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Urinary Incontinence in the Elderly

in General Practice

Doreth Teunissen

ZonMW sponsored this study.

This thesis has been prepared by the Department of General Practice of the Radboud University Nijmegen Medical Centre, the Netherlands, and within the programme Chronic Diseases in General Practice of the Nijmegen Centre for Evidence Based Practice (NCEBP), one of the approved research institutes of the Radboud University Nijmegen. The Department of General Practice participates in the Netherlands School of Primary Care Research (CaRe), which has been acknowledged by the Royal Netherlands Academy of Arts and Sciences (KNAW) in 1995.

Layout: Twanny Jeijnsman
Print: Ponsen & Looijen, Wageningen
ISBN-10: 90-5073-012-4
ISBN-13: 978-90-5073-012-9

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Urinary Incontinence in the Elderly

in General Practice

Een wetenschappelijke proeve op het gebied van de
Medische Wetenschappen

Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de Rector Magnificus prof.dr. C.W.P.M. Blom,
volgens besluit van het College van Decanen
in het openbaar te verdedigen op dinsdag 7 maart 2006
des namiddags om 3.30 uur precies
door

Theodora Alberta Maria Teunissen

Geboren op 22 januari 1966

te Venhorst

Ponsen en Looijen, Wageningen

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1

Introduction

Introduction

This thesis focuses on men and women aged 60 years and over with urinary incontinence (UI) in the general population. It describes the prevalence, the discrepancy between the high prevalence and the relative low consultation rate, the applicability of the UI guideline and the attitude of GPs to elderly patients with UI.

My personal interest in the subject of this thesis arose from the discrepancy between the high prevalence of UI in the elderly and their relatively infrequent consultation for this health problem I experienced in my daily work as general practitioner (GP). I was surprised by this discrepancy because UI seems to me a very unpleasant condition which people might seek help for. Evaluation of help seeking behaviour is particularly important in circumstances that stand in the way of people seeking help, such as embarrassment and cognitions.

The high spending on incontinence material for the elderly in the community suggests that the prevalence of UI is high. In 1999, in the Netherlands an estimated 85 million Euros (58 million Pounds) was spent on incontinence material and this is excluding the materials used in nursing homes.¹ Several studies have reported the prevalence of UI in the elderly in the community with a large variation: 3.7-55%.²⁻¹⁰ But a problem with most of these studies into the community dwelling elderly was a lack of generally accepted definitions of the incontinence. Knowing the prevalence of UI will help to pronounce its relevance for further research in the future. This generated the first research objective of this thesis, i.e. to establish the prevalence of UI in elderly people in the community.

We know from other conditions of the existence of a clinical iceberg, with many people with symptoms not approaching professional caregivers.¹¹ The process that brings people to seek medical help is complex and depends on multiple factors, such as patients' perception of their health status, attitudes towards illness and the availability of services.

Hence not only the condition determines whether patients seek help, but also the patients' personal ideas, attitudes and coping methods play an important part in this decision.

To explore the reasons why elderly patients with UI do or do not present health problems to their GP may explain the discrepancy between the availability of adequate treatment and the low percentage of people taking advantage of this. One of the factors that play a role in help-seeking behaviour is the impact of UI on the individual's daily life. Health related quality of life of patients with UI not only affects the patient's ability and willingness to seek out therapy but also the ability to benefit from treatment. Understanding help seeking behaviour and the impact of UI on daily life not only explains the discrepancy but may also help to identify elderly patients with urinary incontinence who wish to receive treatment better. All the factors mentioned generated this thesis' objective of establishing factors associated with help seeking and the experienced impact of UI on daily life in the elderly.

In general, men and women differ in help-seeking behaviour and experienced impact of several conditions. Men consult their GP less frequently, wait longer before they seek help, consistently do not present psychosocial problems and distress, and their morbidity is associated with stronger forms of illness and disability compared to women.¹²⁻¹⁶ One can also expect differences between the sexes when it comes to seeking help in the event of UI, especially considering the differences in pathophysiology of UI in men and women. It is important to explore these differences between men and women in order to approach male patients differently from female to optimize quality of care. That is why this thesis also focuses on differences in the impact of UI between the sexes and help-seeking behaviour.

Over the past two decades an increasing number of studies have been carried out into UI in the general population. This research made it clear that UI can be managed very well by primary care. As a consequence, treatment of UI became a task for GPs.¹⁷⁻¹⁸ UI guidelines for

primary care have been developed in various countries, including the Netherlands.¹⁹⁻²⁰ Another reason for undertaking this thesis was that in my work as a GP, I noticed that it is not easy to treat elderly patients with UI according to the UI guideline recommendations.

It is a well-known fact that in general the drawing up of guidelines does not guarantee their application in practice.²⁴ It is unclear to what extent the guidelines on UI are actually adhered to by GPs. Sandvik et al's study into part of the prevailing management of UI in women by Norwegian GPs found that GPs had carried out gynaecological examinations in 54% and urinalysis in 73% of the patients.²⁵ Older patients received pads, and to a certain extent drugs, but in comparison to younger patients they did not get less pelvic floor exercises, were referred to a gynaecologist less often and surgical intervention was proposed less often. Penning-van Beest et al studied the treatment of women with UI in the Netherlands.²⁶ They found that only 13% of the women with newly identified UI were actively treated for their incontinence. The adherence to the UI guideline in the elderly and the reasons why actual practice differs from (guideline) proposed care has not been investigated until now. That in the elderly the application of the UI guideline is not optimal might in part be due to the fact that most evidence of diagnosis and treatment of UI is based on studies on middle-aged women. It is unclear to what extent these findings can be translated to elderly people with UI. This is why this thesis investigates the effectiveness of conservative therapy in the elderly with UI. Alongside the applicability of the UI guideline, GPs' approach to the elderly with UI also depends of their attitudes towards and knowledge of UI, data on the application and possible limitations of guidelines in everyday practice, which are essential for optimizing care. It is to be anticipated that the low level of medical treatment sought by elderly patients with UI needs in the practice population will remain unmet, but there could be other problems, for example, the GP's attitude towards the elderly resulting in substandard care for

patients with UI. This is why the application of the UI guideline, GPs' reasons for deviating from the recommendations and GPs' attitudes towards UI in the elderly were analysed.

Gaining more insight into this thesis' themes will help to determine where to direct our attention in the future. The aim is to provide quality care to elderly people with UI on the one hand, and to prevent unnecessary medicalisation on the other.

Besides my personal interest in the subject, UI is a rising problem in society with substantial financial implications. Over the coming decades, the total number of patients with UI will increase considerably due to the ageing of the population and the high prevalence of UI in the elderly. GPs will increasingly be confronted with elderly patients with UI.

Structure of the thesis

Because of the lack of a population-based survey using a well-defined definition of incontinence in independently living elderly people, we performed an epidemiological cross-sectional study. In this part of the thesis faecal and combined faecal-urinary incontinence was also included, as the knowledge about faecal incontinence prevalence rates and its impact on patients' well being is even more scarce (Chapter 2). Our research question was: *how prevalent is urinary, faecal- and double incontinence in men and women of 60 years and older in the general population?*

In the UI guideline, exercise therapy is the first choice in urge, stress and mixed incontinence but is this effective for the elderly? Most previous studies on the effectiveness of exercise treatment for UI were carried out among younger populations. In Chapter 3 we describe a systematic review: *what is the effectiveness of conservative treatment for the elderly with UI?*

Because we want to explore the discrepancy between the high prevalence of UI in the elderly and the low number of patients who seek help Chapter 4 reports the results of research into the question: *what reasons do elderly patients have to present or not present urinary incontinence to their GP? It addresses patient-specific and disease-specific factors.*

In Chapter 5 we analyse differences between the sexes in help-seeking behaviour. In general, men and women differ in help-seeking behaviour and this can also be expected to reflect on the instances in which help is sought for UI, especially given the different pathophysiology of UI in men and women. The research question was: *what are sex differences in help-seeking behaviour in elderly people with UI focusing on disease and patient-specific factors?*

Because the impact of health problems on the quality of life may interfere with help-seeking behaviour and motivation for therapy, Chapter 6 explores *the impact of UI on the quality of life for elderly men and women in the general population and to identify factors with the greatest effect.*

The quality of care of elderly patients with UI also depends on the applicability of the existing guidelines and the attitudes of GPs to incontinence. Chapter 7 describes why and when GPs did not follow the recommendations of the UI guideline. This focused on the bottlenecks to the implementation of the UI guidelines for the elderly in daily practice. Prior to the study, the participating GPs received training on the UI guideline because we wished to study the feasibility of the guideline in daily practice and not deviations from the recommendations due to lack of knowledge. The research question was: *to what extent do the GPs act in accordance with the UI guideline, and which GP and patient factors play a role in the decision to deviate from the recommendations?*

GPs' approaches to the elderly with UI depend not only on the applicability of the UI guideline but also on GPs' attitudes to elderly patients with UI. Therefore we performed focus group discussions (Chapter 8) on *what are general practitioners' current attitudes to UI in elderly patients, and what are their experiences with the application of the guideline in daily practice?*

Finally, Chapter 9 summarises and discusses the most important findings of the set of sub-studies.

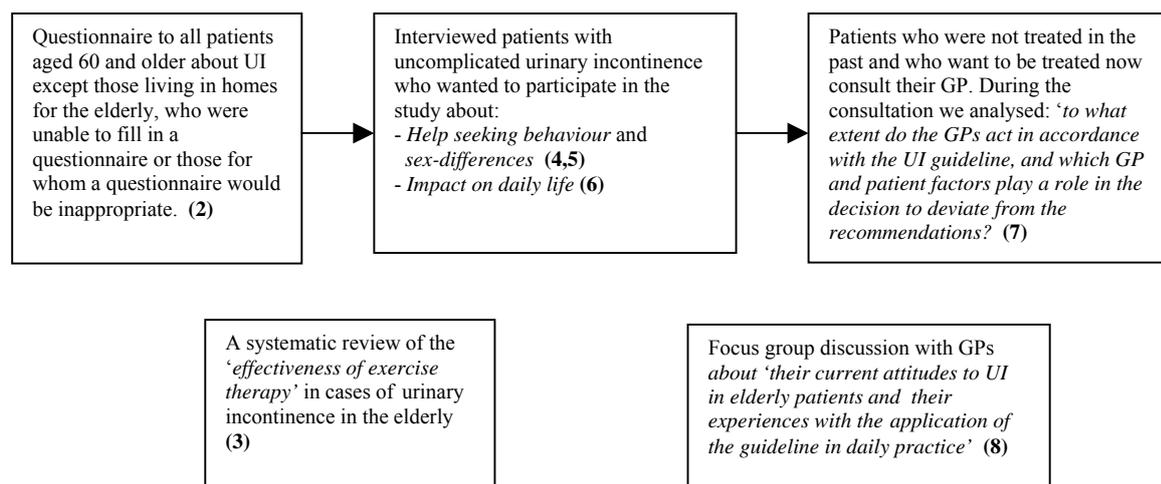
Study design

The subjects of the first study into the prevalence of UI (Chapter 2) were patients aged 60 years and older from nine general practices in the Nijmegen Monitoring Project, the academic registration network of the Department of General Practice of the University of Nijmegen.²⁷ The GPs excluded patients living in homes for elderly, patients who in their opinion were unable to fill in a questionnaire, (who had Alzheimer's disease for example) or for whom they thought a questionnaire would be inappropriate at this time (for example severely ill people) and patients with a urinary catheter. The selected patients received an anonymous questionnaire followed two weeks' later by a reminder. The definition of UI we used was based on the definition in the Guidelines on Urinary Incontinence laid down by the Dutch College of general practitioners.¹⁹ UI was defined as involuntary loss of urine twice or more a month, post-micturition dribbling in men was not considered a symptom of incontinence, faecal incontinence as involuntary loss of faeces twice or more a month and double incontinence as involuntary loss of urine and faeces twice or more a month.

Patients with UI who indicated on the questionnaire that they were willing to participate in the follow-up study were the subjects of the studies about help-seeking and the impact of

UI, which were conducted on the basis of interviews at their homes (Chapter 4-6). Because the study focused on uncomplicated UI in community dwelling elderly, patients with a neurological or psychiatric disorder and patients who had previously undergone unsuccessful surgery for urinary incontinence were excluded from this part of the study. During these interviews we collected: 1) *quantitative* data about background characteristics and validated questionnaires about the type and severity of the UI, the existence of incontinence related symptoms and the impact on daily life; and 2) *qualitative* data about help seeking behaviour and the impact experienced.

Figure 1: Study design



The numbers in the figure indicate the number of the chapter that deals with the results

All patients who had been interviewed and who had not been treated with extensive exercise therapy in the past and still wanted to be treated, formed the study population for research into the application of the UI guideline, (Chapter 7). They were advised to visit their GP for evaluation of the UI. Part of the study we collected; 1) the data of the self-registration forms. The form existed of 24 items concerning history taking, the diagnosis and treatment of

UI and was derived from the UI guideline by a panel of experts. Each GP completed the form after each consultation; and 2) *qualitative* data about the reasons for their decision to not adhere to the guideline's recommendations.

Independently of the previous part of the study we selected thirteen GPs of different ages, genders, practice settings and without a specific affinity to the problem incontinence to participate in the focus groups (Chapter 8).

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2

Prevalence of urinary-, fecal and double incontinence in the elderly living at home

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Published in: *Int Urogynecol J* 2004; **15(1)**:10-3.

Abstract

The aim of this study was to evaluate the prevalence of urinary-, fecal and double incontinence in the elderly, through a population based cross-sectional survey. The study included all patients aged 60 and over of nine general practices in the Nijmegen Monitoring Project. Patients living in a home for the elderly were excluded, as well as patients with dementia, patients who were too ill to participate and patients with a catheter. There were 5278 selected patients who received a postal questionnaire. Of these, 88% returned it. Nineteen percent of the respondents had involuntary loss of urine twice a month or more, six percent loss of feces and three percent both. The prevalence of urinary -, fecal - and double incontinence increased with age in both men and women, and especially in men in the oldest age group. Urinary incontinence was more prevalent in women than in men. The prevalence of fecal incontinence showed no sex differences, but the type of fecal incontinence did differ between men and women. In men loss of mucous was twice as common as in women. Double incontinence was also equally prevalent in men and women, except in the age group 65-74 years. In conclusion, urinary-, fecal and double incontinence are common conditions in the community-dwelling population. The prevalence rates increased with age. Urinary incontinence was more prevalent in women. There were no sex differences in the prevalence of fecal incontinence but the type of fecal incontinence was different in men and women.

Keywords: Double incontinence, elderly, fecal incontinence, prevalence, sex differences, urinary incontinence.

Introduction

Incontinence may be a cause of great discomfort, embarrassment and loss of self-confidence, and may interfere with daily life, general health, and the overall quality of life.^{1,2} Incontinence may also lead to possible rejection on the part of a relative and may therefore be an important factor in the decision whether or not to institutionalise an elderly person. Several studies have determined the prevalence of urinary incontinence (UI) and fecal incontinence (FI) in nursing homes. The reported prevalence rates are approximately 50% for UI³ and 20-40% for FI.^{4,5} Studies into the prevalence of UI and FI in older people living at home are relatively scarce. The prevalence rates of UI in the elderly in the community range between 3,7 and 55% (Table 1).⁶⁻¹⁸ The great variability is attributable mainly to methodological differences between the studies, use of different definitions of incontinence and differences in study samples.

Studies into the prevalence of fecal incontinence in the older general population are even more infrequent and prevalence rates range between 1-19,4% (Table 2).^{5,12,19-21} The prevalence of double incontinence (DoI) in the community-dwelling elderly has not previously been investigated.

Incontinence is important because of the effects on health and quality of life, and also because of economic costs. Conservative therapies such as pelvic floor muscle training and bladder training are very successful also in the elderly.²²⁻²⁵ Nevertheless, only half of the number of people with symptoms of incontinence seek help.²⁶ Knowing the prevalence of incontinence will help us decide on the relevance for further research with regard to causes, management and prevention. Because of a lack of population based surveys using a well-defined definition of incontinence in the elderly, we decided to perform this epidemiological study in the Netherlands.

The aim of this study was to estimate the prevalence of urinary-, fecal- and double incontinence in men and women aged 60 years and older in the general population.

Method

In the period January 1999 to August 2001 we carried out a cross-sectional study in the eastern part of the Netherlands. Subjects were patients aged 60 years and older of nine general practices in the Nijmegen Monitoring Project, the academic registration network of the Department of General Practice of the University of Nijmegen.²⁷ These practices were computerised and used fixed patient-lists. Patients who lived in homes for the elderly were excluded from the study, as well as patients with dementia, patients who were too ill to participate in the study and patients with a catheter. The selected patients received an anonymous questionnaire, with a reminder after 2 weeks. The definition of UI we used is based on the definition of the Guidelines on Urinary Incontinence of the Dutch College of General Practitioners.²⁸ UI was defined as involuntary loss of urine twice or more a month, FI as involuntary loss of feces twice or more a month, and DoI as involuntary loss of urine and feces twice or more a month. In case of UI we asked the following questions: “1) *Do you have involuntary loss of urine twice or more a month?* ” For men who answered yes we asked: “2) *is the involuntary loss of urine only a few drops after voiding?*” We excluded men with only postvoid dribbling because this problem requires a different type of management and is not considered as urinary incontinence. In case of FI we asked: “3) *do you have involuntary loss of feces twice or more a month?* 4) *If yes, are the feces solid, liquid or mucoid of consistency?*” A positive answer to questions 1 and 3 was defined as DoI.

Data from the questionnaires were analysed in five groups. Differences between the five groups and sex differences were calculated by using the Chi square test.

Results

The nine general practices who participated contained of 5748 patients aged 60 and over: 2589 men and 3159 women. After exclusion, 5278 questionnaires were sent (Table 3). The

overall response rate was 88%; the response was similar in men and women and in the different age groups.

Nineteen percent of the elderly population had involuntary loss of urine, 6 % of feces and 3% both (Table 4). The prevalence for UI, FI and DoI increased with age for both men and women.

Urinary incontinence in men was two to three times lower than in women. The prevalence of fecal incontinence showed no gender difference, but the severity of fecal incontinence did differ in men and women. In men loss of mucoid stool was significantly more prevalent than in women (Table 5). The prevalence of double incontinence was also similar in men and women except in the age group 65-74 years, where it was higher in women.

Focussing on patients with UI, one-fourth of the men and one-seventh of the women were also suffering from FI.

Discussion

Urinary incontinence is very common in the elderly living at home: 29% in women and 9% in men. Five previous studies investigated the prevalence of UI in the general population using a well-worded definition.^{6,8,12,13,16} Four of them had much lower response rates as we had. The response rate of 88% in our study was high. A likely explanation for this is that each patient received the questionnaire from their own general practice, with an invitation-letter from their own GP to participate. Maggi e.a.¹³ also had a high response of 88% in their survey. Because the use of different definitions and different spread of ages in the study samples the overall prevalence rate in the different surveys were not comparable. Because the prevalence of UI increased with age, if the spread of age in the study sample were not equal the prevalence rate should be different.

The prevalence of 7% for FI in this study showed that FI is also common in older people, especially in the age group 80 and over. Previous community-based prevalence studies in the elderly by Nakanishi e.a.¹⁹ and Talley e.a.²⁰ found comparable prevalence rates of FI. Thomas e.a.²¹ found much lower prevalence in men and women, but in FI the prevalence also increased with age, so the different surveys could not be compared.

An even more terrible condition is DoI. We were not able to find a previous survey regarding the prevalence of DoI. The estimate of 3% appears rather low but, focusing on patients with UI, one-fourth of the men and one-seventh of the women also suffered from FI.

A two times higher prevalence rate of UI in women compared to men corresponds with other studies.^{6,10,15-18} Women are more at risk of developing UI than men because of their different anatomy, especially the weaker structure of their proximal urethra and the hypermobility of the bladder outlet.

The same prevalence rate of FI in men and women in this study is remarkable. In most studies FI is more frequent in women than in men, but all these studies are based on a population younger than 65 years. In this younger group obstetric injuries to the pudendal nerve or sphincter muscle are described as an important risk factor. At an older age other factors seem to be important. Also, Nakanishi e.a.¹⁹, Talley e.a.²⁰ and Thomas e.a.²¹ found the same prevalence in elderly men and women.

Another important finding in this study is the difference in severity of fecal incontinence in men and women. In men loss of mucoid stool is more common and loss of liquid stool is less common compared to women. This finding suggests another pathophysiology for FI in older women than in older men. We have no clear explanation for this and further studies are needed.

The limitation of this study was that the questionnaire we used was not validated, in particular the question about the severity of FI.

In conclusion, UI, FI and DoI are very common conditions in the older general population. About half of patients with UI do not seek help, and we do not know why. Conservative treatment of UI has proved to be successful.²²⁻²⁵ Little is known about the effect of conservative management of FI in the elderly, nor how many of them seek medical advice. Further studies into the reasons for not seeking help and the effect of conservative management of FI in older community-based people are needed.

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Table 1 Previous studies about the prevalence of urinary incontinence in community dwelling elderly

First Author, year	age	M=male; F=female (n=number of patients)	Definition	Prevalence
Branch [8] '94	>65	M+F (n=1590) ¹	Once or more a month	17% (M/F?)
Brockelhurst [6] '93	>60	M+F (n=4007) ²	Last week	3,7% M; 8,3% F
Damian [9] '98	>65	M+F (n=589) ²	Six times or more a year	15,5% m/M; 15,5% F
Diokno [10] '86	>60	M+F (n=1955) ²	Six times or more a year	18,9 M; 37,7 F
Jitapunkul [11] '98	>60	M+F (n=703) ²	Ever	22,2% (M/F?)
Kok [12] '92	>60	F (n=8967) ³	Two times a week or more	23,5%
Maggi [13] '01	>65	M+F (n=2398) ³	Less then once a month One or two times a month Every week Every day	31,6% M; 26,5% F 13,9% M; 14,5% F 17,7% M; 13,6% F 36,8% M; 45,4% F
Molander [14] '90	>55	F (n=10000) ³	Ever	23%
Nygaard [7] '96	>65	F (n=2025) ³	Ever	55%
Teasdale [15] '88	>65	M+F (n=843) ³	Once a 6 month or more	22% M; 37% F
Thomas [16] '80	>65	M+F (n=1562) ³	Two times or more a month	6% M; 11% F
Tseng [17] '00	>65	M+F (n=504) ²	Ever	15% M; 27,7% F
Vetter [18] '87	>70	M+F (n=1541) ³	Ever	7,3% M; 18,2% F

¹Telephone interview²Interview ad home³Postal questionnaire**Table 2 Previous studies about the prevalence of fecal incontinence in community dwelling elderly**

First Author, year	Age	M=male; F=female (n=number of patients)	Definition (involuntary loss of)	Prevalence
Johanson [5] '96	>70	M+F (n=6959) ¹	stool/soiling, ever	19,4%
Kok [12] '92	>60	F (n=8967) ³	Faeces, ever	16,9 F
Nakanishi [19] '97	>65	M+F (n=1405) ²	soil yourself, twice or more a month	8,7% M; 6,7% F
Talley [20] '92	>65	M+F (n=328) ³	Stool, once a week or more	4% M; 3% F
Thomas [21] '84	>65	M+F (n=1562) ³	Feces, two times a month or more	1% M; 1,3% F

¹Telephone interview²Interview ad home³Postal questionnaire**Table 3 The study population**

	Men	Women	Total
60 years and over	2589	3159	5748
Excluded	173	297	462
- Living in homes for the elderly	48	157	205
- Dementia	17	37	54
- Too ill	104	102	206
- Catheter	4	1	5
Questionnaires	2416 (93%)	2862 (91%)	5278 (92%)
Response rate	2137 (88%)	2513 (88%)	4650 (88%)

Table 4 Prevalence of urinary (UI), fecal (FI) and double incontinence (DoI) in % (95% CI)

Age	UI			FI			DoI		
	<i>UI men</i> % (95% CI)	<i>UI women</i> % (95% CI)	<i>UI total</i> % (95% CI)	<i>FI men</i> % (95% CI)	<i>FI women</i> % (95% CI)	<i>FI total</i> % (95% CI)	<i>DoI men</i> % (95% CI)	<i>DoI women</i> % (95% CI)	<i>DoI total</i> % (95% CI)
	1	2	3	1	2	3	1	2	3
60-64	5 (3,6-6,8)	22 (19,2-25,1)*	14 (12,3-15,9)	6 (4,4-8,1)	4 (2,8-5,7)	5 (4,0-6,3)	1 (0,5-1,8)	3 (1,9-4,6)	2 (1,4-2,8)
65-69	6 (4,3-8,2)	26 (22,6-29,7)*	16 (14,0-18,2)	6 (4,2-8,4)	5 (3,5-7,1)	5 (3,9-6,4)	1 (0,5-2,0)	4 (2,6-6,0)*	3 (2,1-4,3)
70-74	8 (5,6-11,3)	29 (25,1-33,3)*	20 (17,4-22,8)	8 (4,6-11,3)	7 (5,0-9,7)	8 (6,3-10,1)	2 (1,0-3,9)	5 (3,3-7,4)*	4 (2,8-5,6)
75-79	14 (10,2-18,9)	36 (30,9-41,5)*	26 (22,6-29,7)	9 (5,9-13,3)	8 (5,4-11,5)	8 (6,1-10,5)	4 (2,1-7,2)	7 (4,6-10,4)	6 (4,2-8,4)
>80	21 (14,7-28,9)	38 (32,4-44,2)*	33 (28,5-37,9)	16 (10,4-23,7)	8 (5,1-12,1)	10(7,4-13,4)	6 (2,8-11,9)	6 (3,6-9,7)	6 (4,0-8,9)
Total	9 (7,4-10,9)	29 (27,2-30,9) *	19 (17,9-20,2)	7 (6,0-8,2)	6 (5,1-7,0)	6 (5,4-6,7)	2 (1,5-2,6)	4 (3,3-4,8) *	3 (2,6-3,5)

¹ chi²test relation between age and incontinence in men, sign (p<0,01) UI, sign (p<0,05) FI, sign (p< 0,05) DoI.

² chi²test relation between age and incontinence in women, sign (p<0,01) UI, sign (p<0,05) FI, sign (p< 0,05) DoI.

³ chi²test relation between age and incontinence in the total group, sign (p<0,01) UI, sign (p<0,05) FI, sign (p< 0,05) DoI.

* chi²test difference between men women significant for this age group (p<0.05).

Definition of UI (twice or more a month involuntary loss of urine)

Definition of FI (twice or more a month involuntary loss of feces)

Definition of DoI (twice or more a month involuntary loss of feces *and* twice or more a month involuntary loss of feces)

Table 5 Severity of fecal incontinence

<i>Sex</i>	<i>Solid stool</i>	<i>Liquid stool</i>	<i>Muroid stool</i>
Men ¹	41 (30%)	13 (10%) *	80 (60%) *
Women	52 (42%)	37 (29%)	37 (29%)
Total	93 (36%)	50 (19%)	117 (45%)

* chi² test difference men-women sign (p<0,01)

¹ chi² test difference type incontinence in men compared with type incontinence in women sign. (p<0,01)

3

Treatment of urinary incontinence in the community- based elderly- conservative measures that work: A systematic review

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Published in: *J Fam Pract* 2004; **53(1)**:25-31.

Abstract

Objective: To evaluate the effectiveness of conservative treatment in the community-based elderly (aged ≥ 55 years) with stress, urge, and mixed urinary incontinence.

Design : Systematic review of before-after studies or randomized controlled trials on the effect of exercise and drug therapy in urinary incontinence.

Main outcome measures: Reduction of urinary accidents, patient's perception, cystometric measurement, perineometry, and side effects.

Search strategy: MEDLINE (1966–2001), EMBASE (1986–2001), Science Citation Index (1988–2001), The Cochrane Library and PiCarta were searched.

Results: Four before-after studies and 4 randomized controlled trials were identified. Drug therapy alone: no study of sufficient quality. Drug therapy compared with behavioral therapy, 3 studies: bladder-sphincter biofeedback reduced the urinary accidents in case of urge incontinence or mixed incontinence with 80.7%, significantly better compared with oxybutynin (68.5%) or placebo (39.4%). Adding drug to behavioral treatment or behavioral to drug treatment also resulted in significant reduction in urodynamic urge incontinence (57.5% - 88.5% vs 72.7 - 84.3%). Pelvic floor exercises alone reduced the urinary accidents by 48% (compared with 53% for phenylpropanolamine) in patients with mixed incontinence or stress incontinence. Behavioral therapy, 5 studies: bladder-sphincter biofeedback in case of urge incontinence or mixed incontinence, bladder training in case of urge incontinence and pelvic floor exercises in case of stress incontinence reduced the urinary accidents with 68% to 94%.

Conclusion: There are only a few studies of sufficient methodological quality on the effect of conservative treatment of urinary incontinence in the elderly. Behavioral therapy reduced urinary accidents; the effect of drug therapy is unclear. We recommend behavioral therapy as therapy of choice.

Introduction

The physiologic goal of treatment are strengthening urethral resistance or reducing detrusor muscle contractions. Behaviour techniques-pelvic floor exercises and bladder training – and pharmacotherapy are the treatments of choice for the elderly, provided it is possible to assess the likely health gains. Surgery, the most invasive and riskiest treatment, is usually a last resort.

Methods

The authors performed computerized searches of MEDLINE (1966–2001), EMBASE (1986–2001), the Science Citation Index (1988–2001), the Cochrane Library and PiCarta. The search was limited to publications in English and Dutch. Search terms were *elderly* and *aged* combined with *urinary incontinence* and *conservative management*, *conservative therapy*, *conservative treatment*, *bladder training*, *drug treatment*, *pelvic floor muscle training*, *behavior management*, *behavior therapy*, and *biofeedback*. We supplemented this search strategy by checking articles referenced in other publications.

The titles and abstracts were then screened for the following inclusion criteria: longitudinal cohort, before-after studies or randomized controlled trials, age ≥ 55 years, community-dwelling population, and conservative therapy.

The methodological quality of the selected studies was evaluated by a modified Delphi-2 scale (Table 1).¹⁰ Two researchers (TT, AJ) scored the studies independently; they were blinded for information on authors and journals. In cases of disagreement, the researchers met to reach consensus.

After meeting inclusion criteria, randomized controlled trials were scored from 0 to 9; before after studies from 0 to 3. A randomized controlled trial needed a score of at least 7 to

be included; a before-after studied needed a 2.5; in trials where blinding was not possible, a 4 was needed.

TYPES OF INCONTINENCE

Stress incontinence is involuntary leakage on effort or exertion, or on sneezing or coughing. Stress incontinence may result from diminished bulk and tone of perineal tissue or weakness of the pelvic floor muscle.

Urge incontinence is involuntary leakage accompanied by or immediately preceded by urgency. Causes are “deconditioned” voiding reflexes due to chronic low volume voiding, infection, or bladder stones.

Mixed incontinence is involuntary leakage associated with urgency and also with exertion, effort, sneezing, or coughing.

Results

The search yielded 157 publications; 135 studies did not meet inclusion criteria. Of the 22 remaining studies, 6 were excluded because they did not use a general population. Consequently, 16 studies were included: 6 with a before-after design and 11 randomized controlled trials.

Methodological quality

The quality scores for the 6 before-after studies ranged from 0 to 3. Two studies scored less than 2.5 and were excluded (Table 2).

Quality scores for the 11 randomized controlled trials ranged from 0 to 9. Four of the 5 studies with the possibility to blind scored <7 , and 3 of the 6 studies with no possibility to blind scored <4 ; they were excluded.^{11,18}

Results of drug and behavioral therapy

In 3 studies, the effect of medication alone or in combination with behavioral therapy was examined (Table 3).

Biofeedback is superior. Burgio et al¹⁹ studied the effect of bladder-sphincter biofeedback vs oxybutynin and placebo in 190 women with urge or mixed incontinence. Oxybutynin is an anticholinergic drug that reduces detrusor muscle contractions. Anorectal biofeedback helped patients sense pelvic muscles and taught them how to contract and relax these muscles selectively while keeping abdominal muscles relaxed. Patients were taught not to rush to the toilet as a response to the bladder sensation but relax the whole body and contract the pelvic floor. The reduction of urinary accidents in the daily bladder report was significant. This effect was significantly better in the bladder-sphincter biofeedback group compared with the drug group; the drug group had results significantly better than the placebo group.

Success with augmented therapies. Subsequently, researchers offered the patients who were not completely dry to participate in an extension study, which added drug therapy for those in the behavioral therapy group and vice-versa.²⁰ Thirty-five women participated in this study. Both groups had additional significant reductions in urinary accidents as documented in the bladder diary.

Pelvic floor exercises helpful. Wells et al²¹ compared 6 months of pelvic floor exercises without biofeedback with 2 weeks phenylpropanolamine hydrochloride, an alpha-adrenergic agonist. (In the US this product has been taken off the market.) Alpha-adrenergic agents stimulate the receptor located in the urethra, increasing urethral pressure. The subjects were 115 women with urodynamic mixed or stress incontinence. The reduction in urinary accidents was similar in both groups—48% and 53%, respectively. Also the subjective

improvement was similar. Only the digital test of the pelvic floor muscle strength was significantly better in the pelvic floor exercise group.

Results of exercise-based therapy

Five studies focused on the effect of behavioral therapy only (Table 4). Three surveys studied the effect of bladder sphincter biofeedback, 1 the effect of bladder training without biofeedback, and 1 the effect of pelvic floor exercises with biofeedback.

McDowell et al^{22,23} used anorectal biofeedback, demonstrating the abdominal pressure and pelvic floor activity to teach patients to relax abdominal muscles selectively and contract/relax the pelvic floor in case of stress, urge, and mixed incontinence. The home exercises consisted of 10 to 15 contractions of the pelvic floor muscles for 10 seconds, followed by an equal period of relaxation in a lying, standing, and sitting position, 3 times a day.

They also taught urge strategies. Patients were taught not to rush to the toilet but to relax the whole body, contract the pelvic floor, and increase their voiding interval of 2 to 3 hours.

In Burgio et al,²⁴ researchers filled the bladder after voiding; this taught patients to be aware of bladder contractions before they felt any bladder sensation, and to relax the abdominal muscles, contract the pelvic floor, and try to diminish the bladder pressure.

The conclusion of all 3 studies was that bladder-sphincter biofeedback reduced the urinary accidents for stress, urge, and mixed incontinence significantly.

Fantl et al²⁵ examined the effect of bladder training in 123 women with urge incontinence. They were asked to increase their voiding interval until a schedule of once every 3 hours was achieved, or they were admitted in a control group without intervention.

Bladder training reduced the urinary accidents significantly for all 3 types of urinary incontinence.

Baigis-Smith et al²⁶ investigated the influence of behavioral intervention in 54 patients who received pelvic floor biofeedback without measuring the abdominal pressure as in previous studies. Patients had to relax and contract their pelvic floor 50 times for 10 seconds, 3 times a day, until they experienced improvement. The number of urinary accidents reduced from 17.4 times a week to 4.2 times a week for stress, urge, and mixed incontinence.

Discussion

This review discusses 3 types of behavioral therapy for urinary incontinence: bladder training for urge incontinence (sometimes in combination with pelvic floor exercises), pelvic floor exercises for stress incontinence, and both for mixed incontinence. All 3 types of behavioral therapy reduced urinary accidents in the elderly. Remarkable is the conclusion of Fantl et al²⁵ that bladder training is also effective for stress incontinence alone. In almost all previous studies on the effectiveness of bladder training, patients with stress incontinence were excluded. More research is needed before we can recommend this therapy for stress incontinence.

Few studies met our methodological quality criteria. The selected studies were difficult to compare because of differences in treatment, methods, and outcomes. For that reason, more research with standardized outcome measures can help establish the relative effectiveness of behavioral therapy—with or without biofeedback—and to evaluate the effect of each therapy in different types of incontinence.

We found 2 methodologically good surveys about the effect of pharmacotherapy in elderly with urinary incontinence. Just 1 study focused on the effect of anticholinergic agents on urge incontinence and mixed incontinence; it found these agents less efficacious than

behavioral therapy but better than placebo. We also found 1 study on alpha-adrenergic agents for stress or mixed incontinence—their ability to reduce urinary accidents seemed comparable with pelvic floor exercise. The weakness of this study was the lack of a control group.

It was remarkable, however, that pelvic floor exercise was less efficacious compared with the other studies. We need more double-blinded randomized controlled trials to prove clinical efficacy of pharmacology in the elderly with urinary incontinence. In studies with a younger population, anticholinergic agents seem to be effective for urge incontinence, but the effect of adrenergic agents in a younger population is unclear, and has never been investigated in men.^{27–29}

In conclusion, conservative therapy is effective in elderly patients with stress, urge, or mixed incontinence. Given the effectiveness of behavioural therapy, the absence of the side effects, and the low cost and ease of practice at home, we recommend it as the therapy of choice for urge incontinence in the elderly. The effect of pharmacotherapy in the elderly is still unclear and harbours the risk of side effects and interactions particularly in elderly with multi-morbidity and multi-drug treatment. Surgical treatment should be reserved for those who do not respond to either of these.

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Table 1: Quality criteria (modified Delphi list)¹⁰

A) Was randomisation in RCT conducted in a concealed manner? Randomised and concealed (computer, table with random numbers, etc) -1, randomised but not concealed (hospital number, date of birth, length, alternation, etc) -1/2, not randomised or not clear how randomisation was performed -0.	
B) Were the groups similar at baseline regarding the most important prognostic indicators?	
<i>Major indicators</i>	<i>Minor indicators</i>
- severity of incontinence	- using diuretics
- type of incontinence	- previous surgery
- age	- education/social class
if groups are similar for all or all major indicators but one minor indicator -1, if one major indicator or two minor indicators are not mentioned where it should have been -1/2, if more than one major or more than two minor indicators are not mentioned -0.	
If the groups are significantly different ($p < 0,05$) for one or more of the major indicators -0, if the groups are sign. different for one minor indicator - 1/2, if more than one minor indicators sign. different -0.	
C) Were the following eligibility criteria specified (for inclusion in the trial as well as for the inclusion in either the study or control group)? Mental state, urinalysis, pelvic and rectal exam to identify severe pelvic prolapse (extending through the vaginal introitus) and faecal impaction, residual urine volume. All criteria specified -1, one or two criteria no mentioned -1/2, more than two criteria no mentioned -0.	
D) Was the outcome assessor blinded?	
E) Was the care provider blinded?	
F) Was the patient blinded?	
G) Were point estimates and measures of variability presented for the primary outcome measure (frequencies of urinary accidents and/or pelvic muscle activity and/or amount of urine loss and/or patient perception of treatment)? Yes 1. Particularly so -1/2, no -0.	
H) Did the analysis in an RCT include an intention to treat analysis? Yes -1, doubtful -1/2, no -0.	
I) Is the compliance rate (in each group) in an RCT unlikely to cause bias? If $> \text{ or } = 80\%$ have completed the treatment (in each group) -1, 70-80 % -1/2, $< \text{ or } = 70\%$ or not known -0.	
Before-after studies:	- the items C,G en I were scored
Before- after studies:	- total score of $> \text{ or } = 2 \frac{1}{2}$ was sufficient
RCT without the possibility to blind:	- total score of $> \text{ or } = 4$ was sufficient
RCT with the possibility to blind:	- total score of $> \text{ or } = 7$ was sufficient

Table 2: The excluded studies

First author (year) Quality scores	N =number completed (% men)	Drop- out	Age (mean, SD)	Population	Intervention + duration of intervention (design)
Bear ¹¹ (1997) 2 / 2	15 (not given)	0	Mean 68, SD not given	General	Bladder-sphincter biofeedback / control for 10-22 weeks. (B-A)
Burns ¹² (1988) 2 ½ / 1	135 (0%)	10	50-78 (62 +/-6)	General	Bladder-sphincter biofeedback / PFE / control for 8 weeks (RCT)
Burton ¹³ (1988) 2 ½ / 1	17 (22%)	5	64-78 (72, SD not given)	General	PME with biofeedback / PFE without biofeedback for 6 weeks. (RCT)
Molander ¹⁴ (1991) 2 / 2	239 (0%)	33	65-84 (72, SD not given)	General	2mg estriol orally for 2 months. (B-A)
Ouslander ¹⁵ (1993) 6 / 6 ½	81 (0%)	17	60-80 (70, SD not given)	General	4 weeks terodiline 25 mg twice a day / placebo (RCT)
Szonyi ¹⁶ (1995) 5 ½ / 4 ½	60 (8%)	8	72-98 (82 +/-6)	Not given	Bladder retraining + oxybutynin / Bladder retraining + placebo for 1 month (RCT)
Tapp ¹⁷ (1990) 4 / 5 ½	54 (0%)	16	41-87 (61 +/- 13)	Postmenopausal but selection not given	Oxybutynin 5mg four times daily / placebo (cross-over) for 2 weeks. (RCT)
Walter ¹⁸ (1982) 5 ½ / 5 ½	20 (40%)	0	64-88 (74, SD not given)	Not given	Epipronium bromide 200mg 3 times daily / placebo (cross-over) for 4 weeks. (RCT)

SD, standard deviation; B-A, before-after study; RCT, randomised controlled trail; PFE, pelvic floor exercises.

Table 3: The effect of medication in combination with or in comparison with exercised based therapy in the elderly with urinary incontinence (alphabetical)

First author (year) Quality scores	N =number completed (% men)	Drop-out	Population, Age (mean, SD)	Definition of UI (type of incontinence)	Intervention and duration (design)	Measurements and outcomes*
Burgio (1998) 7 ½ / 7	190 (0%)	7	General 55-92 (69.3 +/- 7.9)	At least 2 urge accidents per week for 3 months (urodynamic predominant UI)	Bladder- sphincter biofeedback twice weekly / 2,5 mg oxybutynin 3 times daily / placebo for 8 weeks (RCT)	1a) Biofeedback group: 15.8 -> 2.8 (mean 80.7%, SD 24,8), Drug group: 15.9 ->5.7 (mean 68.5%, SD 37,2)) Placebo group: 15.4 -> 8.2 (mean 39.4%, SD 80,0) 1b) Biofeedback group: 96.5% of was satisfied with treatment. Drug group: 54% satisfied with treatment 2) Drug group: bladder capacity increased significantly, not in placebo and biofeedback group. 4) Drug group: mouth dryness significantly more often
Burgio (2000) 3 / 3	35 (0%)	0	Subjects who were not completely dry or were not completely satisfied after the single intervention in study (3) were offered to participate in this study. 55-91 (67.7 +/- 7.5)	Not given	After behavioral training alone (study 3) add drug therapy. After drug therapy (study 3) add behavioral therapy for 8 weeks. (B-A)	1a) Behavioural therapy -> + drug: 57.5% -> 88.5% (n=8) Drug -> + behavioral therapy: 72.7% -> 84.3% (n=27) Drug -> behavioral therapy: 59.1% -> 77.1% (n=19) Placebo -> behavioral therapy: 22.9% -> 63.9% (n=34) Placebo -> drug: 44.8% -> 76.5% (n=10)
Wells (1991) 3 ½ / 3	115 (0%)	38	Open population 55-66 (66 +/- 8)	Urinary loss of any degree (urodynamic SI, UI or MI)	PFE for 6 months/ Phenylpropanolamide hydrochloride (PPA) 50 or 100 mg a day for 2 weeks.(RCT)	1a) PFE group: 48% improved PPA group: 53% improved 1b) Subjective improvement not significantly different between groups 3) Endurance peak and endurance time of contractions similar in both groups. Digital test of pelvic muscle strength was significantly better in the PFE group.

* Measurements and outcomes

- 1) Severity a) reduction urinary accidents daily bladder record b) patient's perception
- 2) Cystometric measurements
- 3) Perineometry
- 4) Side effects

SD , standard deviation ; SI, stress incontinence ; UI, urge incontinence ;MI, mixed incontinence ;RCT, randomized controlled trial ; B-A, before after ; PFE, pelvic floor exercise ; PPA, phenylpropanolamide.

Table 4: The effect of exercised based therapy in the elderly with urinary incontinence (alphabetical)

First author (year) Quality scores	N =number completed (% men)	Drop-out	Population, Age (mean, SD)	Definition of UI of (type incontinence)	Intervention and duration (design)	Measurements and outcomes*
Baigis-Smith ²⁶ (1989) 3 / 3	54 (17%)	0	General 60-86 (70 +/- 8)	At least once every 2 weeks (SI,UI,MI by history)	PFE + biofeedback until improvement. (B-A)	1a) 17.4 -> 4.2 / week (78%) for all types of incontinence 1b) 90% quality of life improved 4) Peak and duration of contraction improved significantly for all types of incontinence.
Burgio ²⁴ (1985) 3 / 2 ½	39 (23%)	0	General 65-86 (74,4 +/- 7,2)	At least once a month (urodynamic SI,UI,DI)	Bladder + sphincter biofeedback 2-4 weekly, one to 8 sessions depending on progress. (B-A)	1a) SI :30.5 ->7.5 / week (82%, n=19) DI :8.5 -> 1,5 / week (85%, n=12) UI :5.4 -> 0,4 / week (94%, n=8) 3) No changes 4) Amplitude significantly higher at the end of treatment for SI.
Fantl ²⁵ (1991) 4 ½ / 4 ½	123 (0%)	8	General 55-90 (67 +/- 8)	(urodynamic UI,SI or MI)	Bladder training / control for 6 weeks (RCT)	1a) SI :23 -> 10/week control:22 -> 19 / week (n=88) DI +/- SI: 16 -> 6 /week control: 24 -> 19 / week (n=35) DI :11 -> 5 / week control : 20-18 / week (n=14) SI + DI : 20 -> 7 / week control: 29 -> 20 / week (n=20)
McDowell ²² (1992) 3 / 3	29 (7%)	18	Self referred to the continence program or referred by physicians or geriatricians 56-90 (74,6 +/- 8,1)	At least once every 2 weeks for at least 3 months (SI,UI,MI in bladder diary)	Bladder + sphincter biofeedback twice weekly, duration depending on the patient's progress and abilities, average 5.6 sessions. (B-A)	1a) MI : (85%, n=21) UI : (68%, n=7) Total : 16.9 -> 2.5 / week (82%)
McDowell ²³ (1999) 5 / 5	93 (10%)	10	Individuals with urinary incontinence were identified from two large HHAs and asked to participate. 60-97 (76,7 +/- 7,2)	At least twice a week for at least 3 months (SI,UI,MI in bladder diary)	Bladder-sphincter biofeedback weekly / placebo (cross-over) for 8 weeks. (RCT)	1a) Treatment group : 4.0 -> 1.7 / day (median 75%), urge accidents 2.1 -> 0.9 / day; stress accidents 0.9 -> 0.3 / day Control group : 4.1 -> 3.5 / day

* Measurements and outcomes*

- 1) Severity a) reduction urinary accidents daily bladder record b) patients perception
- 2) Cystometric measurements
- 3) Perineometry
- 4) Side effects

SI, stress incontinence ; UI, urge incontinence ; MI, mixed incontinence ; B-A, before- after; RCT, randomised controlled trial; PFE, pelvic floor exercise; HHA, home health agency.

4

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

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Published in : *Br J Gen Pract* 2005; (55): 776-82.

Abstract

Background : Just a little part of the older people with urinary incontinence seeks help despite adequate treatment is available.

Objectives: 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: Qualitative and quantitative analyses of interview data.

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

Method: All the independently living patients aged 60 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 (IIQ) 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 not very serious, or because of a lack of knowledge about cause and treatment options like – comments such as ‘incontinence is age-related’ and ‘there is nothing that can be done about incontinence’. Major reasons for seeking help were perceived increase in severity or distress and the need for incontinence material.

Conclusion: 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 material, they usually do seek help.

Keywords: help-seeking behaviour; older people; urinary incontinence.

Introduction

Urinary incontinence is a common problem among the 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 women⁵. 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% to 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, 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.

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 better older patients with urinary incontinence who wish to receive treatment.

This paper analyses reasons of 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 the 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 20% and 56% of them had indicated that they were prepared to participate in a follow-up study.

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 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:

- 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 following questions.²² ‘does loss of urine occur at moments of increased pressure, for example, when sneezing, jumping or coughing?’ 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 (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 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, and voiding problems. The subjects were asked 19 questions divided into three subscales: stress symptoms (2 questions), irritative symptoms (7 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 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 concentrated on help seeking and that all answers were recorded on tape. This part of the interview consisted of asking 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. During the study we decided to also ask about patients' reason for seeking help to get still better insight in help-seeking behaviour. We did so in the last four practices.

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 chi-square 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', '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 a total of 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 just the domain of obstruction symptoms (such as pressure or pain in lower abdomen, a feeling of constant vaginal pressure, and voiding problems; these usually indicate prostatic hypertrofia 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 ...*’, ‘...*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 happened more often...’, ‘... sanitary towels were no longer sufficient ...’, ‘...it also happened when I had to cough ...’.

As in the questionnaires, the interviews showed that an increase in the number of incontinence-related symptoms was mentioned as the reason to consult 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 material: ‘...sanitary towels no longer helped and I therefore wanted incontinence material ...’.

Apart from severity and distress, cognitions appeared to be an important factor and almost half of the patients presented a rationale for not seeking help. The most important were: 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 ...’. There 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 do not emerge as a key factor in the decision whether or not to seek help for urinary incontinence.

Another important finding in this study is the large number of the patients who do 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 people²⁵. Older people also experience 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 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 well-being, 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 does not emerge as a key factor in the decision to whether or not to seek help for urinary incontinence. This is in contrast with existing literature.²⁶⁻²⁸

The lack of knowledge about cause and treatment also play 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 al¹⁴ and Dugan et al¹⁶ studied independently-living older people with urinary incontinence in the US, Stoddart et al¹⁷ and Peters et al¹⁸ did so in the UK- all these studies only use 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 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 relation 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 this study

This is one of the few studies into help-seeking behavior 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, like other general practices provide, however, 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

The 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 be informed as well 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 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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Fig. 1, Flow chart of the study population

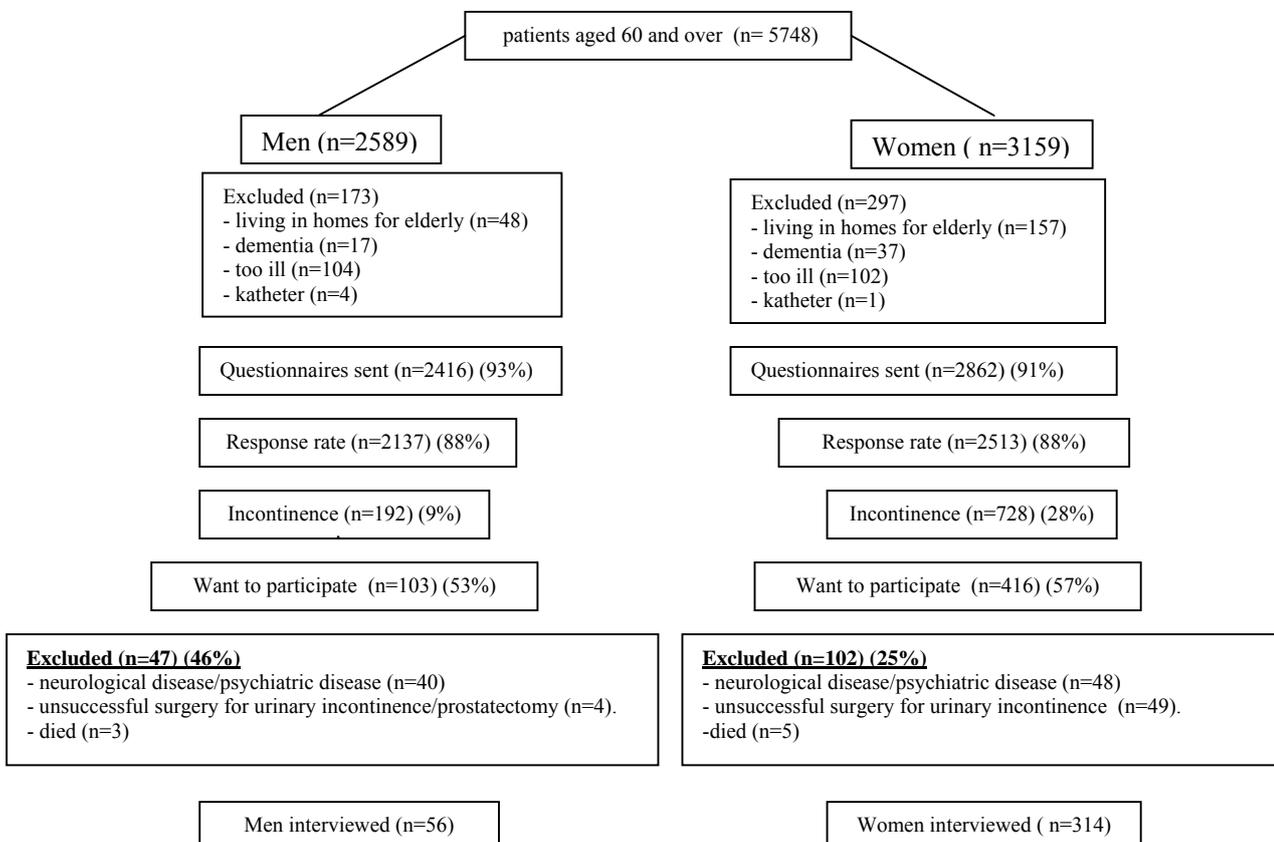


Table 1: The characteristics of the patients who did/did not seek help for urinary incontinence

	Sought help n=170(49%)	Have not sought help n=178(51%)	p value
Mean age, years	71	71	0.643
Gender			
<i>Men</i>	25 (46)	30 (54)	0.583
<i>Women</i>	145 (50)	148 (50)	
Civil status			
<i>Married, living together</i>	109 (47)	121 (53)	0.569
<i>Single</i>	7(64)	4 (36)	
<i>Widow/widower</i>	52 (52)	49 (48)	
<i>Divorced</i>	2 (33)	4 (67)	
Education level			
<i>Low¹</i>	114 (52)	104 (48)	0.213
<i>Medium²</i>	39 (45)	48 (55)	
<i>High³</i>	17 (40)	26 (60)	
Duration of symptoms			
<i>< 6months</i>	0 (0)	0 (0)	0.043
<i>>6months to <2years</i>	13 (33)	27 (67)	
<i>2-5 years</i>	58 (47)	66 (53)	
<i>>5 years</i>	99 (54)	85 (46)	
Type incontinence			
<i>Stress</i>	30 (51)	29 (49)	0.337
<i>Urge</i>	45 (47)	51 (53)	
<i>Mixed</i>	90 (52)	84 (48)	
<i>Other</i>	5 (29)	12 (71)	
Severity of incontinence			
<i>Mild</i>	10 (42)	14 (58)	0.042
<i>Mild to moderate</i>	43 (42)	59 (58)	
<i>Moderate</i>	84 (49)	88 (51)	
<i>Severe</i>	33 (66)	17 (34)	
IIQ total score (mean)	0.24	0.17	0.012*
IIQ subscale score			
<i>Physical activity (mean)</i>	0.21	0.14	0.008*
<i>Social functioning (mean)</i>	0.06	0.05	0.717
<i>Traveling (mean)</i>	0.25	0.23	0.643
<i>Emotional well-being (mean)</i>	0.45	0.29	0.000*
UDI total score (mean)	0.92	0.83	0.006*
UDI subscale score			
<i>Obstruction symptoms (mean)</i>	0.50	0.38	0.003*
<i>Irritative symptoms (mean)</i>	1.40	1.32	0.747
<i>Stress symptoms (mean)</i>	1.33	1.29	0.472
Nycturia (mean)	1.53	1.45	0.380

Statistic analyse by chi-square test for categorical variables en T-test for continuous variables

* p<0,01

¹None/basis/lower professional²Medium general preparatory/ medium professional³Higher general preparatory/higher professional/university

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 <i>mean =0</i> <i>mean 0,01-0,25</i> <i>mean 0,25-0,5</i> <i>[mean 0,5 and >]</i>	2.12 (0.89-5.05) 2.04 (0.95-4.43) 1.09 (0.46-2.63)	ns ns ns
Physical activities <i>mean =0</i> <i>[mean > 0]</i>	1.49 (0.95-2.33)	ns
Social functioning <i>mean =0</i> <i>[mean > 0]</i>	1.53 (0.89-2.61)	ns
Travel <i>mean=0</i> <i>[mean > 0]</i>	1.15 (0.74-1.77)	ns
Emotional well-being <i>mean =0</i> <i>[mean > 0]</i>	1.39 (0.88-2.19)	ns
UDI total score <i>mean 0-0,5</i> <i>mean 0,5-1,0</i> <i>[mean 1,0-4,0]</i>	1.47 (0.79-2.71) 2.49 (1.51-4.13)*	1.57 (0.53-4.69) 2.74 (1.42-5.29)*
Obstruction symptoms <i>mean=0</i> <i>[mean >0]</i>	1.19 (0.74-1.92)	ns
Irritative symptoms <i>mean=0-1</i> <i>mean 1-2</i> <i>[mean 2-4]</i>	0.50 (0.32-2.48) 0.51 (0.31-2.78)	ns ns
Stress symptoms <i>mean=0</i> <i>mean=0,1-1,0</i> <i>[mean = 1 and >]</i>	1.18 (0.68-2.02) 0.84 (0.51-1.41)	ns ns

[] the odds ratio of each characteristic is the difference between the group between brackets and the others.

* p<0.01

Ns= not significant

5

Urinary incontinence in community dwelling elderly: are there sex differences in help-seeking behaviour?

TAM Teunissen

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Published in: *Scan J Prim Health Care* 2004; **22(4)**:209-16.

Abstract

Objectives: To assess sex differences in disorder - and patient-specific factors influencing help-seeking behaviour by independently living elderly people with urinary incontinence.

Design: Qualitative and quantitative analyses of the collected data.

Setting: Patients from nine family practices involved in the Nijmegen Monitoring Project.

Subjects: Independently living elderly aged 60 or over.

Main outcome measures: The study population consisted of participants in a study on the prevalence of incontinence among elderly people. Independently living elderly people aged 60 or over from nine family practices with uncomplicated urinary incontinence were interviewed at home using a disorder-specific questionnaires and open-ended questions.

Results: In total, 56 men and 314 women were interviewed. Half of them had sought help from a general practitioner. Men sought help from their GP when they had less severe incontinence than women.

Help-seeking behaviour in women was related to the duration of symptoms (odds ratio 3.66, 95% CI 1.44-9.39), the presence of incontinence related symptoms like constant feeling of vaginal pressure and pain in the lower abdomen (odds ratio 2.69, 95% CI 1.52-4.76) and the severity of incontinence (odds ratio 1.69, 95% CI 0.99-2.88). In men help-seeking was related to the distress experienced in daily life (odds ratio 7.10, 95% CI 1.15-43.91).

Most men and women who did not seek help consider their incontinence not being serious enough, or they had inappropriate beliefs such as that 'incontinence is age-related' and 'there is nothing that can be done about incontinence'.

Conclusion: Help-seeking in women is determined by the duration of the symptoms, the presence of concomitant complaints and the severity of incontinence. In men help-seeking behaviour is mostly related to the distress experienced in daily life. In men and women the

most important reasons for not seeking help are that they consider the incontinence not serious enough and that they believe that there are no treatment options available.

Keywords: urinary incontinence; elderly; sex differences; help-seeking behaviour

Introduction

Urinary incontinence (UI) is a common problem in the elderly people, in men as well as women. The prevalence varies between 3.7 and 31% in men and 11 and 55% in women, depending on the research populations and definitions used.¹ The difference in prevalence between men and women can be explained by the sex differences in the anatomy of the pelvic and urogynecological track. Therefore the pathophysiology of UI also differs between men and women, for example the role of the prostate in male incontinence and the influence of childbirth on the pelvic floor in women.

Conservative therapies like bladder retraining, pelvic floor exercises and medication proved successful in the treatment of UI, including in the elderly people.² Whether there are sex differences in the effect of conservative therapy is unknown. Although adequate treatment is available, only few seem to take advantage of it. Several studies have investigated help-seeking behaviour in elderly people with UI.³⁻⁷ They found a relation between help-seeking and the severity and distress of UI. The relation with age and type of incontinence was unequivocal. All of these studies did not focus on sex differences in help-seeking behaviour. In general men and women differ in help-seeking behaviour. Men consult their general practitioner (GP) less frequently, wait longer before they seek help, consistently they do not respond psychosocial problems and distress and their morbidity is associated with stronger forms of illness and disability compared with women.⁸⁻¹² One can also expect sex differences in help-seeking in case of UI, especially considering the differences in pathophysiology of UI in men and women. It is important to explore these differences between men and women in care in order to approach male patients differently from female. Addressing the specific needs of men and women should lead to patients with UI being informed in a more efficient way resulting in a greater compliance with therapy. Therefore this study aimed to analyse sex

differences in help-seeking behaviour in elderly people with UI focusing on disorder- and patient-specific factors.

Method

A cross-sectional study was conducted in the eastern part of the Netherlands between January 1999 and January 2002. UI was defined according to the Dutch guidelines for GPs: involuntary loss of urine at least twice a month.¹³ The study population consisted of participants in a study on the prevalence of incontinence in elderly people¹ and came from nine practices involved in the Nijmegen Monitoring Project, the academic registration network of the Department of General Practice of UMC St.Radboud in Nijmegen, the Netherlands.¹⁴ These nine practices with 28 GPs were fully computerized and provided medical care to a total of 46500 patients.

All independently living patients aged 60 or over were sent a questionnaire, patients with dementia or who were seriously ill were excluded. Patients with UI who had indicated on the questionnaire that they wished to participate in the follow-up study were interviewed at home. The study focused on uncomplicated UI, as described in the Dutch guidelines for GPs, therefore patients with a neurological or psychiatric disorder and patients who had previously undergone unsuccessful surgery for UI were excluded (Figure 1). Because the aim of this study was to gain deeper insight into help-seeking behaviour we combined a quantitative approach with validated questionnaires with a qualitative method of in depth interviews.

We collected the following data:

a) Quantitative data on:

- background characteristics (age, gender, marital status, level of education)
- the type of incontinence, by asking the following questions: Does loss of urine occur at moments of increased pressure, for example, when sneezing, jumping or

coughing? Do you experience such a strong urge that you fail to reach the toilet in time? The type of incontinence can be determined reliably with the help of these questions.¹⁵

- disorder-specific and validated questionnaires such as:
 - the PRAFAB score (= Protection, Amount, Frequency, Adjustment, Body image)¹⁶
 - the Incontinence Impact Questionnaire (=IIQ)¹⁷
 - the Urogenital Distress Inventory (=UDI)¹⁷

The PRAFAB score gives an indication of the *severity of incontinence* and includes 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. 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 measures *the impact of involuntary loss of urine on four domains in daily life*, namely daily physical activities (6 questions), social functioning (10 questions), emotional well-being (8 questions) and travelling (6 questions). The subjects were asked to tick one of the following answers; none (=0 points), some (=1 point), moderate (=2 points) and severe (=3 points).

The UDI established the presence of *symptoms often concomitant with urinary incontinence* such as prolapse symptoms, urgency and voiding problems. The questions were divided into three subscales: • stress-related symptoms (2 questions), • irritation symptoms (7 questions), and • obstructive symptoms (10 questions). If the

answer was affirmative, the subjects had to indicate the degree of distress: none (=0 points), some (=1 point), moderate (=2 points) and severe (=3 points).

b) qualitative data on:

- help-seeking behaviour by interviewing the patients. All answers were recorded on tape. The following questions were asked: 'Did you ever seek help?' If the answer was negative: 'What were your reasons for not seeking help?'. All interviews were conducted by the same researcher who was not the patients health worker.

Statistical analysis

Quantitative data were analysed with SPSS for Windows. Differences between men and women who had sought help and those who had not and sex differences in patients who sought help and patients who did not were analysed using a chi-square test for categorical data and a *t* test for continuous data. To calculate the means of the various domains and subscales of the UDI, the total score of each domain and subscale was divided by the total number of questions. To calculate the mean of the various domains and subscales of the IIQ, the total score of each domain and subscale was divided by the total number of the questions reduced by the number of the questions that were not applicable. For example the question about the influence of urine leakage on household chores is not applicable in case of a man who never does household chores. If 50% or more of the questions in the domain or subscale were not applicable, the data were not included in the analyses.

Of each disorder- or patient-factor for which a significant difference was found between the groups seeking help and those who did not, the odds ratio was determined and of all factors with a significant odds ratio in men or women subsequently a multivariate regression-analysis was performed ($p < .05$).

Qualitative data were analysed using the ATLAS software program. The qualitative approach used in this study is based on the categoring process in grounded theory where categories derived at through open and selecting coding.¹⁸ The open coding were done by two researchers independently of each other.

Results

The research population comprised a total of 56 male and 314 female patients with uncomplicated UI. The analysis involved data of 55 men and 293 women. Twenty-two patients dropped out because of a technical error that occurred during the recording of the qualitative part of the interviews.

Half of the patients with UI never sought help from their GP (table 1). This was similar in men and women. Nevertheless, there were differences in help-seeking. Men sought help when their incontinence was significantly less serious than that of women. Their help-seeking was not related to the severity of the incontinence. Help-seeking behaviour in women on the contrary was related to the severity of incontinence. Women with moderate or severe incontinence sought help from their GP 1.7 times more often (95% CI 1.02-2.80) than women with mild or mild-to-moderate UI (Table 2).

The duration of the incontinence also determined help-seeking in women. Women with symptoms for more than 5 years sought help 2.4 times (95% CI 1.31-6.89) more often than women who had symptoms for less than 2 years. In men this relation did not exist.

In men, help-seeking behaviour was strongly related to the emotional distress experienced in daily life, such as feelings of frustration and anger (odds ratio 8.1, 95% CI 1.40-46.98). In women too help-seeking was related to distress experienced in daily life but the relation was less strong (odds ratio 2.3, 95%CI 1.16-4.59).

Finally, women who sought help had more incontinence-related symptoms (Urogenital Distress Inventory). The total score in women who sought help was significantly higher than in women who did not seek help (odds ratio 2.76, 95% CI 1.59-4.78). This was also found within the domain of obstruction symptoms such as voiding problems and a feeling of constant vaginal pressure. Women with obstruction symptoms sought help 2.76 times (95% CI 1.59-4.78) more often compared with women without or with fewer obstruction symptoms.

A multiple regression analysis showed that in women the duration of the incontinence was the best predictor for seeking help followed by the presence of incontinence-related symptoms and the severity of incontinence (Table 2). In men the distress experienced in daily life was the best predictor for help-seeking.

The reasons for not seeking help were further explored in the interviews (Table 3 and 4). Some 80% of the women and 73% of the men did not find the symptoms serious enough to seek help, they had no difficulties dealing with the disorder, or they did not find it troublesome (“...*I don’t have pain, that is important for me...*” “...*I’ve got other complaints that are much more serious...*”).

Set ideas appeared to be another important factor in help-seeking behaviour. In half of the women and one-third of the men beliefs were a reason for not seeking help. The most important were: incontinence is aged-related (“...*what do you expect? I’m almost eighty!...*” “...*that’s what happens when you get older...*”); and there is no treatment for incontinence. Some men thought incontinence was an inevitable consequence of prostate disorders (“...*men will develop prostate disorders when they get older, there is a relation between that?...*”). Some women thought incontinence was a logical consequence of childbirth or having a vaginal prolapse (“...*what do you want after childbirth...*” ; “...*I have a prolapse so nothing can be done about the incontinence...*”).

The third important category of reasons for not seeking help was related to patient-doctor relationship. (“...I’m afraid that my doctor thinks that I’m a fussy person...” “ ... I only go to my doctor when it’s really necessary...” “...I don’t get along with my doctor...” “...My doctor didn’t ask it...”). Within this category we did not find sex differences. Only a few men and women said that they found it difficult to speak about or felt embarrassed to present incontinence to their GP.

Discussion

To our knowledge this is the first study that analyses sex differences in help-seeking behaviour among independently living elderly people with UI.

The most important finding is that although men and women were equally likely to discuss their UI with their GP, there are differences in factors related to help-seeking in men and women. In men who sought help the incontinence is less severe, despite which they experience more distress in daily life compared with women who sought help. This finding is contrary to the literature about help-seeking behaviour in male patients, because in general men consult their GP if the disorder is mostly more serious.⁸⁻¹² Maybe this discrepancy is due to differences in types of incontinence between men and women. Men suffer more from urge incontinence and several studies have shown a relationship between urge incontinence and a greater psychosocial impact.¹⁹ Another explanation is the sex difference in using incontinence pads. Women use incontinence pads more frequently and easily because they are accustomed to use sanitary towels.^{20,21} Therefore women, contrary to men, do not feel uncomfortable and are not distressed by wet clothing.

Our findings suggest that women wait longer before consulting the GP. They seek help especially if incontinence persists, when more incontinence-related symptoms occur, and when the incontinence becomes more severe.

Finally men and women have different ideas regarding the cause of incontinence. Women relate their incontinence to childbirth and the presence of a prolapse. Men relate incontinence to prostate disorders and old age. All are seen as reasons for the untreatability of the incontinence. Men and women share a low expectancy of the effect of treatment of incontinence.

A limitation of this study is that the number of male patients with UI included in the study is quite low. Our study focused on uncomplicated incontinence. One of the reasons for the low number of male patients in our study is that so many male patients had to be excluded because of a neurological disease (flowchart). Because of this the capability to identify factors that predict help-seeking will be much lower in men compared to women. However, to try to identify such factors is not worthless, but one should be careful when interpreting the results. In addition, the study population was composed of patients of general practices of an academic network in the eastern part of the Netherlands; therefore we cannot generalise the results.

In conclusion, women will consult their GP when the incontinence becomes more serious, exists longer and when they have incontinence-related symptoms; men will consult when they experience more distress. In men who consult the incontinence is less severe, despite which they experience more distress.

For daily practice this means that if a male patient consult with UI, the GP has to pay attention to the feelings of fear, anxiety, frustration and anger. This is particularly important because men mostly do not report distress *spontaneously*. The GP has to inform male patients about the possibility and availability of incontinence pads. Men and women should be informed about the success of conservative treatment of UI and should receive proper treatment. In particular older women, who consult when the UI is more serious, should not be handled by a wait-and-see policy on the part of the GP.

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Fig. 1. flow chart of the study population

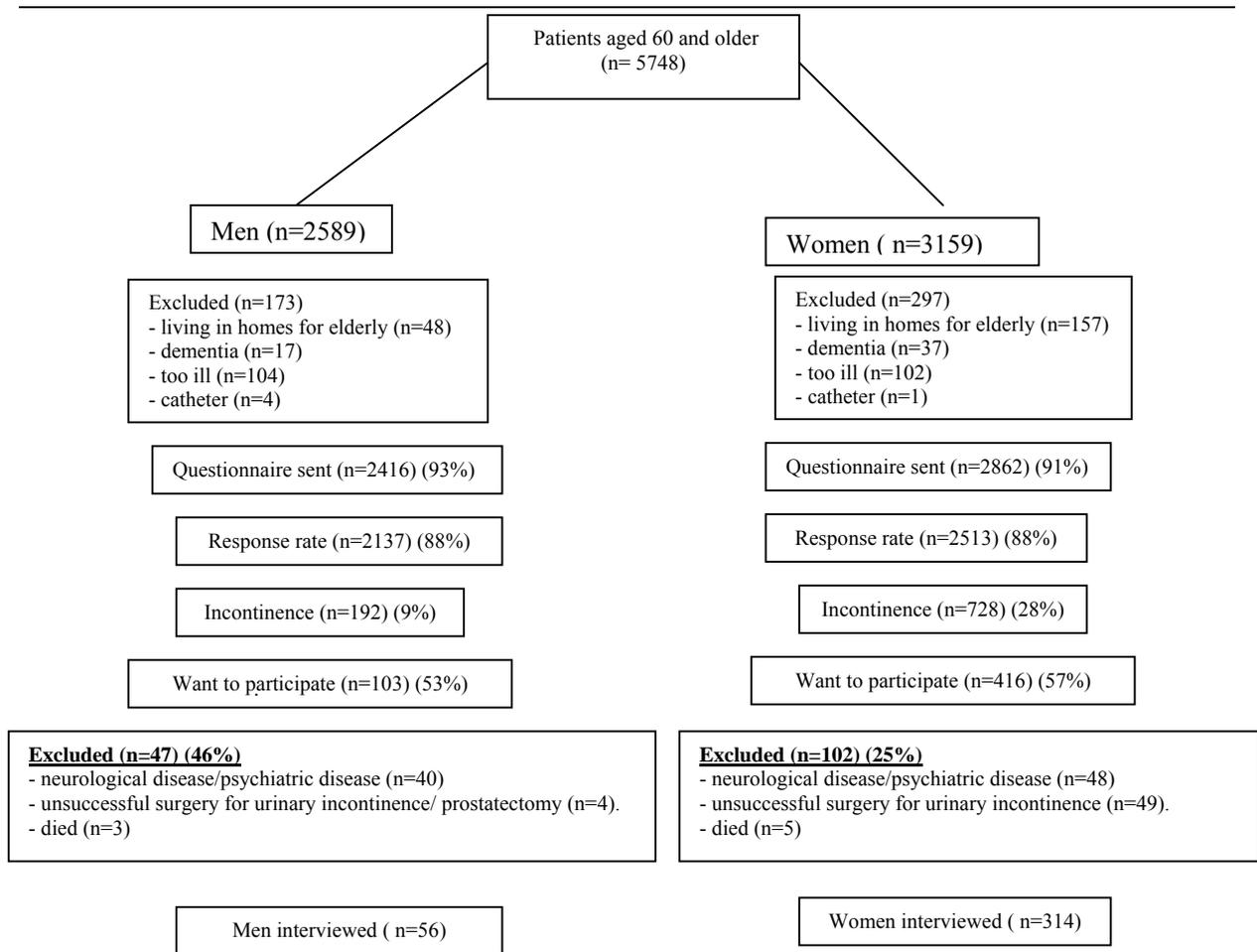


Table 1: The characteristics of the men and women who sought help and those who did not for urinary incontinence

	<i>Men</i>			<i>Women</i>			<i>M/W differences⁴</i>		
	<i>Sought help</i> n=25 (=%)	<i>did not seek help</i> n=30(=%)	<i>not help</i> P ⁵	<i>Sought help</i> n=145(=%)	<i>did not seek help</i> n=148(=%)	P ⁵	<i>Sought help</i> P ⁵	<i>Did seek help</i> P ⁵	<i>not help</i> P ⁵
Mean age, years	70.6	71.3	-	71.0	70.8	-	-	-	-
Marital status			-			-	-	-	-
<i>Married, living together</i>	20 (44)	26 (56)		89 (48)	95 (52)				
<i>Single</i>	1 (50)	1 (50)		6 (67)	3 (33)				
<i>Widow/widower</i>	3 (50)	3 (50)		49 (52)	46 (48)				
<i>Divorced</i>	1 (100)	0 (0)		1 (20)	4 (80)				
Education level			-			-	*	-	-
<i>Low¹</i>	11 (42)	15 (58)		103(54)	89 (46)				
<i>Medium²</i>	9 (50)	9 (50)		30 (44)	39 (56)				
<i>High³</i>	5 (46)	6 (54)		12 (38)	20 (62)				
Duration of symptoms			-			-	-	-	-
<i>< 6months</i>	0 (0)	0 (0)		0 (0)	0 (0)				
<i>>6months to <2 years</i>	4 (50)	4 (50)		9 (28)	23 (72)				
<i>2-5 years</i>	8 (36)	14 (64)		50 (49)	52 (51)				
<i>>5 years</i>	13 (52)	12 (48)		86 (54)	73 (46)				
Type of incontinence			-			-	*	*	*
<i>Stress</i>	1 (33)	2 (67)		29 (52)	27 (48)				
<i>Urge</i>	20 (53)	18 (47)		25 (43)	33 (57)				
<i>Mixed</i>	2 (33)	4 (67)		88 (52)	80 (48)				
<i>Other</i>	2 (25)	6 (75)		3 (33)	6 (67)				
Severity of incontinence			-			*	*	*	*
<i>Mild</i>	4 (40)	6 (60)		6 (43)	8 (57)				
<i>Mild to moderate</i>	14 (48)	15 (52)		29 (40)	44 (60)				
<i>Moderate</i>	7 (47)	8 (53)		77 (49)	80 (51)				
<i>Severe</i>	0 (0)	1 (100)		33 (67)	16 (33)				
IIQ total score (mean)	0.31	0.24	-	0.23	0.15	*	-	*	*
IIQ subscale score (mean)			-			*	-	*	*
<i>Physical activity</i>	0.14	0.09	-	0.22	0.15	*	-	*	*
<i>Social functioning</i>	0.10	0.16	-	0.05	0.03	*	-	*	*
<i>Travelling</i>	0.25	0.38	-	0.25	0.20	-	-	*	*
<i>Emotional well-being</i>	0.68	0.38	-	0.41	0.27	*	-	*	*
UDI total score (mean)	0.92	0.81	-	0.92	0.83	*	-	-	-
UDI subscale score (mean)			*			*	-	-	-
<i>Obstruction symptoms</i>	0.45	0.40	*	0.51	0.38	*	-	-	-
<i>Irritative symptoms</i>	1.60	1.36	-	1.41	1.36	-	-	*	*
<i>Stress symptoms</i>	0.90	0.90	-	1.37	1.32	-	-	-	-
Nocturia (mean)	1.59	1.56	-	1.52	1.42	-	-	-	-

Statistical analysis by using chi square test for categorical variables and T-test for continuous variables.

¹ none / basic / lower professional

² medium general preparatory / medium professional

³ higher general preparatory / higher professional / university

⁴ chi square test for categorical variables and T test for continuous variable to analyse sex differences in patients who sought help and in patients who did not seek help.

⁵ - not significant; * p<0,05

Table 2: bi-variate en multivariate regression –analysis of the patient- and disorder-factors in which a significant difference was found (see table 1), in men and women

	<i>Men</i>		<i>Women</i>	
	Bi-variate analysis Odds Ratio (95% CI)	Multivariate analysis Odds Ratio (95%CI)	Bi-variate analysis Odds Ratio (95% CI)	Multivariate analysis Odds Ratio (95%CI)
Duration of symptoms <2 years 2-5 years [>5 years]	1.08 (0.22-5.33) 1.89 (0.59-6.11)	ns	3.00 (1.31-6.89)* 1.22 (0.73-2.02)	3.66 (1.44-9.39)* 1.21 (0.72-2.04)
Severity of incontinence mild, mild-moderate [moderate, severe]	0.91 (0.28-2.93)	ns	1.69 (1.02-2.80)*	1.69 (0.99-2.88)*
IIQ total score mean =0 mean 0,01-0,05 mean 0,05-0,10 [mean 0,10 and >]	3.30 (0.83-13.18) 0.34 (0.03-3.69) 2.20 (0.52-9.30)	7.10 (1.15-43.91)* 0.31 (0.03-3.53) 3.52 (0.64-19.36)	2.31 (1.16-4.59)* 3.41 (1.39-8.38)* 2.15 (1.09-4.21)*	ns
IIQ subscale score Physical activity mean =0 mean 0.01-.,04 [mean 0.4 and >] Social functioning mean =0 mean 0.01-0.14 [mean 0.14 and >] Travelling mean=0 mean 0.01-0.34 [mean 0.34 and >] Emotional well-being mean =0 mean 0.01-0.13 mean 0.13-.,49 [mean 0.49 and >]	1.25 (0.16-9.88) 1.00 (0.11-9.23)		1.67 (0.89-3.08) 1.18 (0.53-2.63)	
UDI total score mean 0-0.5 mean 0.5-1,0 [mean 1.0-4,0]	1.35 (0.29-6.18) 1.63 (0.48-5.56)	Ns	1.50 (0.78-2.93) 2.76 (1.59-4.78)*	1.43 (0.71-2.88) 2.69 (1.52-4.76)*
UDI subscale score Obstruction symptoms mean=0 mean 0.01-0.4 [mean 0.4 and >] Irritative symptoms mean=0-1 mean 1-2 [mean 2-4] Stress symptoms men=0 mean=0,1-1,0 [mean = 1 and >]	0.34 (0.07-1.65)* 2.01 (0.60-7.14)	0.21 (0.04-1.03)*	1.97 (1.09-3.57)* 1.65 (0.96-2.85)	ns

[] the odds ratio of each characteristic is the difference between the group between brackets and the others.

* p<0.05 ; ns = not significant

Table 3: Reasons for not seeking help in female patients

Category	In vivo code	Women (n=156)	Text
Severity of incontinence N=119	Not serious enough	N=95	'it is not so bad' ; 'it doesn't really bother me'; 'it wasn't yet serious enough that I needed help'; it doesn't really bother me' ; ' I don't have pain and that is important for me'
	Don't need help	N=16	'I uses sanitary towels to solve the problem'; 'I can take care of it myself';
	Not important	N=8	'I 've got other complaints that are much more serious' ; 'it is not important enough for me'; ' it was never a problem for me'; ' I'm to busy with other things'
Cognitions N=69	Aged-related	N=34	'what do you expect? I'm almost eighty!' ; 'that's what happens when you get older' ; 'I thought it's age-related'
	It will gone by itself	N=3	'let's wait for a moment, it will be over in a couple of time' ; 'I though it will gone by itself'
	A lot of people experienced incontinence	N=5	'och, a lot of people experienced urinary incontinence' ; 'a lot of my friends have this complaints'
	There is nothing to do with is.	N=17	'the doctor won't be able to do anything about it' ; 'I'm to old for treatment' ; 'I have a prolapse so nothing can be done about the urinary incontinence'
	Other	N=10	'I'm a woman so you get it' ; ' what do you want after childbirths' ; ' I get it because the medication I use' ; 'it's my own fault' ; ' I'm afraid for an operation'
Patient or patient-doctor relationship factors N=21	Help-seeking behaviour	N=10	'I'm not one to visit a doctor regular' ; 'I only go to the doctor when there's a reason' ; 'When I have complaints I never go immediately to my doctor' ; 'I'm afraid that my doctor think that I'm a fussy person'
	Patient-doctor relationship	N=11	' I have negative experiences with my doctor'; 'I don't get along with the doctor' ; 'the doctor didn't ask'
Others		N=10	'I don't want a treatment'; 'it happened so slowly that I have learned to live with it'; 'It's difficult for me to talk about it' ; 'you can ask to the GP assistance for incontinence pads'

Table 4: Reasons for not seeking help in male patients

Category	In vivo code	Men (n=30)	Text
Severity of incontinence N=22	Not serious enough	N=17	'the symptoms are not serious enough that I would like a treatment' ; 'for this little thing I will not bother my GP'
	Don't need help	N=2	'when I visit the toilet frequently I can control my incontinence'; 'to get other cloths be enough'
	Not important	N=2	'the incontinence is not important enough for me'; ' I'm to busy with other things'
	Other	N=1	'I found voiding frequently much more alarming'
Cognitions N=8	Aged related	N=5	'it's age-related' ; 'most men of my age have this symptoms, it belong to our age'
	Nothing to do with it	N=2	'there is nothing to do with is' ; 'the doctor in not able to do something?'
	Other	N=1	'men get problems with their prostate when they get older, that is a relation between that?'
Patient and patient-doctor relationship factors N=4	Help-seeking behaviour	N=2	'I don't go immediately to my doctor'
	Patient-doctor relationship	N=2	'my doctor didn't give an answer on it' ; 'my doctor did have time for me, so I don't consult him for this'
Other		N=6	'I don't like a treatment' ; 'it's get a part of live so a don't want a treatment' ; 'I shame myself to talk about it' ; ' I don't want an operation'

6

‘It can always happen’: The impact of Urinary Incontinence on elderly men and women

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Submitted

Abstract

Objectives: to determine the impact of urinary incontinence (UI) on the quality of life of elderly men and women in the general population and to identify factors with the greatest effect.

Setting: Independently living elderly patients aged 60 and over from the nine family practices of the Nijmegen University Research Network.

Method: All independently living patients aged 60 and over with uncomplicated urinary incontinence were interviewed at home using the Incontinence Impact Questionnaire and open-ended questions.

Results: In total, 56 men and 314 women were interviewed. 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. Most important effect of incontinence reported in men was 'being out of control' while most women considered 'feeling impelled to take several precautions' the most important consequence of UI.

Conclusion: UI affects nearly half of the patients, particularly in their emotional well being and in public activities. Men experienced more impact compared to women and experienced loss of control more often than women.

Keywords: urinary incontinence; elderly; quality of life, gender differences

Introduction

Urinary incontinence (UI) is a common condition in the general population, especially in the elderly.¹ At the same time, there is a recognised 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^{3,4} A possible 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.^{6,7} Relatively little is known about the impact of UI on daily life in the elderly in the general population, especially in men. Because elderly men seek help for less severe UI than women⁸ this study also focused on the differences between the sexes on the impact of UI on daily life.

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

Method

This study was part of a large study on UI conducted in the eastern part of the Netherlands between January 1999 and January 2002.^{1,2,8} 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.⁹

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.

UI was defined in accordance with the Dutch guidelines for general practitioners (GP) as the involuntary loss of urine at least twice a month.¹⁰ Post-micturition dribbling in men was not considered a symptom of UI. The study focused on uncomplicated UI in community dwelling elderly people. Therefore, patients with a neurological or psychiatric disorder, patients who had previously undergone unsuccessful surgery for UI and patients living in homes for 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
- b) age, gender, civil status, level of education, duration of symptoms
- c) the type of incontinence: determined on the basis of the following questions¹¹;

“does loss of urine occur at moments of increased pressure, for example, when sneezing, jumping or coughing?” 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, 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 PRAFAB score (= Protection, Amount, Frequency, Adjustment, Body image).¹² The questionnaire involved questions about 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 PRAFAB 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.¹³ 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. The IIQ determines the impact of involuntary loss of urine on four domains in daily life, namely 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 multiple-choice question; the possible answers were: none (=0 points), some (=1 punt), 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 not initially anticipated. The same trained interviewer did all interviews. The interview consisted of

the following topics: does UI impact your daily life and if so what are the most troubling aspects? All the answers were recorded to tape.

Statistical analysis

Qualitative data on the impact on daily life were fully typed out and analysed with the help of the ATLAS computer program. The qualitative approach used in this study was based on the categorising process in grounded theory where categories are derived through open and selecting coding (14). Two researchers did the open coding independently from 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 *t* test. We used $p < 0.01$ to indicate statistic significance. If 50% of the questions or more in the domain were not applicable, the data were not included in the analysis.

Results

The research population comprised 56 male and 314 female patients with uncomplicated UI. Twenty-two patients dropped out because of a technical error that occurred during the recording of the qualitative part of the interviews (Fig. 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 1) experienced. In men urge incontinence was the most common type compared with mixed incontinence in women. The incontinence in women was more severe compared to men.

Impact of urinary incontinence.

The IIQ indicated that UI affected emotional well being in particularly (Table 2). 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 (Table 2). The impact score was significantly higher in men. Thirteen percent 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 (Table 2).

Finally, about ten percent 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 in – ‘being unable to control the incontinence’ and ‘feeling forced to take several precautions’. One in ten patients did not experience any impact.

Box 1: 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 en 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 third of the men and four out of ten women felt unable to exert control over their incontinence (Box 1), which resulted in fear of an accident and fear of discovery of the UI, especially in case of urgency and frequency (n=118).

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

Box 2: Quotes related to ‘feeling forced to take several precautions’

“...Every time when 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 near by. 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 by 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...”

One fifth of the men and half the women reported the precautions they had to take as the greatest burden (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 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 of having to use pads distressing (n=56) and finally restrictions in physical activities were also mentioned (n=14).

Discussion

Most studies that evaluated the consequences of UI on the quality of life were performed in selected samples of clinical patients and only a few studies 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 about 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. 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.¹⁵⁻¹⁷

The way in which people respond to stressful events, in this case UI, is called coping. The concept of coping is complex, some basic ‘meta strategies’ for coping have been identified.^{18,19} These involve emotional oriented versus problem oriented and passive or avoiding versus active or approaching methods of coping. In case of UI, a problem and activity oriented way of coping is 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. Passive-emotional oriented way of coping are 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.¹⁷ Therefore patients with UI may benefit from active-problem oriented coping strategies.

Coping strategies can prevent the patients wetting themselves but this does not mean that patients will not experience UI impact. After all, the efforts that have to be taken to prevent urine loss, for example made when leaving the house constitute a time and energy consuming process, especially for elderly people. Changing and going to the toilet will become more difficult because of their impaired mobility and cognitions. This is in agreement with the reported implications for outdoor activities like shopping, travelling and entertainment.

In general men are more used to use active-problem oriented strategies while women apply more passive-emotional oriented strategies.^{21,22} This study shows that because of incontinence men feel more out of control and experience more emotional impact compared

to women. This suggests when affected by UI men apply more passive-emotional oriented strategies, which is contrary to general male coping strategies. This method of coping implies that men experience more impact from UI than women and this is supported by the findings of this study. Men experience more distress than women despite their incontinence being less severe. It can also explain why men seek help while their incontinence is less severe.⁸ These findings are remarkable because in general men consult their GP less frequently, wait longer before seeking help and their morbidity is associated with stronger forms of illness and disability than that of women.^{22,23} 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}

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 al²⁶ and Ouslander et al²⁷ 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 the number of male patients included in the study was quite low. Our study focused on uncomplicated incontinence. One of the reasons for the low number of male patients was that many 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.

We conclude that in a large proportion of the elderly patients UI does not interfere with individual's 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, co-morbidity 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 managing incontinence.

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Fig. 1. Flow chart of the study population

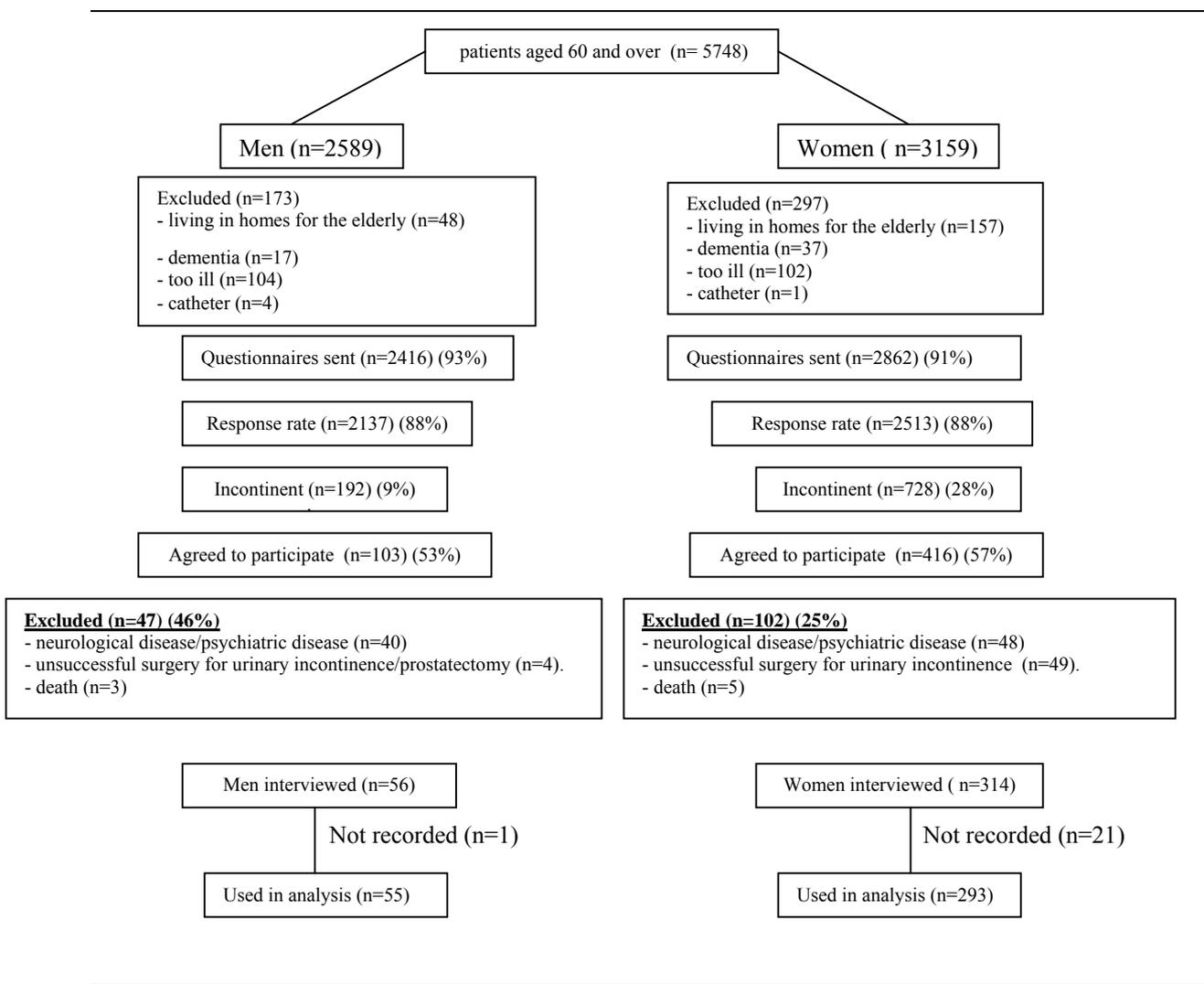


Table 1: Characteristics of the study population

	Male (%) N=55	Female (%) N=293	M/F differences #
Mean age, years	70,9	71,1	Ns
Marital status			Ns
<i>Married, cohabiting</i>	46 (84)	184 (63)	
<i>Single</i>	2 (4)	9 (3)	
<i>Widow/widower</i>	6 (10)	95 (32)	
<i>Divorced</i>	1 (2)	5 (2)	
Education level			Ns
<i>Low¹</i>	26 (47)	192 (66)	
<i>Medium²</i>	18 (15)	69 (24)	
<i>High³</i>	11 (20)	32 (10)	
Duration of incontinence			Ns
<i>< 6 months</i>	0 (0)	0 (0)	
<i>>6 months to <2 years</i>	8 (15)	32 (11)	
<i>2-5 years</i>	22 (40)	102 (35)	
<i>>5 years</i>	25 (45)	159 (54)	
Type of incontinence			p=0.00 *
<i>Stress</i>	3 (5)	56 (19)	
<i>Urge</i>	38 (70)	58 (20)	
<i>Mixed</i>	6 (11)	168 (57)	
<i>Other</i>	8 (14)	9 (4)	
Severity of incontinence			p=0.00 *
<i>Mild</i>	10 (18)	14 (5)	
<i>Moderate</i>	44 (80)	220 (79)	
<i>Severe</i>	1 (2)	49 (16)	

#Statistical analysis by using chi square test for categorical variables and T-test for continuous variables. (* sign p<0.01)

¹ none/basic/lower professional

² medium general preparatory/medium professional

³ higher general preparatory/higher professional/university

Table 2: (%) 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)

	Male (n=55)		Female (n=293)		M/F# differences
	% patients who experienced impact	Impact score	% patients who experienced impact	Impact score	
Physical activity					
Household chores	4%	1.42	14%	6.00*	P=0.000
Repair work in home or garden	8%	2.66	13%	6.33*	P=0.004
Shopping	18%	6.66	20%	9.66	Ns
Hobbies	11%	5.00	6%	3.67	Ns
Physical recreation	11%	5.93	22%	12.00*	P=0.003
Physical health	5%	2.38	4%	1.49	Ns
Travel					
Entertainment	10%	4.87	6%	3.23	Ns
Travel <20 min	4%	2.42	3%	1.28	Ns
Travel >20min	16%	7.88	9%	3.77	Ns
Going to places if you are not sure about the availability of toilets	37%	26.79	31%	19.49	Ns
Holidays	3%	2.56	7%	1.39	Ns
Employment	0%	0	0%	0	Ns
Social					
Church	4%	1.63	4%	1.84	Ns
Volunteer work	0%	0	1%	0.71	Ns
Having friends visit you	0%	0	0%	1.06	Ns
Social activities	4%	3.77	3%	2.17	Ns
Relationship with friends	4%	1.78	1%	0.53*	P=0.004
Relationship with family	2%	1.88	1%	1.15*	P=0.000
Sexual relationships	5%	3.42	5%	3.80	Ns
Clothing	27%	13.10	10%	4.95*	P=0.000
Fear of odour	13%	7.14	1%	0.42*	P=0.000
Emotional					
Fear of embarrassment	7%	6.66	1%	0.64*	P=0.000
Emotional health	27%	13.69	14%	7.22*	P=0.001
Sleep	29%	16.07	14%	7.43*	P=0.00
Nervousness or anxiety	41%	22.62	33%	18.15	Ns
Fear	21%	13.69	16%	8.73*	P=0.005
Frustration	48%	26.79	32%	17.30	Ns
Anger	14%	10.12	12%	6.26*	P=0.008
Depression	14%	4.76	5%	2.55	Ns
Embarrassment	46%	32.74	34%	22.08	Ns
Domain score					
	men		Female		
Physical activity	4.2		6.1		Ns
Travel	10.5		7.5*		0.001
Social	4.5		1.4*		0.000
Emotional	17.6		11.2*		0.001
Total IIQ	9.3		6.5*		0.009

#M/F differences in impact score of each item of the IIQ . Statistical analysis: T-test. (* sign. p<0.01)

7

Urinary Incontinence in older people: When and why do general practitioners not follow the guidelines recommendations.

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Submitted

Abstract

Objectives: To determine to what extent general practitioners (GP) manage involuntary loss of urine in the elderly in accordance with the urinary incontinence (UI) guideline, and to discover the reasons why certain GPs do not follow the recommendations in this guideline.

Setting: Nine general practices (20 GPs) of the Nijmegen University research network.

Method: The study was part of a large study on UI in people aged 60 or over. Patients with uncomplicated UI who had not been treated in the past, were invited to visit their GP. After each consultation, the GP recorded the data of diagnosis, treatment and follow-up. The researcher subsequently compared the data with the UI guideline and discussed with the GP the reasons for not following the guideline.

Results: In total 19 men and 71 women visited their GP for UI. For history taking, physical examination and additional urine testing, the GPs adhered to virtually all recommendations of the guideline, but, in 25% of the cases, they did not ask about vaginal dryness. As far as treatment was concerned, there were major deviations from the guideline. The main deviation was no treatment, as patients did not consider their complaints serious enough for the proposed therapy. Further, despite the fact that the guideline encourages GPs to instruct patients for exercise therapy, the GPs referred one-fifth of the women with stress and one-third with mixed UI to a physiotherapist. They thought physiotherapists were better able to provide this treatment. They particularly experienced mixed UI as too complex and time consuming to be performed by themselves. The GPs who did decide to give conservative treatment themselves adapted the guidelines because of these reasons.

Conclusion: The UI guideline is readily applicable to the elderly for history taking, physical examination and urine testing. According to the GPs, the most important reasons for not following the treatment recommendations was that patients thought the treatment was not

worth the effort. Furthermore, the GPs had little time to spend on their patients, and experienced incontinence in the elderly as rather complex.

Keywords: UI; elderly; general practice; guideline adherence

Introduction

Urinary Incontinence (UI) is a common problem among the elderly, men as well as women, but only half of them seek help from their GP. Help-seeking behaviour is related to the severity of the incontinence and its impact on everyday life. The main reason for not consulting a GP is that elderly patients consider their complaints not serious enough. To them it is related to 'their old age' and they 'do not expect that anything can be done about it, anyway'¹. However, conservative treatments such as pelvic floor exercises and bladder training are effective for UI, also in the elderly². This outcome is significant because UI is one of the major reasons for older people being admitted to nursing homes³. It also affects their quality of life and incurs substantial healthcare costs⁴. For example, in the Netherlands, an estimated €85 million (£58 million) is spent on incontinence material for the elderly in the community, excluding the materials used in nursing homes⁵.

Developing guidelines is a generally accepted method for improving the quality of care, and guidelines for primary care have also been developed for UI in several countries⁶⁻¹². Drawing up guidelines does not guarantee their application in practice. It is unclear to what extent the guidelines on UI are actually adhered to by GPs. Moreover, most research on UI in the general population is focused on middle-aged women. Evidence of diagnosis and treatment of UI, on which the UI guidelines are based, are therefore derived from this population. Can we apply these guidelines also to the elderly, among whom the prevalence of UI is highest¹³?

As data on the application and possible barriers of guidelines in everyday practice are essential for optimising care, we studied the care provided by GPs to elderly patients with UI. The main study questions were: To what extent do GPs act in accordance with the UI guideline? and which GP and patient factors play a role in the decision to deviate from the recommendations?

Method

This study was part of a large, cross-sectional study of UI in elderly people, conducted in the eastern part of the Netherlands between January 1999 and January 2002. UI was defined according to the Dutch guideline for general practitioners as involuntary loss of urine occurring at least twice a month ⁶. The subjects were all patients aged 60 years or over, selected from the populations of nine practices in the academic general practice research network (CMR/NMP) of the Department of General Practice of the Radboud University Nijmegen Medical Centre ¹⁴. At the time of study, these nine practices with 20 GPs were fully computerised and provided medical care to a practice population of 46,500 people.

For the overall survey, a questionnaire was sent to all independently living patients aged 60 or over. The GPs excluded patients who were unable to fill in a questionnaire (e.g. Alzheimer patients) and patients who would be inconvenienced by the request to fill in a questionnaire (e.g. severely ill people). Reminders were sent after two weeks. Patients with UI who had indicated on the questionnaire that they were willing to participate in the follow-up study were subsequently interviewed at home. The study focused on uncomplicated UI as described in the guideline ⁶. Patients with a neurological or psychiatric disorder and patients who had previously undergone unsuccessful surgery for UI were therefore excluded. Patients who had not been treated with extensive conservative therapy in the past and wanted to be treated now, formed the focus of this study. They were advised to consult their GP for UI (see flow diagram, Figure 1). The research assistant made appointments for them.

Prior to the study, the participating GPs received training on the UI guideline because we wished to study the applicability and feasibility of the guideline in daily practice and not deviations from the recommendations due to lack of knowledge.

The data of the study population characteristics were collected during interviews with the patients at home, before the start of the study. We collected:

- age, gender, civil status, level of education, duration of symptoms
- type of incontinence, determined on the basis of the following questions ¹⁵:
“Does loss of urine occur at moments of increased pressure, for example, when sneezing, jumping or coughing?” and “Do you experience such strong urge that you fail to reach the toilet in time?” In line with these questions, urge incontinence was defined as: involuntary loss of urine during a 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.
- severity of incontinence: assessed by the PRAFAB score (= Protection, Amount, Frequency, Adjustment, Body image) ¹⁶. The questionnaire contained questions about the use of protective pads, the amount of urine lost each time, the frequency of involuntary loss of urine, the limitation of activities of daily living, and the effects on self-image. According to the PRAFAB score, the following categories can distinguished: mild (1-7 points), moderate (8-13 points) and severe (14-20 points).

During this study we collected the data from the self-registration forms. A self-registration form is a validated method for measuring the implementation of existing guidelines ¹⁷. The form listed 24 items on history taking, diagnosis and treatment of UI, distilled from the UI guideline by a panel of experts. The GPs completed the form after each consultation.

The first author (DT) checked whether the registration forms were completed in full; if not, she contacted the GP to add the missing data. In those cases in which the guidelines were *not* fully observed, the GPs registered the reasons. All GPs were interviewed later on by the first author (DT) to explain in depth the reasons for their decision to deviate from the recommendations.

Statistic analysis

We analysed the extent to which GPs applied each relevant item of the guideline to male and female patients. The following classifications were used: *high* if the item applied to 80% or more of the patients; *moderate* if the item applied to 50-80% of the patients, and *low* if the item applied to fewer than 50% of the patients. The interviews with the GPs were written out in full. The reasons for deviating from the guideline were grouped according to prevalent themes and also analysed by a second researcher (TLJ).

Results

In total, 19 men and 71 women consulted their GP about their UI. For all these patients, the GPs filled in self-registration forms. As expected the type of UI differed in the two sexes (Table 1). Therefore we decided to analyse the results for men and women separately. The severity also differed: the incontinence in the participating women was more serious than in the participating men.

All aspects of history taking, physical examination and additional urine testing were followed to a high degree for almost all items (Table 2), with the exception of enquiring after vaginal dryness (omitted with regard to 25% of the female patients).

The prescribed therapies deviated from the guideline more often. For the 19 male patients, this was observed in nine cases (Table 2): one of the four men with stress incontinence found his complaint not severe enough for him to start with pelvic floor exercises, the first choice in stress incontinence in the guideline. As far as the ten men with urge incontinence were concerned, bladder training was not prescribed for four, three refrained from treatment because they considered their complaints not serious enough, and in one case the GP decided to assess the effect of reducing his medication first. The male patient with mixed incontinence was referred to a urologist, because the GP found the recommended treatment too complex to perform himself.

Finally, three male patients were advised to void regularly and not to put off voiding for too long. The GPs were convinced that bad voiding habits caused the incontinence.

In the female population, a deviation from the guideline was observed in 39 of the 71 women (Table 2). Although the guideline encourages GPs to instruct patients for exercise therapy, the GPs often referred to a physiotherapist. This was the case for six of the 32 women with stress incontinence. The GPs provided the following reasons for referral: (a) the GP was of the opinion that the physiotherapist could spend more time on the patient and would therefore provide better care, (b) the patient was not able to tighten her pelvic floor muscles during gynaecological examination and therefore required more expert and intensive guidance, and (c) the previous referrals of other patients had proved successful.

Five women with stress incontinence did not want to do pelvic floor exercises, because they considered the complaints not serious enough.

Two of the eight women with urge incontinence took medication as well as bladder training, instead of taking only bladder training as recommended in the guideline, because the GPs expected a better outcome with the combination compared to only bladder training.

Deviation from the guideline was most common in the 31 women with mixed incontinence. Ten women were referred to a physiotherapist for the same reasons as mentioned above, and also because the GP considered mixed incontinence in particular a complex problem. The GPs were of the opinion that complex incontinence was a problem that could be better treated by a physiotherapist with special expertise on this condition. Physiotherapists would also be better able to provide adequate guidance. Six women with mixed incontinence declined treatment because they did not consider their problem worth the effort of exercising. One woman was prescribed pads, and another oestrogens because of vaginal atrophy.

Finally, five women were simultaneously started on bladder training and pelvic floor exercises as therapy because this would be less time-consuming for the GPs. Five other women were prescribed pelvic floor exercises instead of starting with bladder training, because the stress component played a significant part. Moreover, the GPs thought the therapy would otherwise become too complicated for the patients.

The severity of the incontinence in all the patients who declined treatment did not differ from the patients who received therapy.

The follow-up policy was also much more varied than the 6 or 12 weeks recommended in the guideline. Generally, no appointments for follow-up were made for the patients who were referred to a physiotherapist. Regardless of the type of incontinence and the patient's sex, one-third of the GPs usually re-examined their patients after a longer period than the 12 weeks recommended. They were convinced that the effect of therapy could only be measured properly in the long term. Interim checks were of no use to them.

Discussion

As far as history taking, physical examination and urine testing are concerned, the guideline is well observed, also for the elderly. But GPs often do not enquire after vaginal dryness. In vaginal atrophy, oestrogen replacement therapy may have a positive effect on incontinence¹⁸. The guideline therefore recommends taking oestrogens as a possible additional therapy for both urge incontinence and stress incontinence. Full-blown vaginal atrophy – even when not enquired after – will always come to light during physical examination.

Rather striking is that the participating GPs indicate that one-third of the men and one seventh of the women are of the opinion that their incontinence was not serious enough to warrant the efforts required in the therapy proposed. In addition, one-third of the treated patients did not return for the follow-up. The question is not only whether they had actually

completed the therapy, but also whether they had started it at all. This is remarkable because the population of this study were patients who had been interviewed at home, and subsequently decided to see their GP. Despite the fact that, at the end of the interview, the treatment options were thoroughly explained, the larger part did not want to visit their GP for treatment. Even in the remaining, motivated group of patients who did go to consult their GP, i.e. the population of this study, a considerable number declined treatment. Although the patients mentioned the severity of their incontinence as a reason for not be willing to be treated, the objective severity of incontinence as measured by a validated scale does not appear to be different in patients who did and patients who did not want to be treated. Horrocks et al.¹⁹ and Shaw et al.²⁰ demonstrated that elderly are less motivated for therapy and had reduced health expectations.

In addition to low motivation and reduced health expectations, many of the elderly have co-morbidity. This makes the health problem incontinence more complex, and the patient as well as the doctor have to decide which medical problem will be given priority. Obviously, patients and doctors do not always consider UI the most serious problem threatening the quality of life. Good cooperation and shared decision can lead to giving priority to other medical problems than UI.

About one-fifth of the women with stress incontinence and one-third with mixed incontinence were referred to a physiotherapist. Particularly in the case of mixed incontinence, GPs tend to think they have insufficient expertise and they regard the treatment as complex and time-consuming. Furthermore, in pelvic floor exercises and bladder training, adequate guidance is essential for motivating elderly patients and for keeping them motivated. This takes much time, and time is usually a commodity that GPs do not have enough of. Finally, GPs had good experiences with the treatment and guidance of UI by physiotherapists.

GPs who decided to give conservative treatment themselves also regarded the treatment of mixed incontinence, occurring in 40% of the elderly women, as complex and time-consuming. Because of this, they transformed the recommendations from the UI guideline into a more patient-tailored approach, applicable to everyday practice. Not only the type of incontinence, but also co-morbidity such as decreased mobility make incontinence in the elderly more difficult to treat and also more time-consuming if patients are to be instructed adequately.

The follow-up policy was varied. Logically, GPs' adapt the follow-up appointment to the treatment they started. If patients were referred to a physiotherapist, no appointment for follow-up was made. Asking patients to come back after three months if the exercise therapy did not help, made it possible to discuss other treatment options.

This study is somewhat limited by the small number of male subjects. One of the reasons for this is that many male patients had to be excluded due to a neurological disease (flow chart). Because of this, the capability to identify barriers to the application of the UI guidelines will be much lower in men compared to women. The use of a study population composed of patients from general practices in an academic network in the eastern part of the Netherlands calls for caution when generalising the outcomes. Strong points are the link between population data and information on the GPs' treatment of the patients concerned, and the fact that we were able to integrate into the quantitative analysis 'qualitative' information on why GPs did not act as recommended.

Over the past few years, guidelines for the treatment of UI in primary healthcare have been developed in Canada, Germany, the United States and Denmark⁶⁻¹². As in the Dutch guideline, the first choice in all these guidelines is conservative therapy. As far as we know, no international studies have yet been published on the extent to which GPs act in conformity with the UI guideline, and which barriers they experience while applying the guidelines.

Sandvik et al.²¹ investigated only part of the prevailing management of UI in women by Norwegian GPs. They found that GPs had done gynaecological examinations in 54% and urinalyses in 73% of the patients. Penning-van Beest et al.²² studied the treatment of women with UI in the Netherlands. They found that only 13% of the women with newly identified UI were actively treated for their incontinence.

Of all the UI guidelines, only that of the international Scientific Committee makes a distinction between incontinence in adults and incontinence in frail older patients. Only the German UI guideline recommends referring all patients to a physiotherapist for exercise therapy. The other UI guidelines recommend exercise therapy, but do not suggest who should provide guidance in this.

The conclusion must be that adaptation of the UI guideline seems useful in the case of elderly patients. If only because a considerable number of patients with UI consider their complaints not serious enough to warrant the efforts required in the therapy. Our findings revealed that this can be explained partly because they are not motivated for therapy and partly because they give priority to other health problems that have more impact on their quality of life. Further study will need to prove whether this conclusion is correct. It is crucial for providing quality care to the elderly with UI, and preventing unnecessary medicalisation. Because of the high prevalence of UI and its impact on the quality of life and health care costs, this is a serious issue.

In addition, a large part of the elderly with UI is referred to physiotherapists for guidance because of the GPs' lack of time, the complexity of the problem, and the GPs' good experience with referrals. GPs who treat mixed incontinence themselves adapt the guideline because of the complexity and time-consuming aspect.

All in all, it may be said that the diagnostic recommendations of the UI guideline are well applicable to the elderly, but that more attention needs to be paid to the time-consuming

aspect of treatment. Referral to a physiotherapist is an option, and the practice nurse or physician's assistant can also be trained to provide treatment and guidance to elderly patients with UI. Furthermore, the complexity of UI in the elderly, the guidance required, and the presence of co-morbidity necessitate more intensive care. Patients should be advised to consult their GP again if the incontinence does not improve after 3 months of conservative therapy, so that other treatment options can be discussed. Adaptation of the guideline should guarantee the quality of care that the elderly with UI need.

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Fig. 1. Flow chart of the study population

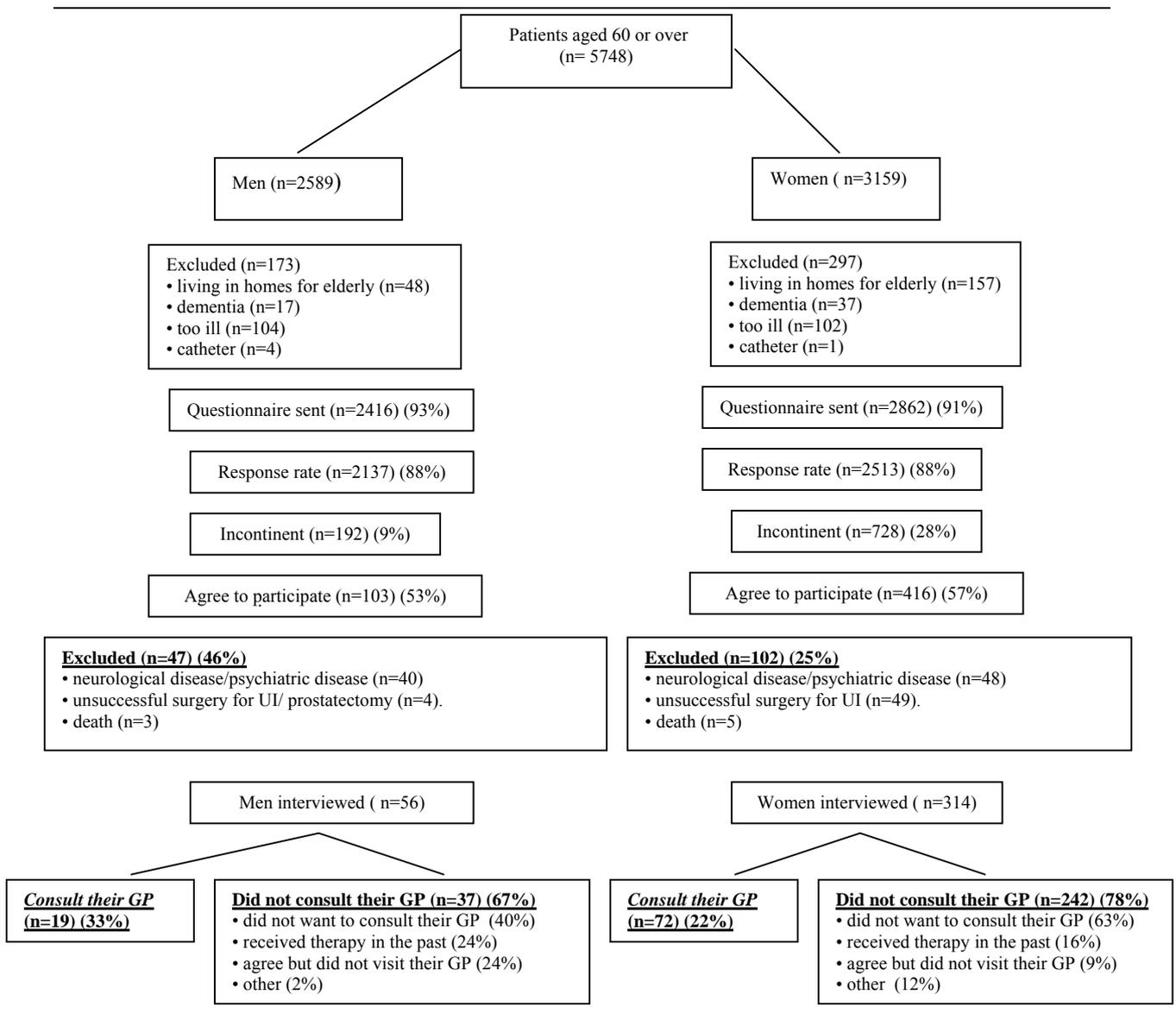


Table 1: Characteristics of the study population

	Female (=n) (total n=71)	Male (=n) (total n=19)
<i>Age (mean)</i>	70 (SD 5.7)	72 (SD 7.9)
Civil status		
Married, living together	52	16
Single	1	-
Widower/widow	15	3
Divorced	3	-
Level of education		
Low ¹	43	8
Medium ²	18	8
High ³	10	3
Severity		
Mild	15	10
Moderate	43	8
Severe	13	1
Type		
Stress incontinence	32	4
Urge incontinence	8	10
Mixed incontinence	31	2
Other	-	3
Additional problems		
Cystocele	29	-
Descensus uteri	7	-
Vaginal atrophy	9	-
Enlarged prostate	-	6

¹ No/ primary/junior secondary vocational education

² Junior general secondary/senior secondary vocational education

³ Higher general secondary/higher professional/university education

Table 2: Adherence to the items of the guidelines

Item of the guidelines	Male patients (%) (Total n=19)	Female patients (%) (Total n=71)
History taking		
<u>Type</u>		
• Loss of urine during increased pressure?	High (100%)	High (100%)
• Loss of urine during strong urge?	High (100%)	High (100%)
• Continue loss of urine?	High (100%)	High (97%)
<u>Severity</u>		
• Amount of urine loss?	High (100%)	High (100%)
• Use of incontinence pads?	High (100%)	High (93%)
• Frequency of the loss of urine?	High (100%)	High (100%)
• Influence on daily life?	High (100%)	High (90%)
<u>Relevant factors</u>		
• Use of medication	High (95%)	High (97%)
• Surgery in the past	High (95%)	High (100%)
• Mobility	High (95%)	High (96%)
• Neurological disease	High (95%)	High (100%)
• Problems due to vaginal atrophy	-	Moderate (78%)
• Pain during micturition	High (100%)	High (91%)
• Change of the micturition pattern	High (90%)	High (87%)
Urine testing	High (100%)	High (98%)
Physical examination		
• Gynaecological examination	-	High (94%)
• Assessment of the strength of the pelvic floor muscle	-	High (85%)
• Rectal examination	High (84%)	-
Treatment		
• Pelvic floor exercises in case of stress incontinence	Moderate (75%)	Moderate (68%)
• Bladder training in case of urge incontinence	Moderate (60%)	High (80%)
• Bladder training combined with pelvic floor exercises after 6 weeks in case of mixed incontinence	Moderate (50%)	Low (16%)
Follow-up		
• Stress incontinence appointment after 6 weeks	Moderate (50%)	Low (22%)
• Urge incontinence appointment after 6 to 12 weeks	Moderate (60%)	High (88%)
• Mixed incontinence appointment after 6 weeks	Low (0%)	Moderate (52%)

8

Urinary incontinence in the elderly: attitudes and experiences of general practitioners. A focus group study

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Abstract

Objective: To assess general practitioners (GPs') attitudes to UI in elderly patients and their experiences in the application of the Dutch College of General Practitioners' guideline in daily practice.

Design: Two groups existed of six GPs working in villages and seven GPs working in urban practices

Method: Two focus groups discussions with recording of discussions and transcription. Transcripts were analysed by two independent researchers.

Results: During the discussions three main themes of attitudes came forward: 1) therapeutic nihilism of GPs and a low motivation of patients, 2): GPs experienced lack of time because of difficulties to explain the therapy and because impaired mobility of older patients, 3) because of the complexity of the problem and co-morbidity, GPs as well as patients were reluctant to treat the UI.

The most remarkable findings in the application of the guideline were: 1) because of the barriers mentioned above, physical examination did not take place in spite of GPs' conviction of the benefit of it, 2) GPs' knowledge about treatment options in the elderly with UI is substandard.

Conclusion: Several patient - (co-morbidity, impaired mobility, low motivation and acceptance of the problem) and GP factors (therapeutic nihilism, lack of time and knowledge) interfere with a good management of UI in the elderly.

Keywords: urinary incontinence; elderly; general practitioner; attitude; implementation

Introduction

Urinary incontinence (UI) is a common condition in elderly men and women, with prevalence in the community ranging between 15-30%.¹

UI affects general well-being, self-esteem and social functioning.²⁻⁴ Non-surgical treatment (bladder training, pelvic floor exercises and medication) is effective in the treatment of involuntary loss of urine, also in elderly patients.⁵ This treatment can be very well managed in primary care.⁶ But only half of the elderly with UI contact their GP for this problem. The most important reasons of not seeking help are that they do not experience problems with their UI and lack of knowledge of the cause of the disorder and its treatment options.⁷

In several countries – including the Netherland (Dutch College of General Practitioners) – guidelines for UI in primary care have been developed.⁸⁻¹² The existence of guidelines, however, does not guarantee their use.¹³ Sandvik e.a.¹⁴ investigated GPs management of UI in the elderly in Norway. They found that old patients received pads, and to a certain extend drugs, but compared to younger patients they did not get pelvic floor exercises, were less often referred to gynaecologist and surgical intervention was less often proposed. Penning-van Beest e.a. studied the treatment of women with UI in the Netherlands.¹⁵ They found only 13% of the women with newly identified UI were actively treated for their incontinence. However, the reasons *why* actual practice differs from (guideline) proposed care has to the best of our knowledge not been investigated. It is important to have insight in this - skills and attitudes may play a role as well or guidelines might encounter problems with patients' attitudes or health care facilities. Surveillance of such barriers can help the implementation process of guidelines.¹⁶ This study analysed the barriers to implementation of the Dutch College of General Practitioners' guideline for UI. It can be anticipated that with only half of the elderly patients with UI actually seeking help there will remain unmet needs in the practice population, but there could be other barriers –

for example in the GPs' attitudes towards the elderly – resulting in substandard care for patients with UI. Empirical data of GPs' experiences with the guideline and insight in the existing bottlenecks in the care of older patients with UI can be used for training and education of GPs or amending the guideline when it is up for an updated review.

The aim of this study is to assess GPs' current attitudes to UI in elderly patients, and their experiences with the application of the guideline in daily practice.

Method

This study is part of a large research project of uncomplicated UI in elderly people. In this project we evaluated prevalence, help-seeking behaviour, consequences and impact of UI on daily life, and, reported here, barriers in the implementation of the UI guideline in GP' care of elderly people with uncomplicated UI. As we were particularly interested in the GPs' attitudes of elderly people with UI, we used a focus group discussion as a qualitative research method, to enable in-depth exploration.

We selected GPs working in villages near the practice of the first researcher (TT) and GPs working in urban practices near the practice of the co-authors (ALJ). GPs of different ages, gender, different practices settings and without any specific affinity with the problem incontinence were invited to participate in the focus groups. To be able to explore GPs' genuine thoughts and attitudes about UI it was essential to create a safe environment for an open discussion, and for that reason small groups of six to seven participants were formed. We decided to start with two groups and analyse the discussions for becoming repetitive. If this was not the case, more groups were to be recruited until saturation of themes and issues was reached.

Basic rules of confidentiality are a prerequisite for convening the groups, and all participants had to agree to keep all discussions in the group strictly confidential.

The focus groups took place at the Department of General Practice of the Radboud University Nijmegen Medical Centre from June 2003 onwards and were led by a moderator experienced in leading groups but with no special interest in UI. A topic guide with eight key questions was developed (Table 1). All these questions were used to generate discussion among the participants.

Each focus group discussion lasted one hour and a half each with a short break of 10 minutes and was recorded on audiotape and fully transcribed. The GPs received a small token of appreciation for their participation.

Analysis

Qualitative data were analysed using the ATLAS software program. Two researchers independently searched the script for patterns that emerged from each question and subsequently they together defined the most important themes. In case of controversy both researchers tried to reach agreement to defined the most important themes. In case of discrepancies a third researcher read the transcripts and gave her opinion and mutual discussion took place between the three until agreement was reached.

Results

In total eighteen GPs were approached to participate in the focus groups. Five refused because of lack of time (three male and two female GPs) resulting in thirteen participants. The participants were divided into two groups, seven in the first group and six in the second group. The demographics of the participants are showed in Table 2.

Attitude

In both groups three main themes came forward: therapeutic nihilism, lack of time and complexity of the problem and co-morbidity.

Therapeutic nihilism was the first main theme. We started the discussions with the question about the first thoughts of GPs in case of an elderly woman with UI. Spontaneously GPs noted that they couldn't do a lot with it;

“...This case is not a challenge for me, because you can't do so much...”

“...I'm pessimistic in case of an older woman with urinary incontinence. I will do a urinary analysis and if this is normal she will get incontinence pads...”

Because of this the GPs mostly didn't do an optimal physical examination and consequently were pessimistic about the benefits of therapy. The first important reason for this pessimism was that in older women pelvic examination often showed very weak pelvic floor muscles. Half of the GPs were convinced that weak pelvic floor muscles strongly decreased the effect of training.

“...In patients with a very wide introitus you know that treatment will not be very successful...”

“...When I find any strength of the pelvic floor muscles then I am more motivate to advice a training...”

As several GPs were also convinced that therapy was more effective in younger patients, almost all GPs were more inclined to refer younger patients than older ones to a physiotherapist.

“...In younger women I push a referral to the physiotherapist stronger because they have to live with it for so long...”

“...Because I'm not always convinced that therapy is efficient in elderly patients I'm reluctant to refer to a physiotherapist...”

The second reason for the pessimism was the low motivation for therapy GPs encountered in elderly patients.

“...Most patients stopped the exercises because the severity of the incontinence was not worth the efforts of doing exercises...”

“...When you tell the patient they have to train the pelvic floor muscles for a long time they ask for incontinence pads because they feel that doing exercises at their age is difficult...”

“...I’m much more reluctant to start training to a patient who visits you frequently and who never does anything with my advices...”

Several GPs mentioned that older patients were also less motivated to go to the physiotherapist, while half of the participating GPs believed that the physiotherapist had more expertise and more time to guidance the patient.

“...My experience with older patients is that if you suggest to refer to a physiotherapist, almost all of them don’t want to...”

A few GPs put forward that a lot of elderly accept UI as part of their life believing that no effective treatment was available

Lack of time was the second main theme during the group discussions. The majority of the GPs stressed the time consuming aspect of the management of UI in the elderly.

“...My first thought is ‘this takes me a lot of time’, especially in elderly patients. You have to ask about their medical history and after that they have to undress themselves and climb on the examination table. You need a lot of time to evaluate it and to motivate the patient...”

Almost all GPs agreed with the statement of lack of time for a proper diagnostic analysis and consequent adequate treatment. The reasons why it costs a lot of time were that in elderly patients it was usually more difficult to explain the therapy and that older patients were less mobile so you had to visit them at home.

“...In case of an old woman living in a residential home who presents with UI, I usually don’t do a physical examination. This would take too much time, and it is too difficult to perform an adequate pelvic examination...”

“...When I get a request of a residential home for incontinence pads, it’s much easier to prescribe than to visit the patient for an analysis of the incontinence problem...”

Lack of time was also a reason to refer to a physiotherapist. The GPs especially proposed a referral when they thought that the patient needed a lot of explanation. But as described earlier, elderly patients are less motivated to go to the physiotherapy.

“...During a training about the incontinence I learned that most female patients need a month before they know how to tighten the pelvic floor muscles. I don't have enough time to instruct a patient...”

Most GPs experienced requests to the practice assistant for a prescription of incontinence pads as very bothersome. Although they were convinced that they had to invite the patient for a proper analysis of their UI problem first, this was too difficult to manage in daily practice. As a consequence they prescribed the pads without further analysis.

The last main theme was the complexity of the problem and co-morbidity

Elderly patients had often co-morbidity, and because of this the GPs as well as the patients themselves were reluctant to additionally treat the UI.

“...They most often have also a lot of other medical problems. I focus my attention on the most serious problems. For me and the patient the incontinence frequently is the less serious one...”

Also the experiences that often UI got presented at the end of consultation as a new problem, irritated the GPs and did lead to an insufficient management.

“...When the problem is presented as part of many other problems, my heart is sinking...”

“...If a patient only consults me for this problem then I will do a pelvic examination. If the patient comes for several problems including UI then I feel frustration about this way of presentation. Then I ask to make a new appointment or sometimes I decide to give prescription for incontinence pads without further discussion...”

Applying the UI guideline

During the discussion about the application of the UI guideline two major themes came to the fore.

The first one was the barriers experienced by GPs in elderly patients with UI. These barriers were already reviewed in the previous section: low motivation, impaired mobility, difficulties to understand the explanation of the therapy, co-morbidity and acceptance of the problem. All GPs were convinced of the benefit of a pelvic examination. But because of these barriers physical examination did not always take place.

It was also clear to GPs that pelvic floor exercises were the first treatment option in stress incontinence. But, as already elaborated, a lot of elderly patients did not comply with it because of the barriers mentioned before.

The second major theme during the discussion about the feasibility of the UI guideline was GPs' lack of knowledge about treatment of UI. For example, only four GPs prescribed, according to the guideline, bladder training as the stand-alone first treatment option in urge UI. Only two did so with detailed instructions and a follow-up appointment and just one GP used the recommended frequency volume chart. Three GPs started always with bladder training and medication together because they were used to it and had good experience with it.

Two GPs were used to start with medication alone. Both didn't know that bladder training was effective in this case.

“...I have to admit I never give bladder training, I always start with medication...”

“...I have good experiences with the use of medication in elderly with urge incontinence. I think that bladder training is difficult for them...”

The same pattern was found in the first choice treatment in mixed UI. For five GPs mixed UI was reason to refer to the physiotherapist because of the complexity of the problem. Just one of the 13 GPs started with bladder training in mixed UI and later on added pelvic floor exercises, in accordance with the UI guideline. The other participants did start with bladder training and pelvic floor exercises together, because they were used to it, because they

expected a lack of time to see the patient for follow-up appointments and because they didn't know what the UI guideline advised.

Discussion

This is the first study into GPs' attitudes to UI in elderly patients and experienced barriers to perform sufficient management in daily general practice. This study gives us insight in several reasons why the treatment of elderly patients with UI by GPs is substandard. The most important ones are the therapeutic nihilism of the GP and the low motivation of the patient, which intensify each other. But also GPs' lack of knowledge and lack of time declined the quality of care. A very interesting finding is that co-morbidity in the elderly and the complexity of UI often result in a dilemma. After all GPs and patient have to decide which medical problem will get priority. UI not always experienced by patients as the most serious problem that threatens the quality of life. Good cooperation and shared decision can lead to give priority to other medical problems than the UI.

Lack of knowledge of GP and patient about treatment options nevertheless leads to substandard care.

Our study is somewhat limited by the small number of GPs. But because in de second focus group no new themes were coming up, a third focus group discussion was not necessary. Apparently, the themes that came forward represented the view of the profession. The strength of this design is the opportunity to explore GPs' attitudes and experiences and to approach this in depth. Although this study was exploratory in nature, and our findings cannot be generalised to all GPs, this was the first in-depth analysis of this topic. And – at least in the Netherlands – GPs showed a high level of homogeneity in their dealings with elderly patients with UI. From the answers and comments, we cannot identify specific issues

from Dutch patients or the structure of health care in the Netherlands in the GPs' comments. That makes our findings relevant for further testing in international primary practice setting.

The lack of knowledge of GPs is in accordance with a study in Denmark by Lose e.a who found that only 24% of the GPs felt that their knowledge was sufficient to manage incontinence and more than 50% would refer a patient to a specialist.¹⁷ Grealish e.a. also found that many GPs avoided dealing with women with UI because they found it a difficult and chronic problem to treat.¹⁸

Our conclusion is therefore that different factors related to older patients interfere with a good management of UI, like co-morbidity, impaired mobility, low motivation and acceptance of the problem. Also GP factors interfere with optimal care, as therapeutic nihilism, lack of time and substandard knowledge about treatment options and their effectiveness. This makes it imperative to focus our attention to several domains in implementing UI guidelines.

Firstly, we have to improve GPs' knowledge about therapeutic options and their effectiveness in UI. GPs are only able to motivate patients if they are convinced themselves of the benefits of therapy.

Further investigation is necessary to verify the low motivation for treatment in elderly with UI. Is this because of wrong information, because of the unconvincing explanation of the therapy, or because of the effort of the exercises?

Furthermore, in the future UI guidelines have to take into account the complexity of UI in the elderly. Co-morbidity is a main feature of the health status of elderly patients. UI might be influenced by the treatment of other diseases – in particular pharmacotherapy. Several drugs exert influence on bladder, bladder neck and diuresis and will influence UI.¹⁹ Therefore, a critical look to the polypharmacy in the elderly is imperative and this includes

the treatment of UI itself. Consequently, treatment of UI might, in individual cases, be freighted because of (treatment of) other morbidity.

Lastly, to tackle the GPs' experienced time load and patients' low motivation, and effectiveness of the contribution of the practice nurse in the treatment and guidance of elderly patients should be assessed in future research.

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Table 1: Interview guide

Attitude

- A woman aged 75 years with moderate UI consults you because of UI; what is your first thought?
- Do you send elderly patient with urinary incontinence more often to the physiotherapist compared with younger patients? If you do so, why? If you do something else, what and why?

Application of the UI guideline

- Which barriers do you experience in case of older patients with urinary incontinence?
 - Do you do a diagnostic analysis as proposed in the guidelines?
 - Do you perform pelvic examination in elderly with UI? If not, why not? If yes, why? What brings it to you?
 - The guidelines for UI advice to start with pelvic floor exercises in case of stress UI. What do you think about this? If you do something else what do you do and why?
 - The guidelines for UI advise to start with bladder training in case of urge UI. What do you think about this? If you do something else, what do you do and why?
 - The guidelines for UI advice to start first with bladder training and after 6 weeks to add pelvic floor exercises in case of mixed UI. What do you think about this? If you do something else, what do you and why?
-

Table 2: Demographics of the participants

Demographic characteristic	Number
Male/Female GP	6/7
Practice type	
- Solo	2
- Group#	11
Full-/part-time	
- Full time \geq 4 days	4
- Part time $<$ 4 days	9
Age group	
- $<$ 40 year	6
- 40-50 year	3
- $>$ 50 year	4

2 or more doctors in one family practice

9

General discussion

General discussion

This thesis focuses on community-dwelling elderly with urinary incontinence (UI). Its objectives are in the first place to explore the discrepancy between the assumed high population prevalence of the condition and the relatively limited number of patients seeking help. Secondly, to investigate the applicability of the prevailing UI guideline for general practice¹, the barriers in treatment as encountered by GPs, and the GPs' attitudes towards elderly people with UI.

The discrepancy between high prevalence and relatively low medical consumption

With regard to the discrepancy between the assumed high prevalence of UI and the relatively limited number of patients that seek help, the following has become clear: as already assumed, UI is a common problem among the community-dwelling elderly aged 60 or over. This study shows that 29% of the female patients and 9% of the male patients experience involuntary urine loss at least twice a month. Post-micturition dribbling in men has been excluded from this.

The twice as high prevalence in women compared to men has been reported before and is explained by the differences in the anatomy of the two sexes.²⁻⁷

An even more troublesome problem, namely faecal incontinence - and particularly the combination of faecal and urinary incontinence – is also a regular health problem. We found that seven percent of the elderly in our research population have complaints of faecal incontinence (FI) and three percent of FI combined with UI. Rather striking in this respect is an equally high prevalence in women and men. This is particularly striking because obstetric damage is often considered the main cause of faecal incontinence.⁸⁻¹⁰ Apparently, there are also other factors that play a part in the development of faecal incontinence in old age. We

also found indications that FI is more serious in women than in men. As the questionnaire we used was not validated for this particular question, however, caution should be exercised in interpreting these data. Further study of this aspect is certainly warranted.

An important finding of this study is that many of the elderly do not experience UI as a problem and therefore did not seek help from their GP. Shame does not seem to play any role whatsoever in this decision. Other reasons for not seeking help are the presence of co-morbidity, which makes UI not always first priority, and the health belief that UI is something that comes with old age and cannot be treated adequately.

However, there are also patients who experience UI as a serious inconvenience, not only in their emotional life, but also in such activities as travelling and socializing. Incontinence may cause feelings of anxiety, frustration or anger, and may limit activities outside their homes. Patients report that they were afraid to go out and go to places without toilets, or avoided long journeys or physical activities. Particularly men are afraid that others might smell or otherwise notice their urine loss. Men experience UI more often as an inconvenience than women, even though incontinence in men is less severe. For men experienced emotional distress and seeking help correlate, in that they were more likely to seek help if they experienced more emotional distress of their UI. For women, seeking help is correlated to the severity of the incontinence, which is not the case in men. For both sexes there is no relation between seeking help and the type of incontinence. So women seek help when their incontinence gets worse and men seek help with mild incontinence. This is a remarkable finding because generally men tend to wait longer before they seek help, and once they do, their complaints are often more severe than those of women.¹¹⁻¹⁵

The experienced distress is not merely determined by the UI as such, but also by patients' coping. In coping an active problem-oriented approach can be distinguished from a passive emotion-oriented strategy. Van der Vaart proved that a passive, emotional way of

coping leads to a more detrimental influence of the stressor on everyday life, whereas active, problem-oriented coping improves quality of life.¹⁶ In the case of UI, active, problem-oriented coping would mean, for example, wearing incontinence material and taking along clean clothes, and passive, emotion-oriented coping would mean avoiding particular situations and being angry and frustrated. Men generally tend more towards active problem-oriented coping, whereas women opt more often for passive, emotion-oriented coping.^{17,18} The findings in this study, however, point to the reverse: we found an emotion-oriented coping in men with UI and active, problem-oriented coping in women. This is even reinforced by the fact that two-thirds of the men consider loss of control the most troublesome consequence of UI. Women, on the other hand, report the practical measures to prevent themselves from getting wet as most bothersome. This reveals the question: do coping strategies shift in domains attributed to the other gender?

One possible explanation for this discrepancy is that men do not use incontinence material as much as women. Women are throughout important periods of their life already used to wearing sanitary towels. In addition, women consider incontinence something that comes with old age and as a result of having had babies. Men regard incontinence more as a prostate disorder.^{19,20} Furthermore, men generally tend to have a much stronger need for keeping a situation under control, whereas women adjust themselves more quickly.¹¹⁻¹⁵

In the decades to come we will be confronted with a new generation of elderly who will probably be much more accustomed to travelling and outdoor activities than the current generation. Thus UI may have an even greater impact on the quality of life, and eventually resulting in more elderly seeking help.

Applicability of the standard, barriers and the GPs' attitudes

With regard to the applicability of the NHG guideline for UI, the barriers in treatment as experienced by GPs, and the GPs' attitudes towards the elderly with UI, the following has become clear: GPs experience a number of bottlenecks in applying the NHG guideline for UI to elderly with involuntary urine loss. The elderly accepts physical complaints more readily than younger people and are therefore not always motivated for therapy.^{21,22} In addition, as a consequence of the presence of co-morbidity, incontinence is not always the patients' or GPs' first priority. Furthermore, GPs experience the treatment of incontinence in the elderly as complex and time-consuming. Particularly where mixed incontinence is concerned (i.e. the type that covers 40% of the total incontinence in the elderly), GPs experience a lack of expertise. Due to the decrease in mobility and cognitive functions of the older population, physical examination and the explaining of exercises take up a considerable amount of the GPs' time. The lack of time and expertise is often the reason for GPs to refer the motivated elderly with involuntary urine loss to a physiotherapist, who – in their opinion – has more time and expertise. As only a few of the elderly are eventually referred to the physiotherapist, this makes one wonder about the motivation of the elderly.

The GPs have sufficient diagnostic skills but are not always familiar with the treatment options for UI. They are above all, often pessimistic about the effectiveness of conservative therapy in the elderly. This pessimism will reduce the patient's diminished motivation even further. Also, this pessimism does not seem justified, because – as the literature search described in this thesis makes clear – the effect of conservative therapy in the elderly is in all studies positive. Our literature search concludes that exercise therapy seems to be even more effective than drug therapy.

Limitations of the study and recommendations for further research

In order to determine the prevalence and severity of faecal incontinence, we used a non-validated questionnaire, which makes the results less reliable. This aspect certainly deserves to be studied in more detail as faecal incontinence does occur rather frequently and very little research has been done in this field.

In addition, we aimed our research at the elderly with uncomplicated incontinence because this is a frequent health problem in general practice and the guideline aimed at it. However, particularly in the elderly, UI is also often of *complicated* origin. There is no information on to how GPs deal with this, or how GPs' care could be improved. This is another aspect that requires further research.

This study has shown that complicated UI occurs particularly in men. This was also the reason why we eventually could not include as many men in the research as we had originally wanted. The relatively small number of men makes it difficult for us to study male-female differences. We expect to see our results concerning the differences between the sexes in impact and help-seeking behaviour confirmed by future studies in which more men will have been included. The results with respect to combined FI and UI, and the different coping of men and women warrant further research.

Finally, the study of the applicability of the guideline used a selected group of patients and took place in a select setting of university-related general practices. A major selection was that patients who did not want to participate in the initial survey or refused the study interview, but who still might be seeking treatment of their GP, could not be included in the guideline analysis. Implementation and effect of treatment in this group might have been different from the study participants. Also excluded were patients who did not want to consult their GP for treatment, but in all probability this will not have influenced the real life value of the study as these patients would not come under treatment in the first place. The selected

nature of the practices and GPs might have limited the external validity of the study findings. However, the results of this study correspond well with the results of the focus group study, in which GPs from various non-academic general practices participated. Here too, future studies in this field using a less selective research population and more diverse GP practices may corroborate our results.

The consequences for practice

Firstly, GPs have to be aware that some of the elderly patients do not seek help because they think UI cannot be treated. Therefore, GPs have to be more alert to detect UI and should not wait until the patients ask for help.

Furthermore, the current UI guideline need accommodation with respect to elderly people with UI. Because of the complexity of UI in the elderly, the guidance required, and the presence of co-morbidity more intensive care is necessary than for younger people. Referral to a physiotherapist is an option, and the practice nurse can also be trained to provide treatment and guidance to elderly patients with UI.

In the training and education of GPs, more attention should be paid to UI in the elderly. Particularly the high prevalence, male-female differences, treatment options, and the effects thereof need to be discussed. If GPs are to be made more aware of the high prevalence of UI and the good efficacy of treatment by improving GPs' lack of knowledge and the knowledge of effective treatment in the elderly, GPs probably become more motivated to propose a form of treatment to the patient and to instruct and to treat the patient by themselves. A better motivated GP will also be better able to motivate the patient. Furthermore, when GPs keep the treatment of UI in elderly in their own hands prevent a referral to a physiotherapist. After all, a referral could always be a barrier for the patient.

When GPs get confronted with elderly with UI they have to realise that a small percentage of them also have FI, which is a condition, in which probably embarrassment stands in the way seeking help.

Moreover, GPs should realise that particularly men seek help because they experience inconvenience due to incontinence. Generally speaking, men do not like to talk about their emotional complaints, so their GP could help male patients to overcome this psychological obstacle. Women often only seek help once their incontinence gets really serious.

In many cases UI is not treated because of co-morbidity. In this respect GPs should realise that, although UI may be considered a small problem, compared to other health problems, quality of life in the case of UI can be improved through a relatively much smaller intervention, compared to most other disorders.

Another point is that the elderly often use various types of medication, many of which affect diuresis, or the bladder wall or bladder neck, and can thereby precipitate incontinence. Adapting the medication may therefore also be a way of improving incontinence.

If, eventually, it is decided not to treat the UI, or if treatment should not be sufficiently effective, recommendations on how to deal with incontinence may also have a positive influence on the quality of life. This may, for example, involve promoting the use of incontinence materials among men, or more and better accessible public conveniences.

Finally, we argue in favour of always evaluating UI in elderly who request incontinence materials or drop a hint that they have UI. In this way both the GP and the patient will get to know the possible cause and treatment options. Ultimately, the approach will always need to be determined in consultation with the patient. This is, of course, obvious as treating an unmotivated patient will not be effective. The GP will have to make a careful assessment of all the problems of the elderly patient including UI. Unnecessary treatment of patients should be avoided, whereas serious and treatable complaints need to be addressed.

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Summary

Urinary incontinence (UI) is a common condition in elderly people. In the coming decennia the total number of patients with UI will increase considerably, due to the ageing of the population and the high prevalence of UI in old age. GP will be confronted more and more with elderly with UI.

In **Chapter 1** the research questions of this thesis are introduced. It points out the background of the decisions: 1) to focus on men and women aged 60 years and over with UI in the general population, and 2) to describe the prevalence, the discrepancy between the high prevalence and the relative low consultation rate, the applicability of the UI guideline and the attitude of GPs to elderly patients with UI.

In **Chapter 2** we describe the results of a population based cross-sectional survey about the prevalence of urinary, faecal- and double incontinence in men and women of 60 years and older in the general population. We sent a postal survey to 5748 independently living elderly aged 60 or over from 9 practices involved in the Nijmegen Monitoring Project. The response rate was 88% after one reminder. We found that 19% of the respondents have involuntary loss of urine twice a month or more, 6% loss of faeces and 3% both. The prevalence of urinary -, faecal - and double incontinence increases with age in both men and women, and especially in men in the oldest age group. UI is more prevalent in women than in men. The prevalence of faecal incontinence shows no sex differences, but the type of fecal incontinence do differ between men and women. In men loss of mucous is twice as common as in women. Double incontinence is also equally prevalent in men and women, except in the age group 65-74 years.

In **Chapter 3** the results are presented of a literature review that evaluate the effectiveness of conservative treatment in the community-based elderly (aged ≥ 55 years) with stress, urge, and mixed urinary incontinence. The review reveals that there are only a few studies that met our methodological quality criteria. We conclude that conservative therapy is effective in elderly patients with stress-, urge and mixed incontinence. The effect of pharmacotherapy in the elderly is still unclear and harbours the risk of side effects and interactions in particular in elderly with multi morbidity and multi drug treatment.

In **Chapter 4** we studied factors that determine whether medical care for urinary incontinence is sought by independently living older people with UI. We combined qualitative and quantitative data. Subjects of the study were patients with UI who indicated on the questionnaire, used in the study described in chapter 2, that they were willing to participate in the follow-up study. Because the study focused on uncomplicated UI, patients with a neurological or psychiatric disorder and patients who had previously undergone unsuccessful surgery for urinary incontinence were excluded from this part of the study. We collected data of the study during an interview with 56 male – and 314 female patients. We found that half of the patients seek help from a GP. Help-seeking is 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. Most of the patients who do not seek help do not do so because they consider incontinence not very serious, or because of a lack of knowledge about cause and treatment options like – comments such as ‘incontinence is age-related’ and ‘there is nothing that can be done about incontinence’. Major reasons for seeking help are perceived increase in severity or distress and the need for incontinence material.

In **Chapter 5** we discussed the results of the study about sex differences in factors influencing help-seeking behaviour by independently living elderly people with UI. The subjects were the same as described in chapter 4. We found that men seek help from their GP when they have less severe incontinence than women. Help-seeking behaviour in women is related to the duration of symptoms, the presence of incontinence related symptoms like constant feeling of vaginal pressure and pain in the lower abdomen and the severity of incontinence. In men help-seeking is related to the distress experienced in daily life. Most men and women who do not seek help consider their incontinence not being serious enough, or they have inappropriate beliefs such as that ‘incontinence is age-related’ and ‘there is nothing that can be done about incontinence’.

In **Chapter 6** we assess the impact of UI on the quality of life of elderly men and women in the general population and to identify factors with the greatest effect. We combined quantitative and qualitative data. The data were derived from the interviews, on which we report in chapter 4 and 5. We found that in a large proportion of the elderly patients UI does not interfere with individual’s 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.

In **Chapter 7** we examined to what extent GPs manage UI in the elderly in accordance with the UI guideline, and the reasons why certain GPs do not follow the recommendations in this

guideline. After the interview, as which we described in chapter 4 to 6, patients who had not been treated in the past were invited to visit their GP. In total 19 men and 71 women aged 60 and over participated in this study. Twenty GPs of the Nijmegen University research network recorded after each consultation data of diagnosis, treatment and follow-up. The researcher subsequently compared the data with the UI guideline and discussed with the GP the reasons for not following the guideline. We found that for history taking, physical examination and additional urine testing, the GPs adhere to virtually all recommendations of the guideline, but, in 25% of the cases, they do not ask about vaginal dryness. As far as treatment is concerned, there are major deviations from the guideline. The main deviation is no treatment, as patients do not consider their complaints serious enough for the proposed therapy. Further, GPs refer one-fifth of the women with stress and one-third with mixed UI to a physiotherapist. They think physiotherapists are better able to provide this treatment. They particularly experience mixed UI as too complex and time consuming to be performed by themselves. The GPs who do decide to give conservative treatment themselves adapt the guidelines because of these reasons.

Chapter 8 analyses the study about GP attitudes to UI in elderly patients and their experiences in the application of the Dutch College of General Practices' guideline in daily practice. We performed two focus group discussions. The most important finding of this study is the therapeutic nihilism of the GP and the low motivation of the patient, which intensify each other. But also GPs' lack of knowledge and lack of time decline the quality of care. Co-morbidity in the elderly and the complexity of UI often result in a dilemma. Because of the barriers mentioned above, physical examination do not take place in spite of GPs' conviction of the benefit of it.

Chapter 9 discusses the most important findings of this thesis.



Samenvatting

Urine-incontinentie (UI) is een vaak voorkomend probleem bij ouderen. Naar verwachting zal in de komende decennia het totale aantal patiënten met UI aanzienlijk toenemen, vanwege de vergrijzing en vanwege de hoge prevalentie van UI op oudere leeftijd. De huisarts zal hierdoor steeds vaker geconfronteerd worden met ouderen met UI.

In **hoofdstuk 1** worden de onderzoeksvragen van het proefschrift geïntroduceerd. Het gaat in op de achtergrond om: 1) te focussen op UI bij mannen en vrouwen van 60 jaar en ouder in de algemene populatie, en 2) te kijken naar de prevalentie, de discrepantie tussen de hoge prevalentie en de relatieve lage medische consultatie, de toepasbaarheid van de huisartsen richtlijn (NHG) voor UI, en de attitude van huisartsen betreffende ouderen met UI.

In **hoofdstuk 2** beschrijven we de resultaten van een cross-sectionele studie over de prevalentie van urine-, fecale-, en gecombineerde incontinentie bij mannen en vrouwen van 60 jaar en ouder in de algemene populatie. We hebben in deze studie een enquête gestuurd aan alle zelfstandig wonende patiënten van 60 jaar of ouder (in totaal 5748) uit 9 huisartspraktijken verbonden aan het Nijmeegse Monitoring Project (NMP). Het responspercentage was 88 na de eerste reminder. We vonden dat 19% van de onderzochte ouderen minimaal twee keer per week last heeft van ongewild urineverlies, 6% van ongewild verlies van feces en 3% van beide. De prevalentie van urine-, fecale- en gecombineerde incontinentie stijgt zowel voor mannen als vrouwen met de leeftijd, bij mannen met name boven de 80 jaar.

De prevalentie van UI is bij vrouwen hoger in vergelijking tot mannen, respectievelijk 29% en 9%. De prevalentie van fecale incontinentie laat geen significant verschil zien tussen beide sekse, maar het type fecale incontinentie verschilt wel tussen mannen en vrouwen. Bij mannen komt het verlies van slijm uit de anus twee keer zo vaak voor dan bij vrouwen. De

prevalentie van gecombineerde incontinentie is 2% bij de mannen en 4% bij de vrouwen, dit is niet significant, behalve voor de leeftijdsgroep 65-74 jaar.

In **hoofdstuk 3** worden de resultaten gepresenteerd van een literatuurstudie over het effect van conservatieve therapie bij ouderen met stress-, urge-, en gemende incontinentie. De review laat zien dat er slechts een beperkt aantal studies zijn die voldoen aan onze methodologische kwaliteitscriteria. We concluderen dat conservatieve therapie effectief is bij ouderen met stress-, urge- en gemengde incontinentie. Het effect van farmacotherapie bij ouderen met UI is nog steeds onduidelijk en geeft kans op bijwerkingen en interacties, met name bij ouderen met co-morbiditeit en poly farmacie.

In **hoofdstuk 4** bestuderen we de factoren die bepalen of zelfstandig wondende ouderen in de algemene populatie medische hulp zoeken voor UI. We combineerden hiervoor kwalitatieve en kwantitatieve gegevens. De onderzoekspopulatie van deze studie werd gevormd door de patiënten met UI die op de vragenlijst, gebruikt in de studie beschreven in hoofdstuk 2, hadden aangegeven dat ze mee wilde doen aan het vervolgonderzoek. Omdat de studie zich richtte op ongecompliceerde UI werden de patiënten met een neurologische of psychiatrische afwijking of patiënten die een mislukte urine-incontinentie operatie hadden ondergaan, uit het onderzoek gehaald. De resultaten van deze studie zijn afkomstig uit de interviews met 56 mannen en 314 vrouwen. We vonden dat de helft van de patiënten met UI hulp zoekt bij de huisarts. Het zoeken van hulp is gerelateerd aan de duur van de klachten, de ernst van de incontinentie, de ervaren emotionele en/of fysieke hinder, en de aanwezigheid van aan incontinentie gerelateerde klachten, met name obstructie klachten. De meeste patiënten die *geen* hulp zoeken doen dat niet omdat ze de incontinentie niet ernstig genoeg vinden, of vanwege een gebrek aan kennis over oorzaak en behandelingsmogelijkheden. Een toename

van de ervaren ernst van de incontinentie of van de ervaren hinder in het dagelijks leven, of de vraag om incontinentiemateriaal zijn de belangrijkste redenen om *wel* hulp te zoeken voor de incontinentie.

In **hoofdstuk 5** bediscussiëren we de resultaten van de studie over sekse verschillen in het zoeken van medische hulp bij zelfstandig wonende ouderen met UI. De studiepopulatie was dezelfde als beschreven in hoofdstuk 4. We vonden dat mannen met minder ernstige incontinentie vaker hulp zoeken bij de huisarts in vergelijking tot vrouwen.

Het zoeken van hulp is bij vrouwen gerelateerd aan de duur van de klachten, de aanwezigheid van aan incontinentie gerelateerde klachten, zoals druk op de vagina en pijn in de onderbuik, en de ernst van de incontinentie. Bij mannen is het zoeken van hulp gerelateerd aan de hinder die ze ervan ervaren in het dagelijks leven. De meeste mannen en vrouwen die *geen* hulp zoeken voor de incontinentie doen dit niet omdat ze de incontinentie als niet ernstig genoeg beschouwen, of vanwege de verkeerde ideeën die men heeft over de incontinentie zoals ‘incontinentie is gerelateerd aan de leeftijd’ en ‘er is toch niets aan te doen’.

In **hoofdstuk 6** beschrijven we de impact van UI op de kwaliteit van leven bij ouderen in de algemene populatie en identificeren we de factoren met de grootste impact. We combineerden hiervoor kwalitatieve met kwantitatieve data. De data waren afkomstig van de interviews die we hebben beschreven in hoofdstuk 4 en 5. We vonden dat bij een groot deel van de ouderen UI niet interfereert met het dagelijks leven en dat dit de reden is waarom men geen hulp zoekt. Taboe blijkt geen belangrijke factor te zijn om van hulp af te zien. In ongeveer de helft van de patiënten heeft UI een effect op hun emotionele en sociaal welbevinden. Ondanks dat de incontinentie bij mannen minder ernstig is in vergelijking tot vrouwen ervaren ze meer hinder van de incontinentie in het dagelijks leven. De meeste mannen vinden ‘het verlies van

de controle' het vervelendste van de UI, terwijl vrouwen 'de noodzakelijke voorzorgmaatregelen' als het vervelendst ervaren. Coping strategieën blijken een belangrijke rol te spelen bij de ervaren impact van UI op het dagelijks leven.

In **hoofdstuk 7** onderzoeken we in hoeverre huisartsen ouderen met UI behandelen conform de huisartsen richtlijn (NHG) voor UI en de redenen waarom sommige huisartsen de aanbevelingen niet nakomen. Na het interview, zoals beschreven in hoofdstuk 4 t/m 6, werden de patiënten die in het verleden nog niet behandeld waren voor UI uitgenodigd om naar de huisarts te gaan. In totaal hebben 19 mannen en 71 vrouwen van 60 jaar en ouder meegedaan aan de studie. Twintig huisartsen van de Nijmeegse Universiteit onderzoeksnetwerk rapporteerde na ieder consult de gegevens over anamnese, diagnose, behandeling en follow-up. De onderzoeker vergeleek deze data met de UI richtlijn en bediscussieerde met de betreffende huisarts de redenen om anders te handelen dan de huisartsen richtlijn adviseert. We vonden dat anamnese, lichamelijk onderzoek en aanvullend urine onderzoek nagenoeg door alle huisartsen wordt uitgevoerd conform de richtlijn, maar in 25% vraagt men niet naar vaginale droogheid. Er wordt qua behandeling wel vaak afgeweken van de richtlijn. Regelmatig wordt er *geen behandeling* ingesteld omdat de patiënt de klacht niet ernstig genoeg vindt voor de voorgestelde behandeling. Daarnaast wordt 1/5 van de vrouwen met stress- en 1/3 van de vrouwen met gemengde incontinentie door de huisarts verwezen naar de fysiotherapeut. Huisartsen vinden vaak dat de fysiotherapeut beter in staat is om de behandeling uit te voeren. Huisartsen ervaren met name de gemengde incontinentie als te complex en te tijdrovend om zelf te behandelen. De huisartsen die besluiten om de conservatieve behandeling zelf uit te voeren wijken vanwege dezelfde redenen af van de huisartsen richtlijn.

Hoofdstuk 8 analyseert de studie over de attitude van huisartsen betreffende ouderen met UI en hun ervaringen met het toepassen van de huisartsen richtlijn voor UI bij ouderen in de dagelijkse praktijk. We voerden voor deze studie twee focusgroepsdiscussies uit. De belangrijke bevindingen zijn het therapeutische nihilisme van de huisarts en de lage motivatie van de patiënt, welke elkaar ook nog eens versterken. Maar ook het tekort aan kennis over incontinentie bij de huisarts en het gebrek aan tijd verslechtert de kwaliteit van zorg. Ook de co-morbiditeit bij de ouderen en de complexiteit van UI resulteert vaak in een dilemma. Vanwege de eerder genoemde barrières vindt er vaak geen lichamelijk onderzoek plaats ondanks de overtuiging van de huisarts van het nut ervan.

Hoofdstuk 9 bediscussieert de belangrijkste bevindingen van dit proefschrift.

Dankwoord

En dan ben ik nu eindelijk toe aan het laatste en waarschijnlijk meest gelezen deel van dit proefschrift. Inmiddels, ruim zes jaar en drie bevallingen verder, is het me gelukt om dit project succesvol af te ronden. Achteraf gezien misschien niet de meest ideale fase in mijn leven om een proefschrift te schrijven, maar ik ben wel trots op mezelf dat het me gelukt is. De naïeviteit, dat je ook in de aanwezigheid van kinderen het nodige werk kunt verrichten voor dit project, bleek in werkelijkheid behoorlijk tegen te vallen. Op het moment dat je kinderen hebt bepalen zij het ritme van de dag en niet jezelf. Dat neemt niet weg dat ik ze voor geen goud meer kan missen.

Met de hulp en steun van vele mensen heb ik uiteindelijk dit proefschrift tot een goed einde gebracht. Dit is een mooie gelegenheid om een ieder daarvoor hartelijk te danken. Het is onmogelijk iedereen te noemen, maar ik wil een aantal mensen naar voren halen.

Lieve Toine (Lagro-Janssen), promotor en voorzitter van de begeleidingscommissie. Ik vind dat jij als eerste genoemd moet worden in dit dankwoord. Ik vind je begeleiding van de afgelopen jaren echt geweldig. Jij was degene die vroeg of dit promotieonderzoek iets voor mij was. Ik was toen net zwanger van mijn oudste zoon en twijfelde. Jouw enthousiasme heeft mij uiteindelijk doen besluiten om het te doen. Ik heb daar ook zeker geen spijt van gehad. Ook tijdens de begeleiding van de afgelopen zes jaar heb ik je altijd bewonderd om je grote gedrevenheid en enthousiasme. Dit wist je ook altijd heel goed op mij over te brengen. Als ik even vast liep in analyses of schrijven dan was een afspraak met jou weer genoeg om met veel enthousiasme en inspiratie verder te gaan. Als ik vragen had of als ik wilde dat je commentaar gaf op iets wat ik geschreven had, kon ik altijd meteen bij je terecht en had ik razendsnel antwoord. Je was ook degene die er voor zorgde dat ik een stok achter de deur had. Dat was

goed voor mij, anders had het afronden van dit proefschrift waarschijnlijk nog langer geduurd. Ik heb ontzettend veel van je geleerd, maar het gemak waarmee jij schrijft en corrigeert valt niet te evenaren.

Beste Chris (van Weel), jij bent mijn andere promotor. Ook met jou heb ik de afgelopen jaren erg prettig samengewerkt. Ook bij jou kon ik altijd terecht als ik vragen had en ook jij was altijd uiterst snel met het becommentariëren van mijn stukken. Je was altijd goed om de artikelen die ik schreef te plaatsten binnen de brede context van de huisartsenzorg. Ook was je sterk in het corrigeren van mijn niet zo vloeiende engels.

Beste Wil (van den Bosch) en Henk (van den Hoogen), beide leden van de manuscriptcommissie. Als ik behoefte had aan een bespreking met de begeleidingscommissie dan was dat snel geregeld. Henk, jij had vaak aan enkele woorden genoeg om de zwakke plekken bloot te leggen. Wil, jij gaf me altijd veel vrijheid in wat ik schreef. De opmerkingen die je hadden waren altijd erg bruikbaar. Ik wil jullie beiden hiervoor hartelijk danken.

Marjolijn Cuppes, ook jouw bijdrage aan het slagen van dit proefschrift was groot. Het is alweer een lange tijd geleden dat je als onderzoeksassistente werkte aan dit project. Dit werk was nieuw voor je. Je startte met veel enthousiasme. Je hebt gedurende de eerste jaren van het project veel organisatorisch werk verricht en in je eentje het ongelofelijke aantal van 370 patiënten geïnterviewd. Je had altijd weer leuke anekdotes uit deze interviews waar we veel om gelachen hebben. Inmiddels vier jaar geleden zat voor jou het werk erop en ben je weer iets heel anders gaan doen. Hartelijk dank voor al het werk dat je voor me gedaan hebt.

Gedurende het project hebben verschillende studenten in het kader van hun wetenschappelijke stage een gedeelte van de data geanalyseerd. Tamara Verhagen, Nienke Vlaar, Monique

Lommers, Cindy Venema en Mariska Lasage, hartelijk dank voor al het voorwerk wat jullie voor mij hebben gedaan. Mieke Janssen, jij was degene die samen met Cindy en Monique nog aanvullende data heeft verzameld. Dit heeft mij veel werk bespaard en de data zullen opgenomen worden in een nog te verschijnen artikel.

Beste Marianne Oudenhuisen, jij hebt een van de vervelendste taken van dit proefschrift mogen vervullen. Jij hebt het ongelooflijke aantal van 370 interviews mogen uittypen. Een hele klus, niet alleen vanwege de grote hoeveelheid, maar ook de niet altijd optimale kwaliteit van de bandjes en het gesproken dialect maakte deze taak bepaald niet eenvoudig. Uiteindelijk kon je het woord ‘urineverlies’ dan ook niet meer horen, maar inmiddels is dat geloof ik alweer bijgetrokken.

Beste Ank de Jonge, gedurende een aantal jaren werkte je in een kamer tegenover mij. Het was altijd gezellig als jij er was en ik heb veel geleerd van jou wetenschappelijke kennis. Jij heb me ook enorm geholpen met mijn review artikel, niet alleen doordat je medeauteur was maar ook vanwege je kennis, mijn hartelijke dank hiervoor. Het is echt een gemis voor de vakgroep dat jij weg bent gegaan.

Hans Bor, zonder jou waren de statistische bewerkingen in dit proefschrift een puinhoop geworden. Je was altijd behulpzaam om me van adviezen te voorzien.

Alle medewerkers van de NMP praktijken. Dankzij jullie medewerking was ik verzekerd van patiënten en huisartsen voor het verzamelen van mijn data. Jullie waren zo ingesteld op het doen van onderzoek dat het verzamelen van mijn data binnen jullie praktijken heel soepel verlopen is.

Een van de laatste onderdelen van mijn proefschrift waren de focusgroepgesprekken. Het bleek lastig om huisartsen te vinden. Uiteindelijk is het toch gelukt om twee groepen bij elkaar te brengen. Fokke Meima, Sandra Jeursen, Otto Quatero, Max Kramers, Nico Vlaar, Saskia Moonen, Marielle van de Hoek-Nieuwenhuys, Joop Blaauw, Loes Veraert, Maria Elbers, Eric van Rijswijk, Jeanette Steendam, Karin van Veen en Tonnie van Kessel. Hartelijk dank voor jullie deelname en waardevolle discussies.

Beste Twanny (Jeijnsman), jij bent inmiddels expert in het verzorgen van de lay-out van proefschriften. Ook ik had de eer deze taak door jou te laten verzorgen. Zonder jouw bijdrage was de lay-out van dit proefschrift vele malen minder geweest dan het nu uiteindelijk is geworden. Hartelijk dank hiervoor.

Het werk als huisarts combineren met onderzoek doen is alleen mogelijk als je kunt varen op de steun van de praktijk. Beste Joop (Blaauw), met jou heb ik de eerste 5 jaar van het project erg prettig samengewerkt. Als ik wel eens op een andere dag naar Nijmegen moest was dat allemaal snel en makkelijk te regelen. Beste Kees (van Die), daarna ben ik jouw maat geworden. De goede en prettige werksfeer heeft zich voortgezet. Het lukte vaak om mijn praktijkdagen met jou te ruilen als dat nodig was. Dit was prettig voor de continuïteit voor de praktijk. Nancy, Sabina en Wijnanda, jullie als assistentes denken daar mogelijk wat anders over. Jullie mochten steeds weer achter de patiënten aan bellen om hun afspraken te verzetten. Ik vrees echter dat dat in de toekomst nog vaker gaat gebeuren.

Ten slotte wil ik mijn ouders hartelijk danken voor de vrijheid die ze me altijd hebben gegeven. Daarnaast heb ik doorzettingsvermogen en geduld van jullie meegekregen. Beide factoren zijn zeer bruikbaar geweest bij het voltooien van dit proefschrift.

En last but not least, lieve Maarten en lieve Haile, Jarno en Thomas. Het is gebruikelijk om je naasten in je dankwoord als laatste te vernoemen, dat doe ik dan ook maar. Jullie verdienen natuurlijk als eerste genoemd te worden, want natuurlijk zijn jullie de aller-aller belangrijkste factor geweest die er voor hebben gezorgd dat dit project zover is gekomen. Maarten, doordat jij al die jaren ouderschapsverlof hebt genomen was ik in staat aan dit proefschrift te werken. Ook stond je altijd klaar om zonder mij met drie kinderen op stap gaan, zodat ik even rustig kon werken aan mijn onderzoek. Haile, Jarno en Thomas, voor jullie was ik al die jaren dokter, maar ik deed ook werk achter de computer. Ik hoop de komende jaren weer vaker met jullie mee te gaan en dat jullie eerst reactie dan niet meer zal zijn ‘mama ga jij ook mee, hoef je niet achter de computer?’

Inmiddels zijn jullie alle drie uit de luiers. Ik hoop voor jullie dat het lang mag duren voordat jullie ze weer nodig hebben, wat dat betreft een geluk dat jullie ‘jongens’ zijn!

Curriculum vitae

Theodora Alberta Maria Teunissen werd op 22 januari 1966 geboren in het Brabantse dorpje Venhorst. Na het behalen van het VWO-diploma aan het Kruissheren College in Uden, studeerde ze van 1984-1991 geneeskunde in Nijmegen. Daarna was ze gedurende 4 jaar arts-assistente in Haarlem, Beverwijk en Lelystad. Van 1995-1998 deed ze de driejarige huisartsenopleiding vanuit Nijmegen in Bathmen en Heino. Na het beëindigen van de huisartsenopleiding begon ze als onderzoekster in Nijmegen op de afdeling huisartsgeneeskunde wat resulteerde in de start van een promotieonderzoek in 1999. Dit combineerde ze met deeltijdwerk gedurende 5 jaar als huisarts in dienstverband in Bathmen. In 2004 stapte over ze naar een eigen praktijk in Deventer.

Doreth woont in Deventer samen met Maarten en hun drie kinderen Haile, Jarno en Thomas.