able to carry or lift as part of daily activities because otherwise I am wet."

Forty-two patients expressed feelings of disgust at being wet and dirty almost all the time and the feeling of becoming old.

Table I. Characteristics of the study population.

Characteristics	Male (%) n = 55	Female (%) n = 293
Mean age, years	70.9	71.1
Marital status		
Married, cohabiting	46(84)	184(63)
Single	2(4)	9(3)
Widow/widower	6(10)	95(32)
Divorced	1(2)	5(2)
Education level		
Low ^a	26(47)	192(66)
Medium ^b	18(15)	69(24)
High ^c	11(20)	32(10)
Duration of incontinence		
< 6 months	0(0)	0(0)
> 6 months to < 2 years	8(15)	32(11)
2–5 years	22(40)	102(35)
> 5 years	25(45)	159(54)
Type of incontinence*		
Stress	3(5)	56(19)
Urge	38(70)	58(20)
Mixed	6(11)	168(57)
Other	8(14)	9(4)
Severity of incontinence*		
Mild	10(18)	14(5)
Moderate	44(80)	220(79)
Severe	1(2)	49(16)

^aNone/basic/lower professional; ^bmedium general preparatory/medium professional; ^chigher general preparatory/higher professional/university. *Chi-squared test for sex differences, $p < 0.001$.

One-fifth of the men and half the women reported the precautions they had to take as the greatest burden (see Box 2) ($n = 80$). Trying to prevent odour, wetness, and discovery, patients felt forced to change pads and/or clothes frequently and therefore they always had to take pads and/or extra clothes with them. In addition, they always needed the security of a toilet nearby. Changing pads or clothes at night was considered particularly unpleasant.

Furthermore some patients considered the necessity off having to use pads distressing ($n = 56$) and finally restrictions in physical activities were also mentioned ($n = 14$).

Discussion

Most studies that have evaluated the consequences of UI on the quality of life have been performed in selected samples of clinical patients and only a few studies have measured the impact of UI in men as well in women with a disease-specific health-related quality of life questionnaire. As far as we know this is

the first study concerning the impact of UI on elderly men and women in the general population using a disease-specific questionnaire combined with a qualitative approach.

UI affects emotional well-being more than anything else. Half to one-third of the patients, more men than women, experienced feelings of anxiety, frustration, and embarrassment. Men also experienced more sleep disorder and feelings of depression. Travelling, going to places where they do not know whether there is a toilet present, and shopping are the outdoor activities most restricted by UI. The men in particular made efforts to prevent odour and felt UI imposed clothing restrictions. About 10% of the patients felt restricted in physical activities. A substantial number of the patients also indicated that UI did *not* interfere with their daily life. This is probably the reason why some are reluctant to seek help. The interviews did not provide any indication that UI is considered a taboo by patients.

The most distressing consequences of UI were said to be being out of control and feeling forced to take several precautions to prevent an “accident”.

Previous studies asserted that those patients who are most successful at managing incontinence are able to “pass for normal” and remain socially and physically active [19–21].

The way in which people respond to stressful events, in this case UI, is called coping. Changing pads or clothing, locating and staying near a toilet, reorganizing daily activities, and taking clean clothes or protective pads with them when they leave the house are considered a problem- and activity-oriented way of coping. A passive-emotional-oriented way of coping is avoiding situations and feeling angry or frustrated. Passive-emotional-oriented coping strategies have a significant correlation with a reduction in well-being and active-problem-oriented coping strategies improve quality of life [21]. Therefore patients with UI may benefit from active-problem-oriented coping strategies.

In general men are more used to use active-problem-oriented strategies while women apply more passive-emotional-oriented strategies [22,23]. This study shows that because of incontinence men feel more out of control and experience more emotional impact compared with women. This suggests when affected by UI men apply more passive-emotional-oriented strategies, which is contrary to general male coping strategies. An explanation for this discrepancy might be that women associate UI with pregnancy and childbirth and they consider UI a normal part of being female. Moreover, women have acquired skills whilst managing menstrual bleeding and that also might explain their more frequent and less inhibited use of pads [24,25].

Table II. Percentage of patients who indicate experiencing some, moderate, or severe impact, the impact score for each question of the IIQ, and the impact score for each domain, in male and female patients with UI (n = 348).

IIQ question	Male (n = 55)		Female (n = 293)	
	Patients who experienced impact (%)	Impact score	Patients who experienced impact (%)	Impact score
Physical activity				
Household chores	4	1.42	14*	6.00
Repair work in home or garden	8	2.66	13*	6.33
Shopping	18	6.66	20	9.66
Hobbies	11	5.00	6	3.67
Physical recreation	11	5.93	22	12.00
Physical health	5	2.38	4	1.49
Travel				
Entertainment	10	4.87	6	3.23
Travel <20 min	4	2.42	3	1.28
Travel >20 min	16	7.88	9	3.77
Going to places if you are not sure about the availability of toilets	37	26.79	31	19.49
Holidays	3	2.56	7	1.39
Employment	0	0	0	0
Social				
Church	4	1.63	4	1.84
Volunteer work	0	0	1	0.71
Having friends visit you	0	0	0	1.06
Social activities	4	3.77	3	2.17
Relationship with friends	4	1.78	1	0.53
Relationship with family	2	1.88	1	1.15
Sexual relationships	5	3.42	5*	3.80
Clothing	27	13.10	10 ^{*,**}	4.95
Fear of odour	13	7.14	1 ^{*,**}	0.42
Emotional				
Fear of embarrassment	7	6.66	1*	0.64
Emotional health	27	13.69	14	7.22
Sleep	29	16.07	14 ^{*,**}	7.43
Nervousness or anxiety	41	22.62	33	18.15
Fear	21	13.69	16	8.73
Frustration	48	26.79	32 ^{*,**}	17.30
Anger	14	10.12	12	6.26
Depression	14	4.76	5 ^{*,**}	2.55
Embarrassment	46	32.74	34	22.08
Domain score				
	Men		Women	
Physical activity	4.2		6.1	
Travel	10.5		7.5 ^{***}	
Social	4.5		1.4 ^{***}	
Emotional	17.6		11.2 ^{***}	
Total IIQ	9.3		6.5 ^{***}	

*p < 0.01 (chi-squared test of sex differences in patient who experienced impact and in those who did not); **p < 0.01 (chi-squared test of sex differences in the four groups; patients who experienced no impact, who experienced some impact, who experienced moderate impact and those who experienced severe impact); ***p < 0.01 (t-test sex differences).

The fact that as far as UI is concerned the emotional and social well-being of men is more affected than that of women is in line with a study by Fultz et al. [4]. In contrast, Dugan et al. [26] and Ouslander et al. [27] did not find any differences between the sexes; the latter studied a selected population of outpatients from an incontinence clinic.

The strengths of the study are that we combined quantitative and qualitative data to determine the

impact of UI on the several domains of daily life and at the same time examined which aspects patients find most distressing. A limitation is that, because we focused on uncomplicated UI, the number of male patients included in the study was quite low. Many men had to be excluded because of complicated neurological diseases. Furthermore, selection based on the selective response to the invitation for an interview among the people who were part of the

initial sample could have influenced the results. It may be that embarrassment was an important factor in the decision not to participate in the interview. However, previous research on the impact of UI on in middle-aged women in the Netherlands also concluded that the impact of UI on daily life seemed to be limited. In these studies too embarrassment was not a factor of importance for not seeking help [28,29].

Finally, we used the IIQ to measure the impact of UI on daily life. In the last few years several studies have been performed on the validity of this questionnaire [15–17]. The results of these studies are contradictory, especially for the use of the IIQ in clinical trials to determine the effect of treatment. Because the aim of this study was to determine the impact of UI on different aspects of daily life and to identify factors with the greatest effect the IIQ is a useful and valid instrument.

We conclude that in a large proportion of the community-dwelling elderly patients uncomplicated UI does not interfere with individuals' daily life and that this is why they do not seek help. A taboo does not appear to be an important factor in the reluctance to seek help. In about half the patients UI has a notable effect on their emotional and social well-being. Despite incontinence in men being less severe they experience more distress than women. Most men report feeling that it is impossible to control incontinence while women feel forced to take precautions and for them that is the worst aspect of incontinence. Coping strategies seem to play an important part in the impact of UI on daily life.

Because of low motivation, comorbidity, and reduced health expectation in elderly patients we have to focus our attention not only on an effective treatment for incontinence itself but also on the improvement of strategies for coping with incontinence.

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