Pelvic floor dysfunction and Quality of Life in women

Cover

Memorial bust Wilhelm Reich.

Born March 24, 1897 - Died November 3, 1957

Vaart van der, Carl Huibert

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Pelvic floor dysfunction and Quality of Life in women

Bekkenbodem functiestoornissen en kwaliteit van leven bij vrouwen
(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit van Utrecht,
op gezag van de Rector Magnificus, Prof. dr. W.H. Gispen,
ingevolge het besluit van het College voor Promoties
in het openbaar te verdedigen
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door

Carl Huibert van der Vaart
geboren op 26 mei 1960 te Amsterdam

Promotor

Prof. dr. A.P.M. Heintz

Co-promotor

Dr. J.R.J. de Leeuw

“Every muscular rigidity contains the history and meaning of it’s origin”

Wilhelm Reich, 1937

Aan mijn ouders
Johanna
Tim
Lisa
Ruben

Contents

Chapter 1

Introduction

Introduction

Symptoms of pelvic floor dysfunction are common in the female population.[1,2] Urinary incontinence, voiding difficulties, constipation, anal incontinence and genital prolapse are all related to a disturbance in the normal pelvic floor function. Women are more likely than men to develop symptoms of pelvic floor dysfunction. The main reason for this is believed to be childbirth, which has been related to the occurrence of both damage to the muscular and connective tissue of the pelvic floor as well as its innervation.[3] Besides childbirth, ageing, with it's consequences on muscular, nerve and connective tissues, will affect the function of the pelvic floor. Therefore, as compared to men, the longer life expectancy of women also increases their life-time risk of becoming confronted with symptoms of pelvic floor dysfunction. Despite the high prevalence of symptoms of pelvic floor dysfunction among community-dwelling women, the attention of clinicians and decision makers in health care has almost completely been focussed on women asking for treatment for urogenital symptoms. However, the fact that seventy-five percent of women with symptoms of urinary incontinence do not seek medical attention does not necessarily imply that they are not bothered by it.[4] Feeling embarrassed about their symptoms may be an important factor for not seeking help.

If we could identify, (1) risk factors for the development of pelvic floor dysfunction symptoms, (2) factors that are related to help-seeking behaviour in women with pelvic floor dysfunction, and (3) to what extent the quality of life is negatively affected in community-dwelling women with symptoms of pelvic floor dysfunction, this could lead the way to early counselling and prevention in health-care.

Risk factors for pelvic floor dysfunction

The pelvic floor is the lower border of the abdominal cavity and includes the levator ani muscles, the urethral and anal sphincter muscles and the endopelvic fascia with it's related condensations like the sacrouterine, cardinal and pubourethral ligaments. The m.levator ani forms an U-shaped sling, encircling the urogenital hiatus, the midline space through which the vagina and urethra pass. The part of the levator ani that inserts into the rectum to form a sling around it is referred to as the puborectalis muscle. The levator ani has two important functions. First, it provides a constant basal tone, thereby keeping the urogenital hiatus closed.[5] Secondly, the levator ani contracts reflexively in response to increased abdominal pressure, thereby supporting it's related pelvic organs. This action most likely contributes to the maintenance of continence.[6] The levator ani and the sphincter muscles of the pelvic floor are innervated by anterior sacral nerve roots S2-S4. Direct motor branches of these nerve roots travel over the cranial surface of the pelvic floor, making them vulnerable to stretching or compression during parturition. The external anal sphincter muscle and the striated urethral sphincter are innervated by the pudendal nerve, which also arises from sacral nerve roots S2-S4.

Several factors have been related to injury of the pelvic floor. First of all, childbirth stretches and distends the pelvic floor, resulting in functional and anatomic alterations in the muscles, nerve supply and connective tissue. Pelvic floor neuropathy has been demonstrated to occur in up to eighty percent of the women after vaginal delivery when measured during the first 48-72 hours after delivery.[3] Fortunately, after two months pelvic floor innervation had recovered in 60% of these women. Delivery trauma to the anal sphincter complex is often not directly visible as was elegantly demonstrated by anorectal ultrasonography studies after childbirth. Occult damage to the anal sphincter muscle occurred in thirty-five percent of primipara.[7] Although this subclinical damage has been postulated to be the main reason for faecal incontinence in women, epidemiological data to support this theory are lacking. A second factor which has been related to the occurrence of pelvic floor dysfunction is gynaecological surgery. A lot of attention has been focussed on hysterectomy and its possible causal relationship with the development of urinary incontinence.[8] However, the evidence is far from conclusive and is often based on retrospective studies.[9,10] A third factor that has been related to damaging the pelvic floor is chronic straining at stool or during micturition. Indeed, damage to the nerve supply of the levator muscle and external anal sphincter was shown to exist in chronically constipated patients.[11] Finally, ageing has been related to the development of urinary and faecal incontinence as symptoms of pelvic floor dysfunction. The high prevalence of urinary and faecal incontinence among institutionalized elderly probably results from a combination of diminished pelvic floor function, impaired mobility and loss of cognitive function.[12]

Pelvic floor dysfunction and Quality of life

Definition

Historically, *disease* has been viewed in terms of a biomedical model, with the outcome of treatment measured in terms of cure, disability or death. Endpoints, such as cure and complications, were obtained by using biological data from diagnostic tests.[13] In 1947, embodied in the World Health Organisation constitution, *health* was defined as not only an absence of infirmity, but also as a state of physical, social and mental well-being.[14] From this point of view and enhanced by social and economic changes, outcome assessment of treatment by biological data alone is largely insufficient. Furthermore, the latter half of the twentieth century has been characterized by an increasing life expectancy in most western countries. Prevention and management of infectious diseases, an increase in environmental toxins, the use of less healthy life styles and the overall ageing of the population all contribute to an increasing prevalence of chronic diseases. It is intuitively clear that chronic diseases have a negative effect on the individual's quality of life. Overall, it can be stated that nowadays determining the consequences of disease states and their treatment modalities requires examining both the physical and psychosocial sequella of disease.

The concept of quality of life (HRQoL) is complex. Overall HRQoL includes not only health-related factors (physical, functional, emotional and mental well-being) but also non-health-related elements, such as jobs, income, quality of environment, social factors and other life circumstances. This is reflected in the definition by Schumacher et al, who defined HRQoL as 'an individual's overall satisfaction with life and the general

sense of well-being'.[15] However, when studying the consequences of disease states on HRQoL the definition of Bowling is more comprehensive. Bowling described HRQoL as 'a concept representing individual response to the physical, mental and social effects of illness on daily living which influences the extent to which personal satisfaction with life circumstances can be achieved'.[16]
In this thesis this definition of 'Health-related Quality of life' (HRQoL) will be used.

Health-related quality of life is a multidimensional concept with essentially four broad domains: physical, functional, psychological and social health. Other important health-related factors like vitality, pain, anxiety and depression are often included within these four categories.[17] The basic concept is shown in figure1.

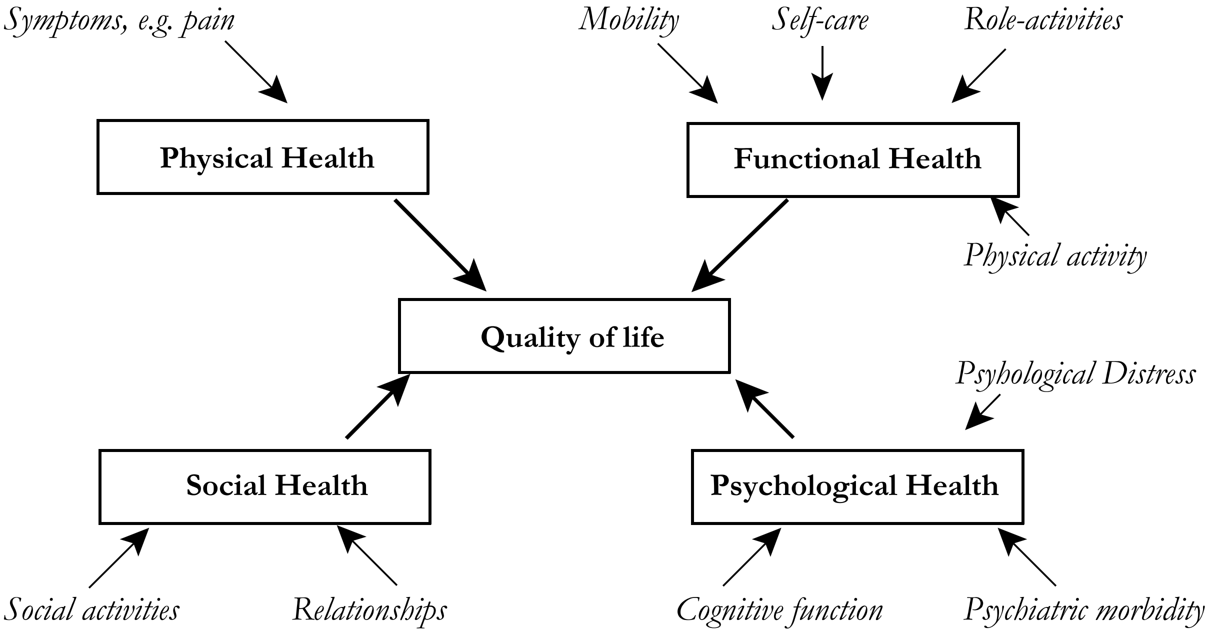

Figure 1. Interactions in Quality of Life models. From MacDonagh 1996.[17]

Since HRQoL questionnaires measure the perception of health and not the physiological state of disease, they are often viewed as 'soft' or subjective by clinicians and regarded as less meaningful than physiological measures. However, HRQoL measures are really outcome measures that represent a patient's perception of health outcome of treatment.[18] Physiologic measures provide information to the clinician but are of limited interest to patient. They often correlate poorly with functional capacity and well-being, the areas in which patients are most interested and familiar with.[19] Apart from the individual patient's view, HRQoL measures are also clinically meaningful from a population point of view. Measuring HRQoL in patients with chronic disorders will provide health care workers with information on costs and resource utilities, which will hopefully add to the development of adequate, high-standard health-care systems.

Instruments for measuring HRQoL

Usually, HRQoL is measured by two of the following types of instruments: generic instruments that provide a summary of HRQoL and disease-specific instruments that focus on problems associated with a particular disease state or patient group. They have in common that they are usually made up of a number of items that are added up in a number of domains. A domain refers to the area of behaviour or experience that we are trying to measure. Both generic and disease-specific measurements have their advantages and disadvantages. The main advantages of generic HRQoL measurements is that they can be used to compare different patient populations and different conditions. A major disadvantage is that they may not focus adequately on a specific area of interest of a particular disease and therefore have limited sensitivity to changes induced by treatment.[19] Advantages of disease-specific HRQoL measures are that (1) they include only domains of interest regarding the disease under study, which may enhance the patient's compliance and (2) they are more sensitive to change and therefore more useful as outcome measure of treatment. A possible disadvantage of disease-specific HRQoL measures is that they cannot be used to compare different disease groups. In general it is advocated to use both generic and disease-specific HRQoL measurements. The results of the disease-specific measurement will be of importance to the patients themselves and the clinician.

The results of the generic measurement, because of it's ability to compare different diseases and populations, may be of greater value for decision makers in health-care.

Several disease-specific HRQoL questionnaires for urogenital symptoms have been developed in recent years. [20-24] An important problem of these questionnaires is that, after they have been constructed in relatively small, specific populations, their generalizability has not been properly tested It is therefore unclear if the use of these questionnaires in populations with different characteristics as the population it was constructed in, will provide reliable results.

Help-seeking behaviour

Despite the high prevalence of symptoms of pelvic floor dysfunction it is well known that only a minority of women affected will seek professional help. Several factors can be related to this "help-seeking" behaviour. First of all, the type and objective severity of the disease may determine if one seeks help or not. Secondly, individual and socio-demographic factors may affect help-seeking behaviour. The likelihood of visiting a doctor is reported to be higher for women, unemployed people, people with chronic diseases and those with a public insurance.[25] This effect is stronger for persons who are considered to have minor psychiatric disturbances. For example, in women with Irritable Bowel Syndrome (IBS), psychosocial factors were shown to be associated with health-care seeking.[26] Symptoms included in the concept of (IBS), like constipation, abdominal pain and faecal incontinence, are comparable to symptoms of anorectal dysfunction due to pelvic floor disorders. Therefore, it is very well possible that psychosocial factors also play a role in help-seeking behaviour for symptoms of pelvic floor dysfunction. However, the way in which psychosocial factors determine help-seeking behaviour is poorly understood. The way in which individuals cope with the problems and stress induced by illness may be an important factor in this relationship between help-seeking behaviour and psychosocial factors.

The last two decades, the concept of coping has received much attention in psychosocial research.[27,28] However, coping with the stressful circumstances or events of pelvic floor dysfunction has only been marginally studied.[29] Coping refers to the way in which people respond and behave in the response to stressful events. Several distinctions in coping strategies have been made. The most commonly used dimensions are problem-oriented versus emotional-oriented ways of coping and active or approaching versus passive or avoiding ways of coping. In general, which coping process is good or bad, depends on the particular person, the specific type of encounter, in the short or long run and the outcome modality being studied, for example emotional, social functioning or physical health. Where coping refers to the way people behave in response to stress, the psychological concept of "locus of control" refers to beliefs people have whether the cause or course of specific events is attributed to personal (internal control) or situational (external control) elements.[30] It is regarded as a stable personality characteristic and internal and external locus of control each have been associated with certain coping strategies. For example, people who hold an internal locus of control make greater use of problem-oriented coping. In contrast, those who regard their illness as out of personal control (accidental or controlled by powerful others) make more use of emotion-oriented strategies.[31,32]

Determining the factors that are associated with help-seeking behaviour in women with symptoms of pelvic floor dysfunction is important from two perspectives. First, women who tend to seek help at low symptom levels are at increased risk of undergoing diagnostic and therapeutic procedures, where in fact it is not the severity of the illness but their response to it that determines their help seeking. Therefore, they are exposed to iatrogenic risks (inherently related to diagnostic procedures and treatments) that may well outweigh the possible benefits they can gain. On the other hand, less efficient coping strategies may be responsible for delay in help-seeking by women with severe symptoms. As a consequence, they may not benefit from treatments that could improve their quality of life substantially.

Aims of the thesis

At the time of the initiation of the study, no validated disease-specific HRQoL questionnaire for measuring pelvic floor dysfunction symptoms was available in the Dutch language. Such a questionnaire was needed to measure these symptoms and their influence on HRQoL in general and in relation to two major female life events, namely childbirth and hysterectomy.

In addition, such a questionnaire is essential to assess whether HRQoL and help-seeking behaviour can be predicted by the severity of symptoms, coping strategies and locus of control. From the few available disease-specific HRQoL questionnaires for pelvic floor dysfunction we selected the Urogenital Distress Inventory and Incontinence Impact Questionnaire.[20] These questionnaires were the only one available that measure both different symptoms of pelvic floor dysfunction as well as all important aspects of HRQoL.

The aims of the thesis are fourfold:

1. To test the reliability and validity of the Dutch version of the Urogenital Distress Inventory and Incontinence Impact Questionnaire;
2. To study the consequences of symptoms of urogenital dysfunction on HRQoL in community-dwelling women as well as in clinical patients;
3. To study the consequences of childbirth and hysterectomy on the prevalence and severity of certain symptoms of pelvic floor dysfunction;
4. To study the effect of sociodemographic factors, coping strategies and locus of control on disease-specific HRQoL and help-seeking behaviour in women with symptoms of pelvic floor dysfunction.

Outline of the thesis

To address the research questions we conducted the following studies.

In *Chapter 2* we report on the prevalence of urogenital symptoms and the impact of these symptoms on HRQoL. Furthermore we tested the psychometric qualities of the Dutch version of the Urogenital Distress Inventory (UDI) and Incontinence Impact Questionnaire (IIQ). Subjects for the study were; (1) women from a random, cross-sectional community sample, who responded to our invitation to participate in a study on urogenital and defecation disorders and; (2) women who presented themselves at the outpatient gynecological clinic of the University Medical Center Utrecht with symptoms of pelvic floor dysfunction. Data on the overall prevalence of urogenital symptoms as well as the internal consistency, content, construct and criterion validity of the Dutch UDI and IIQ are presented.

In *Chapter 3* we describe the results of a study on the risk factors for urinary incontinence and symptoms of overactive bladder in a random, cross-sectional population of young and middle aged women. In addition, the impact of these symptoms on HRQoL, both generic and disease-specific, are presented. This chapter ends with remarks and a hypothesis about the pathophysiological background of symptoms of an overactive bladder and urinary urge incontinence.

In *Chapter 4* we comment on the effect of childbirth on flatus and faecal incontinence. We studied a random population based, cross-sectional cohort of women aged 20-70 years to assess the prevalence of flatus and faecal incontinence in parous and nulliparous women. The aim of this study was to find out if childbirth was an independent risk factor for flatus or faecal incontinence.

In *Chapter 5* we used data from our population based cross-sectional study and data from a prospective study on the consequences of hysterectomy. We compared the prevalence and bothersomeness of urgency-related and stress-related urinary incontinence of women without a history of hysterectomy and women scheduled for hysterectomy. The aim of this study was to find out if women scheduled for hysterectomy differed from women without a history of hysterectomy regarding the type and severity of urinary incontinence.

In *Chapter 6* we report the results of a study comparing the long-term consequences of hysterectomy on urgency-related and stress-related urinary incontinence. We used a population based, cross-sectional design as was described in Chapter 2. Women with a history of hysterectomy were compared to women without a history of hysterectomy. Potential confounders like age and parity were controlled for. The aim of the study was to find out if hysterectomy increases the risk of one or both types of urinary incontinence in later life.

In *Chapter 7* we describe the effect of sociodemographic factors and coping strategies on HRQoL in women with symptoms of pelvic floor dysfunction. HRQoL was expressed in general (RAND-36), disease-specific (IIQ) and depressive symptoms as measured with the Center of Epidemiologic Studies-Depression scale (CES-D). The sample we used was the same as described in Chapter 2. In addition to the research question, this chapter was also used to report on the development and internal consistency of the Defecation Distress Inventory (DDI). The DDI is a disease-specific questionnaire for defecation symptoms. Together with the UDI, this questionnaire provides an overall view of both urogenital as well as defecation symptomatology.

In *Chapter 8* we present the results of a study on the relationship of coping strategies and locus of control with help-seeking behaviour in adult women. Both data from the population sample as well as the clinical sample were used. Separate analysis are presented for women with mild symptoms and women with severe symptoms as measured with the UDI and DDI.

Chapter 9 contains the general discussion.

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Chapter 2

Measuring Health-related Quality of Life in women with urogenital dysfunction: The Urogenital Distress Inventory and Incontinence Impact Questionnaire revisited.

CH van der Vaart, MD, JRJ de Leeuw, PhD, JPWR Roovers, MD, APM Heintz, MD, PhD

Introduction

Symptoms of urogenital dysfunction are common in the female population.[1,2] In the last two decades, there is an increasing awareness that the consequences of these symptoms for general well-being is not only determined by the type and severity of the symptoms but also by the individual's psychosocial adjustment to it. This is especially true for chronic disorders like urinary incontinence or genital prolapse that are often not characterized by severe physical abnormalities or have impact on mortality. Although these symptoms are not life-threatening, women affected often report limitations in their physical, social and emotional functioning. However, it is known that these physical and psychosocial limitations are poorly associated with objective tests like urodynamic assessment.[3] Objective tests, how accurate they may be in establishing a diagnosis, do not account for the patient's perception of the problem. It is therefore recommended to include measurements of well-being or Health-related Quality of Life (HRQOL) in the outcome assessment of treatment for urogenital dysfunction.

Essentially, there are two approaches for measuring HRQOL. First, a general profile of perceived health, with dimensions such as physical, psychological and social health can be assessed using generic measures. These instruments are not specific to any particular condition and therefore allow comparisons among different conditions. However, these instruments do not determine the specific impact a given condition has on HRQOL. Condition- or disease specific HRQOL instruments are designed to measure the specific consequences a particular disease has on quality of life. Therefore, they allow a more in-depth assessment of specific concerns pertinent to that particular condition. An example of a disease-specific HRQOL questionnaire for urogenital symptoms is the Urogenital Distress Inventory (UDI) and the Incontinence Impact Questionnaire (IIQ).[4]

In the Netherlands, no disease-specific HRQOL measurement for urogenital symptoms was available that has passed the process of translation and validation adequately. Simple translation is not enough to consider a questionnaire to be valid.

Cultural differences may reflect themselves in different perception of the impact of particular symptoms and therefore validity of a translated version has to be tested. Three types of validity are distinguished: content validity, criterion validity and construct validity. Content validity refers to the adequacy with which a specific domain or content is sampled. Criterion validity refers to how well the instrument correlates with a "golden standard" measure. A "golden standard" for different urogenital symptoms does not exists and therefore criterion validity has to be accounted for by known-groups comparison. Construct validity refers to whether the questionnaire scales measure the underlying construct adequately.

Besides problems that may occur due to cultural differences, the original UDI/IIQ was developed in a selected population of higher educated women, aged 45 years or older. This implies that it is possible that using the UDI/IIQ in a population with different characteristics will yield different results. If this is true, comparing data obtained with the UDI/IIQ between different study groups may not accurately reflect true differences. Ideally, a disease-specific HRQOL questionnaire on urogenital symptomatology should be tested in a broad population sample, adequately representing different age groups and socio-demographic characteristics.

The aim of this study was to report on the prevalence of urogenital symptoms in a large random population sample and on the psychometric qualities of the Dutch translation of the UDI and IIQ.

Material and Methods

Study population

The study population consists of two samples of women. The first sample is a random population sample of 3200 women, between 20 and 70 years of age, that was obtained from the population registration office of a suburban area in the central part of the Netherlands in 1999. These women were invited to participate in a study on the prevalence and consequences of urogenital and defecation symptoms in the female community. All women received a questionnaire with an accompanying letter explaining the purpose of the study. Care was taken to encourage women without any urogenital symptoms to participate, emphasizing the importance of their cooperation to compare their situation with that of women with symptoms. All women were sent a reminder after four weeks. Two-thousand forty-three women responded (63.8%).

The second sample consists of 196 consecutive women who reported themselves with urogenital dysfunction to the gynecologic outpatient clinic of the University Medical Center Utrecht, The Netherlands. These women represent 85% of women that were eligible (34 out of 230 women refused to participate). Women that refused to participate did not differ from participators regarding their age and main symptoms.

Study design

All women received a self-administered questionnaire. The community sample in the second half of 1999. The clinical sample received the questionnaire between April 1999 and June 2000, at the time of their first visit to our clinic. The study was approved by the local ethics committee, with the restriction that contacting non-responders of the community-sample was not allowed.

Socio-demographic data were collected for all women, including age, marital status, parity and educational level. The educational level was dichotomized in analysis into primary only (low education) and secondary or higher (higher education).

Quality of life is measured with a generic and disease-specific questionnaire. The Rand-36 is a generic HRQoL questionnaire that measures functioning on 8 domains: general health, physical functioning, mental health, social functioning, vitality, bodily pain, role limitation because of physical functioning and role-limitation because of emotional functioning [5,6]. The domain scores range from 0 to 100, with 100 representing the best HRQoL. Disease-specific quality of life is measured with the Urogenital Distress Inventory (UDI) and the Incontinence Impact Questionnaire (IIQ).[4] The UDI consists of 19 items and every item consists of two parts: whether or not a *symptom* is present and the amount of the bother the woman experiences from that symptom. The latter is measured with a four-point Likert scale ranging from not at all to greatly. The original UDI consists of three domains, namely: stress incontinence symptoms, irritative symptoms and obstructive/discomfort symptoms. For factor analysis, the scores of both parts of each question were transformed into: 1 = no symptom, 2 = symptom present, no bother, 3 = symptom present, slightly bothersome, 4 = symptom present, moderately bothersome, 5 = symptom present, greatly bothersome. In calculating domain scores, women not having a symptom or having a symptom without bother are scored equally. The domain scores are transformed into a continuous scale ranging from 0 to 100. A high score on the UDI domains indicates more bothersome symptoms on that particular domain. The original IIQ consists of 30 items about the impact of urogenital symptoms on four aspects of quality of life: physical functioning, emotional functioning, travel/mobility and social functioning. The impact on each item is measured with a four-point Likert scale, ranging from not at all (1) to greatly (4). The domain scores are transformed into a scale ranging from 0 to 100. A high score on the IIQ domains indicates that the person's well-being on that particular domain is negatively affected. The original UDI and IIQ was translated by the process of forward-backward translation by two native speakers.[7]

Data about the diagnosis and the grading of the genital prolapse were collected from the medical records of the clinical sample. A distinction was made between anterior vaginal wall prolapse (cystocele), posterior vaginal wall prolapse (rectocele), descensus uteri and enteroceles. Grading of the prolapse was performed at maximal straining in the 45° supine position and was graded as follows: 0 = no prolapse, 1 = prolapse ≥1 cm above the hymenal ring, 2 = prolapse between 1 cm above and < 1cm below the hymenal ring and grade 3 = prolapse >1 cm below the hymenal ring.
In analysis the grading of the prolapse was used as an interval variable.

Statistical analysis

Principal axis factoring with varimax-rotation was used to test the construct validity of the Dutch translation of the UDI and IIQ. Cronbach's alpha was used as a measure for internal consistency of the domains.[8] A Cronbach's alpha value > 0.70 is considered to represent a good internal consistency. Pearsons' correlation coefficients were calculated between the UDI/IIQ domains and the RAND-36 domains.

We hypothized that women from the clinical sample ("clinical cases") had more severe complaints as compared to women from the community sample with urogenital symptoms ("community cases"). This difference should be reflected in statistical significant differences on the IIQ domains. An unpaired t-test was used to compare the two samples on the IIQ domains. If statistical significant unequal variances were identified with the Levene's test for equality of variance, the significance level was adjusted for these unequal variances.

As a second indication for criterion validity we tested how well the individual UDI domains could predict the existence of a genital prolapse or urinary incontinence. We therefore had to assume that the diagnosis made by the physician was accurate enough to be used as a "Golden standard" in this analysis. Receiver Operating Characteristics (ROC) curves were calculated to test the quality of the individual UDI domains as a diagnostic test for making a diagnosis of genital prolapse or urinary incontinence. All statistics were performed with the statistical package SPSS 10.0.

Results

The baseline characteristics of the community sample and clinical sample are shown in Table 1. Women from the clinical sample were statistical significantly older, lower educated and reported more symptoms on the UDI as compared to the community sample. A total of 1644 women (79.5%) from the community sample had at least one positive symptoms on the UDI.

Table 1. Characteristics of the study population

	Community sample n = 2043	**Clinical sample** n = 196
Mean age	46.5 (0.3)	54.7 (0.8)‡
Educational level		
Primary only	439 (21.5)	81 (41.0)‡
Secondary or higher	1604 (78.5)	115 (59.0)
Marital status		
Married	1360 (66.6)	152 (77.6)
Divorced	146 (7.1)	23 (11.5)
Widow	98 (4.8)	13 (6.9)
Never married	439 (21.5)	8 (4.0)
Race		
White	2002 (98.0)	190 (97.0)
Non-white	41 (2.0)	6 (3.0)
Diagnosis *		
Genital prolapse	-	142 (72.4)
Urinary incontinence	-	88 (44.9)
Positive symptoms on UDI		
0	399 (20.5)	-
1-5	1132 (55.2)	37 (18.9)‡
6-10	464 (22.6)	111 (56.6)
11-15	53 (2.6)	47 (24.0)
16-19	3 (0.1)	1 (0.5)

Values are expressed as numbers (%) or means (standard error)

* For clinical sample only. Diagnosis made by the physician, combination of genital prolapse and urinary incontinence possible.

‡ $p<0.01$ Pearsons chi-square or unpaired t-test

Factor solution and internal consistency

Data from the community sample were used to perform a factor analysis on the UDI and IIQ. The results of the UDI factor analysis is presented in Table 2.

Table 2. Factor analysis of the 19-items Urogenital Distress Inventory

	Factor loading				
	1	2	3	4	5
Lower abdominal pressure	0.74	0.10	0.21	0.01	0.15
Pain or discomfort lower abdomen	0.72	0.01	0.11	0.01	0.12
Heaviness or dullness in pelvic area	0.68	0.01	0.10	0.18	0.02
Pelvic discomfort while physically exerting	0.64	0.10	0.01	0.29	0.03
Pain when urinating	0.28	0.10	0.02	0.01	0.14
Push on vaginal wall to have bowel movement	0.27	0.20	0.01	0.01	0.15
Urine leakage related to a feeling of urgency	0.15	0.72	0.29	0.01	0.01
Small amounts of urine leakage (drops)	0.19	0.70	0.16	0.01	0.12
Urine leakage without physical activity/urgency	0.12	0.68	0.01	0.01	0.18
Urine leakage related to physical activity	0.19	0.65	0.14	0.01	0.01
Large amounts of urine leakage	0.04	0.53	0.02	0.01	0.12
Frequent urination	0.12	0.20	0.79	0.01	0.17
Strong feeling of urgency to empty the bladder	0.21	0.30	0.59	0.01	0.01
Frequent nighttime urination	0.15	0.12	0.52	0.01	0.18
See a bulging or protrusion in the vaginal area	0.12	0.01	0.01	0.87	0.01
Feel a bulging or protrusion in the vaginal area	0.27	0.10	0.10	0.78	0.01
Feeling of incomplete bladder emptying	0.32	0.22	0.21	0.11	0.73
Difficulty emptying the bladder	0.20	0.21	0.14	0.18	0.72
Bed-wetting	0.01	0.01	0.06	0.01	0.15

Principal axis factoring with Varimax rotation. Factor solution explained 58.8% of variance in the model.

The following five domains explained 58.8% of the variance in the model: Discomfort/Pain (6 items; Cronbach's alpha .78), Urinary incontinence (5 items; Cronbach's alpha .77), Overactive bladder (3 items; Cronbach's alpha .74), Genital prolapse (2 items; Cronbach's alpha .82) and Obstructive micturition (2 items; Cronbach's alpha .80). One item (bed-wetting) had a low factor loading on all domains and did not explain an additional proportion of variance in the factor analysis model. Therefore this item was deleted from the UDI. The same domains emerged when performing factor analysis on the data of the clinical sample. Finally, we tried to identify if different factor solutions occurred when comparing data of the lower educated with the higher educated women and between women younger and older than 45 years. No differences were found.

The results of the factor analysis of the IIQ is presented in Table 3a and Table 3b. Besides the four domains as described by Schumaker (factor 1 = mobility/travel; factor 2 = emotional functioning; factor 3 =physical activity; factor 4 = social functioning), we identified an extra domain that contains 4 items about embarrassment (factor 5). Cronbach's alpha for these five domains ranged from 0.83 (embarrassment) to 0.93 (mobility). The factor solution of the IIQ explained 65.1% of the total variance. Again in subgroup analysis (age and educational level) the same domains emerged.

For both the UDI and IIQ the factor solution data showed that there was a high item discriminant validity (the correlation of an item with its own scale as compared with other scales). Only one of the items of the IIQ (physical health) had a factor loading > 0.40 on both the IIQ emotional (0.47) and IIQ physical (0.45) domain. For obvious reasons we decided to add this items to the IIQ physical domain.

Table 3a. Results of factor analysis of the 30 items of the IIQ.

		Factor loading				
	Original domain*	1	2	3	4	5
Travel > 30 minutes	T	0.73	0.21	0.28	0.22	0.13
Places - not sure of rest rooms	T	0.70	0.26	0.21	0.10	0.23
Entertainment	T	0.67	0.25	0.24	0.39	0.13
Shopping	A	0.65	0.26	0.21	0.15	0.31
Social activities	So	0.59	0.26	0.33	0.39	0.22
Travel < 30 minutes	T	0.59	0.15	0.33	0.38	0.01
Physical recreation	A	0.57	0.25	0.28	0.14	0.21
Hobbies	A	0.54	0.31	0.27	0.10	0.19
Vacation	T	0.50	0.30	0.21	0.32	0.25
Church/Temple attendance	So	0.44	0.27	0.10	0.36	0.16
Nervousness	E	0.18	0.69	0.10	0.21	0.24
Frustration	E	0.22	0.66	0.22	0.18	0.27
Fear	E	0.21	0.65	0.17	0.20	0.21
Depression	E	0.15	0.63	0.14	0.11	0.11
Emotional health	E	0.23	0.60	0.19	0.30	0.29
Anger	E	0.22	0.52	0.17	0.01	0.10
Physical health	A	0.30	0.47	0.45	0.14	0.01
Sleep	E	0.34	0.42	0.32	0.11	0.01

Principal axis factoring with Varimax rotation. Factor solution explained 65.1% of variance in the model. * Original domains; T = Travel; A = Physical activity; E = Emotional: So = Social.

Table 3b. Results of factor analysis of the 30 items of the IIQ.*

		Factor loading				
	Original domain	1	2	3	4	5
Volunteer activities	So	0.36	0.10	0.59	0.36	0.19
Household chores	A	0.34	0.32	0.58	0.13	0.11
Employment	T	0.38	0.16	0.57	0.29	0.24
Sexual relations	So	0.15	0.32	0.57	0.21	0.21
Relationship with friends	So	0.32	0.28	0.22	0.79	0.21
Having friends visit	So	0.37	0.19	0.25	0.66	0.25
Relations with family	So	0.22	0.29	0.38	0.62	0.24
Fear of odor	So	0.16	0.16	0.10	0.17	0.76
Fear of embarrassment	E	0.26	0.29	0.21	0.22	0.66
Embarrassment	E	0.25	0.32	0.16	0.10	0.54
Way dress	So	0.23	0.30	0.37	0.34	0.45

* Legend as Table 3a.

Construct validity

Construct validity was investigated by comparing the scores of the UDI domains and IIQ domains with scores on the RAND-36 domains. Because of the disease-specific character of the IIQ, only women who replied positively to one or more questions of the UDI were invited to fill out these IIQ questions. A total of 960 out of the 1644 women (58.4%) with UDI symptoms answered the IIQ questions. The relationship between the number of UDI symptoms and answering the IIQ questions was as follows. Of the 1132 women with 1 to 5 positive UDI symptoms, 529 (46.7%) answered the IIQ questions. Eighty-one percent of women with 6-10 positive UDI symptoms, 98.1% of women with 11-15 positive UDI symptoms and 100% of women with more than 16 positive UDI symptoms answered the questions of the IIQ.

The Pearsons' correlation coefficients between the five IIQ domains and the eight RAND-36 domains are shown in Table 4.

Table 4. Correlation coefficients between the RAND-36 and IIQ domains

	Incontinence Impact Questionnaire				
	Mobility	Physical functioning	Social functioning	Emotional health	Embarrassment
RAND 36					
Physical functioning	- .46	- .47	- .33	- .40	- .28
Social functioning	- .34	- .37	- .27	- .35	- .22
Role limitations physical	- .33	- .37	- .23	- .33	- .20
Role limitations emotional	- .22	- .25	- .19	- .31	- .21
Vitality	- .29	- .32	- .20	- .34	- .21
Mental health	- .24	- .28	- .17	- .35	- .23
Pain	- .31	- .36	- .17	- .29	- .16
General health	- .29	- .33	- .22	- .33	- .20

Pearsons correlation coefficients. All significant at p<0.001

All correlations were significant at p<0.001. However, because of the large sample size, statistical significant correlations occur at relatively low correlation coefficients. In general the IIQ mobility, physical and social functioning domains correlated moderately to good (correlation coefficient > 0.30) with corresponding RAND-36 scales.

The IIQ emotional health domain also correlated moderately well with the emotional/mental health domains of the RAND-36.

Because of the condition-specific nature of the IIQ we expected the correlation coefficients between the UDI domains and the IIQ domains to be higher than those between the UDI domains and the RAND-36 domains. The Pearsons' correlation coefficients between the UDI domains and RAND-36 domains ranged from -0.06 to -0.30. The only correlation coefficient > 0.30 was that between the UDI obstruction/discomfort domain and the RAND-36 pain domain. The Pearsons' correlation coefficients between the domains of the UDI and the five IIQ domains are shown in Table 5.

Table 5. Correlation coefficients between the UDI domains and IIQ domains

	Incontinence Impact Questionnaire				
	Mobility	Physical functioning	Social functioning	Emotional health	Embarrassment
UDI					
Discomfort/Pain	.34	.38	.28	.36	.25
Overactive bladder	.44	.31	.25	.36	.24
Obstructive micturition	.39	.33	.27	.36	.30
Genital prolapse	.16	.25	.18	.23	.12
Urinary incontinence	.30	.24	.21	.28	.38

Pearsons correlation coefficients, all correlations are significant at $p<0.0001$

Overactive bladder, discomfort/pain and symptoms of obstructive micturition correlated best with the IIQ mobility, physical functioning and emotional domains (correlation coefficient between .31 and .44). Genital prolapse symptoms showed a weak correlation with all IIQ domains. Urinary incontinence symptoms showed the highest correlation with the IIQ embarrassment domain (correlation coefficient 0.37).

Criterion validity

The criterion validity of the IIQ and UDI was tested in several ways.

First, we used the data of the diagnosis made by the physician in the clinical sample. These data were used to analysis the correlations between the type and grade of genital prolapse and the UDI domains. The UDI prolapse domain score showed a statistical significant positive correlation with the severity of the descensus uteri (Pearsons' correlation .37) and enterocele (Pearsons' correlation .27). The UDI discomfort/pain domain was only significantly positively correlated with the enterocele grading (Pearsons' correlation .23).

Secondly, data about the diagnosis were also used to assess how well the UDI domain scores could predict the presence or absence of genital prolapse or urinary incontinence. When we used the UDI prolapse score to try to identify women with a diagnosis of genital prolapse we found an area under the ROC curve of .81. Thus, with the UDI prolapse scale, the score of a randomly selected prolapse patient exceeds that of a randomly selected non-prolapse patient an estimated 81% of time. The areas under the ROC curve for the other four domains of the UDI in relation to genital prolapse were approximately 0.50 (0.35 - 0.57). The same analysis was performed for the diagnosis urinary incontinence obtained from the medical record. The UDI incontinence scale showed an area under the ROC curve of .81. Again the area's under the ROC curve for the other four domains of the UDI in relation to urinary incontinence were approximately 0.50 (0.35 - 0.60).

Finally, we tested the criterion validity of the IIQ by known-group comparison. We compared the community sample cases and the clinical sample with regard to their mean scores on the IIQ domains. Table 6 shows the results of this analysis.

Table 6. IIQ domain scores for the community sample and the clinical sample

	Community sample (n=960)	Clinical sample (n=196)
IIQ domains		
Mobility	8.3 (0.5)	24.1 (1.7)*
Physical	4.9 (0.4)	24.1 (1.7)*
Social	3.3 (0.4)	10.0 (1.4)*
Emotional	6.8 (0.4)	18.8 (1.5)*
Embarrassment	6.8 (0.4)	14.7 (1.7)*
Total	30.1 (1.7)	91.6 (6.5)*

Independent sample t-test. * $p< 0.0001$

Women from the clinical sample had a significant higher score (worse HRQoL) on all the IIQ domains as compared to women from the community sample.

Discussion

Our study shows that urogenital symptoms are common among adult women. As measured with the UDI, four out of five women will have at least one urogenital symptom. Increasing number and bothersomeness of symptoms were positively correlated with a reduction in well-being, especially when measured with the disease-specific IIQ. Furthermore we found that, when used in a large population of adult women, the UDI and IIQ showed a different scale construction as compared to the original version. Five domains were identified in the UDI namely: Discomfort/Pain, Urinary incontinence, Overactive bladder, Genital prolapse and Obstructive micturition. In addition to the four original domains, factor analysis of the IIQ showed a fifth domain with 4 items related to embarrassment. In the analysis of the psychometric qualities of these UDI domains and IIQ domains we demonstrated an adequate internal consistency, content-, criterion- and construct validity.

Questionnaires that are used to identify urogenital symptoms should be easy to understand, applicable to a broad defined domain, and most important of all be able to distinguish clinical relevant conditions. The original UDI was developed with data from a selected population of 162 women with urinary incontinence. These women were well educated, had upper-middle incomes and were > 45 years old. Among the exclusion criteria were lower urinary tract infection and urinary obstruction. Excluding these women while developing a questionnaire on urogenital symptoms somehow seems odd. Furthermore, some of the items that were originally pre-selected to belong to one of the three domains (Stress -, Irritative - or Obstructive/Discomfort symptoms), proved to fit better in another domain after factor analysis. However, in the original UDI, the scale membership of these items was not adjusted after factor analysis. This is in part reflected by the poor internal consistency of the original UDI Stress domain (Cronbach's alpha .48). Therefore, the reliability and validity of the original UDI has only been established for the selected domain it was derived from. The strength of our study is that we applied the UDI to a random sample of women, both low and higher educated, in a broad age-range, and did not make a domain division of items before factor analysis. The domains that emerged are clinically sound, reliable, have good discriminative properties and proved to be of adequate criterion validity when comparison was made with the clinical diagnosis.

Questionnaires that are used to estimate condition-specific HRQoL should include the three principal dimensions of HRQoL, namely physical, emotional and social functioning. In addition, specific domains of the condition-specific HRQoL should reflect specific consequences of the disease state itself. The main difference between our version of the IIQ and the original one is that we identified a fifth domain with four items about embarrassment. Several studies showed that embarrassment (fear of odour, fear of embarrassing situations) is an important factor by which urinary incontinent women report to be bothered substantially.[9,10] Our results confirm this. We found that the UDI Incontinence domain had the highest positive correlation with the IIQ embarrassment domain. The higher correlation coefficients between the UDI and IIQ as compared to the UDI and RAND-36 further supports the validity of the IIQ as condition-specific HRQoL instrument for urogenital symptoms.

Our study has several possible limitations that need to be discussed. First, our study was performed with the Dutch translation of the UDI and IIQ on a Dutch population. Although we carefully handled the translation process (Forward-backward translations, native speakers, discussion after both translations) some small aberrations from the English version are inevitable. However, the UDI and IIQ factor solutions are solid, with a high item discriminant validity (the correlation of an item with its own scale as compared with other scales). We therefore do not believe that the translation is responsible for the differences between the original and the Dutch version.
Secondly, because of the design of our study the sensitivity to change of the UDI and IIQ could not be established. It is usually recommended to compare the sensitivity to change of a HRQoL questionnaire with a change in an objective parameter, preferably a "Golden standard". However, there is no golden standard in outcome analysis of treatments for urinary incontinence or genital prolapse. Symptoms of urinary incontinence were shown to correlate poorly with urodynamic assessment and the reliability of the "pad-test" (urine loss in weight per hour or 24-hour period) as measurement of the severity of urine loss is subject of discussion.[3,11] Only the frequency of incontinent episodes has been shown to have a positive correlation with the degree of bothersomeness.[1] The original UDI/IIQ proved to be sensitive to change and to correlate significantly with the number of incontinence episodes but not with the pad test results. However, the primary goal of a condition-specific HRQoL questionnaire is to account for the subjective intra-personal characteristics that are part of the complex mechanism by which a particular patient will respond to a particular symptom. Therefore, it is difficult to make statements about the responsiveness of an HRQoL measurement by comparing it to changes in an objective parameter. The latter may not give credit to changes in the perceived severity of the problem, which can be of more importance from

a patients point of view.

A final point of concern is the fact that only 58.4% of women with at least one urogenital symptom present answered the questions of the IIQ. There was a clear relationship between the number of reported symptoms on the UDI and the willingness to fill in the IIQ questionnaire. We believe that women with few symptoms were less likely to feel bothered by these symptoms and therefore decided to skip the IIQ questions in the questionnaire. Since the IIQ is intended to measure disease-specific HRQoL for urogenital symptoms, we believe that it is especially important that women with moderate to serious complaints answered the IIQ to give a valid impression of the specific problems they encounter (like embarrassment). Therefore, the fact that especially women with more symptoms responded to the IIQ questions is likely to have improved the face validity of the IIQ domains we found.

In the last few years, several other HRQoL questionnaires on urinary incontinence have been developed.[12-15] These instruments were all constructed in selected (small) populations and often do not contain information on both the different types of urogenital symptoms as well as on the disease-specific HRQoL like the combination of UDI and IIQ does. The Bristol Female Lower Urinary Tract Symptoms questionnaire evaluates the presence or absence of symptoms and the degree of bothersomeness.[12] It does not measure the impact of symptoms on HRQoL dimensions.

The I-QoL (Incontinence-Quality of Life) questionnaire was derived from interviews with 37 patients (gender not stated) and tested on 62 patients, both male and female.[13] It assesses only the impact of urinary incontinence and not of other urogenital symptoms. The total score of the I-QoL showed a good correlation with the generic MOS SF-36 domains. In a later version, factor analysis of the I-QoL revealed three domains namely; avoidance and limiting behaviour, psychosocial impact and social embarrassment.[14] These findings are in accordance with our results, showing a highly significant positive correlation between the UDI incontinence domain and the IIQ embarrassment domain. Finally, the York Incontinence Perception scale (YIPS) is an eight item questionnaire that emphasises on psychosocial issues related to urinary incontinence.[15] Coping, control and acceptance of incontinence were assessed but dimensions like physical functioning or emotional well-being were not addressed.

Symptoms of urinary incontinence, frequency and urgency (overactive bladder), lower abdominal discomfort or pain, genital prolapse and obstructive micturition are common among adult women and many women experience more than one symptom. When measuring the impact of urogenital symptoms on quality of life a distinction between subgroups can be useful. For example, women with stress urinary incontinence are reported to experience less impact of their incontinence on HRQoL as compared to women with urge incontinence.[16-18] This could be due to the amount of urine loss but also to the effect of related symptoms. If women with urge incontinence also experience more often symptoms of overactive bladder or discomfort as compared to stress incontinent women, this may well be a confounder for the perceived HRQoL and therefore has to be accounted for in analysis. We strongly believe that the combined use of our version of the UDI and IIQ is suitable for both epidemiological as well as clinical studies on urogenital problems in women.

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Chapter 3

Urinary incontinence and overactive bladder in community-dwelling women aged 20-45 years: Risk factors and quality of life.

CH van der Vaart, MD, JRJ de Leeuw, PhD, JPWR Roovers, MD, APM Heintz, MD, PhD

Introduction

Urinary incontinence and overactive bladder symptoms (frequency and urgency) are common among adult women. The reported prevalence for urinary incontinence ranges between 14 and 71.5%.[1-4] The majority of studies focus on urinary incontinence. Less information is available about the prevalence of overactive bladder symptoms, but symptoms of urgency are reported to occur in up to 38% of women aged 40-60 years.[4] Increasing age and parity are among the most commonly reported risk factors for urinary incontinence [3], but information on risk factors for overactive bladder symptoms is limited.

In the past two decades, much of the attention of researchers has focussed on the impact that urinary incontinence has on health-related quality of life (HRQoL). Both gynaecologists and urologists are increasingly aware that patients' satisfaction and improvement of HRQoL is an important outcome measure of therapeutic interventions for urinary incontinence and overactive bladder.[5] Where there is increasing information on HRQoL issues in clinical populations available, information on the impact of urinary incontinence or overactive bladder symptoms on HRQoL in community-dwelling women is much more limited. However, this information is important from a socio-economic point of view since it will provide health-care decision makers with information for future planning of care. Reports that do address the impact of urogenital symptoms on quality of life in the female population have some limitations.[6-8] First, HRQoL is usually measured with a generic quality of life instrument. Although these instruments are useful to compare HRQoL between different diseases, they are often less sensitive in measuring certain specific HRQoL aspects of a particular disease as compared to condition or disease-specific measurements. Secondly, attention has focussed on the consequences of urinary incontinence and not on symptoms of overactive bladder. Finally, the study population is usually a cohort of middle-aged or older women. Consequently, detailed information about urinary symptoms in younger women is not available.

The aim of our study is to explore risk factors for symptoms of urinary incontinence and overactive bladder in young community-dwelling women and to study the consequences of these symptoms on HRQoL.

Methods

Study population

The study population consists of a random population sample of 1393 women, between 20 and 45 years of age. This sample was obtained from the population registration office of a suburban area in the central part of the Netherlands in the first half of 1999. These women were invited to participate in a study on the prevalence and consequences of urogenital symptoms in the female community. All women received a questionnaire with an accompanying letter explaining the purpose of the study. Care was taken to encourage women without any urogenital symptoms to participate in the study, emphasizing the importance of their cooperation to compare their situation with that of women with urogenital symptoms. All women were sent a reminder after four weeks. One-thousand twenty-nine (73.9%) questionnaires were returned. Forty questionnaires were returned because of unknown address and 56 women refused to participate, leaving 933 (67%) fully evaluable women.

Measurements

All women received a postal questionnaire that consisted of 162 items. The study was approved by the local ethics committee. For this particular study we used the data from the following items and scales that were included in the questionnaire.

For every woman data on age, parity, educational level (primary only versus secondary or higher), co-morbidity, body weight and length were collected. Data on weight and length were transformed into a Body Mass Index (BMI = weight/(length)^2). Co-morbidity factors that were measured were: diabetes, obstructive pulmonary disease, neurological diseases and rheumatological diseases.

Disease-specific quality of life was measured with the Urogenital Distress Inventory (UDI) and Incontinence Impact Questionnaire (IIQ).[9] The UDI consists of 19 items and each item measures if a *symptom* is present and the amount of bother the woman experiences from that symptom. The latter is measured on a four-point Likert scale ranging from not at all to greatly which was dichotomized in the analysis into: not bothersome (not at all, slightly) and bothersome (moderate, greatly). Following the recommended ICS definition of different types of urinary incontinence [10] and in concordance with other studies,[4,11] we selected two questions from the UDI to distinguish two types of urinary incontinence. A woman was considered to have stress-related urinary incontinence when she replied positively to the question "do you experience urine leakage related to physical activity, coughing or sneezing?"(hereafter referred to as stress incontinence). A woman was considered to have urgency-related urinary incontinence when she replied positively to the question "do you experience urine leakage related to the feeling of urgency?"(hereafter referred to as urge incontinence). Women were considered to have an overactive bladder when they replied positively to both the following questions: " do you experience frequent urination?" and " do you experience a strong feeling of urgency to empty your bladder?". Finally, we decided to add the question "do you experience difficulty emptying your bladder" from the UDI, as an indicator of obstructive micturition, into our study.

The reason for this was that we wanted to test if the well-known relationship between difficulty emptying the bladder and overactive bladder symptoms in men with benign prostate hypertrophy also exists in women.

The original IIQ consists of 30 items about the impact of urogenital symptoms on four aspects of quality of life: physical functioning, emotional functioning, travel and social functioning.[9] A high score on the IIQ domains indicates that the person's well-being on that particular domain is negatively affected. The original UDI/IIQ was translated by the process of forward-backward translation and the construct validity and internal consistency were tested on a population sample of 2043 women between 20-70 years of age (Chapter 2 of this thesis). Factor analysis (principal axis factoring with varimax rotation) of the translation of the IIQ revealed a fifth factor that contains 4 items about embarrassment. Cronbach's alpha for our five domains ranged from 0.83 (embarrassment) to 0.93 (mobility). Cronbach's alpha > 0.70 is considered to indicate good internal consistency.[12] Pearsons' correlations of the original domains with our domains were high and ranged from 0.84 (physical activity) to 0.96 (mobility and emotional). The embarrassment scale showed a high correlation with the original emotional (0.71) and social (0.76) scales. Data presented in this study are based on this five-scale version.

Generic quality of life was measured with the RAND-36. [13,14] The RAND-36 is a generic quality of life questionnaire that consists of 36 items about functioning on 8 domains: general health, physical functioning, mental health, social functioning, vitality, bodily pain, role limitation because of physical functioning and role-limitation because of emotional functioning. The total score on each domain ranges between 0 (worst) and 100 (best) quality of life.

Statistical analysis

Logistic regression was used to obtain crude and adjusted odds ratio's (OR) with 95% confidence interval (CI) for the different types of urinary incontinence and overactive bladder for possible associated factors. In multivariate logistic regression analysis the goodness-of-fit of the model was tested with the Hosmer-Lemeshow test. Since we expected that a substantial proportion of women would report more than one symptom and we were interested in the unique effect of each symptom, we used an ANOVA model with an experimental design to compare the main effects of the urogenital symptoms and possible interactions on the interval scales of the RAND-36 and IIQ domains. Age and BMI were entered into the model as co-variates and standardized regression coefficients were calculated with linear regression analysis. The significance level was set at $p < 0.05$. All statistics were performed with SPSS 10.0.

Results

Characteristics and urinary symptoms of the population

Table I shows the characteristics and comorbidity factors of the study population.

Table 1. Characteristics of the study population (n=933)

Age in years	34.2 (5.2)
Weight (Body mass index)	23.6 (4.2)
Education level	
Primary only	111 (11.8%)
Secondary or higher	822 (88.2%)
Parity	
0	389 (41.7%)
1	146 (15.6%)
2	260 (27.9%)
≥3	138 (14.8%)
Comorbidity	
Diabetes	4 (0.4%)
Obstructive pulmonary disease	75 (8.0%)
Rheumatological diseases	15 (1.6%)
Neurological diseases	20 (2.1%)

Values are numbers (%) or means (SD)

The prevalence of stress incontinence, urge incontinence and overactive bladder symptoms and combination of symptoms are shown in Table 2. The occurrence of combinations of symptoms were as follows. Women with stress incontinence were more likely to have urge incontinence as compared to women without stress incontinence (OR 4.8, 95%CI 3.2 - 7.0). Women with urge incontinence were more likely to have overactive bladder symptoms as compared to women without urge incontinence (OR 3.6, 95%CI, 2.5 - 5.2). The odds for women with stress incontinence to have overactive bladder symptoms was not significantly increased (OR 1.3, 95%CI, 0.9 - 1.7).

Table 2. Micturition symptoms of the study population (n=933)

Overall urinary incontinence (UI)	406 (43.7%)
Stress symptoms	365 (39.1%)
Urgency symptoms	143 (15.3%)
Overactive bladder	224 (24.0%)
Stress symptoms and urgency symptoms	100 (10.7%)
Overactive bladder and urgency symptoms	66 (7.1%)
Overactive bladder and stress symptoms	95 (10.3%)
Overactive bladder, stress- and urgency symptoms	47 (5.0%)

Symptoms are not mutually exclusive. Values are numbers (%)

The perceived impact of different symptoms was assessed by reporting the percentage of women who reported to be bothered by the symptom. Fifty-seven out of 224 women (25.5%) with overactive bladder symptoms considered this symptom as bothersome. For stress symptoms this was 11.3% (41/365 women), and for urgency symptoms 7% (10/143 women).

Among the 224 women with overactive bladder symptoms 19 women (8.5%) reported to have counselled their physician because of these symptoms. For women with stress symptoms this was 8.8% and for urge symptoms 12.7%.

Uni- and multivariate analysis of possible determinants for urinary symptoms.

We could not demonstrate any significant effect of comorbidity on the prevalence of any type of urinary incontinence nor on overactive bladder symptoms.

Table 3 shows the crude and adjusted odds ratio's of different types of urinary symptoms for possible associated factors. Only factors that were significantly associated in univariate analysis were entered into the multivariate analysis.

Table 3. Crude and adjusted odds ratio's of overactive bladder, stress- and urgency symptoms for possible associated factors

	Overactive bladder		**Stress incontinence**		**Urge incontinence**	
	Crude	Adjusted†	Crude	Adjusted †	Crude	Adjusted †
Parity						
0 (reference)	1.0	-	1.0	1.0	1.0	1.0
1	1.2 (0.8-1.9)		2.5 (1.7-3.8)*	2.0 (1.3-3.1)*	1.6 (0.9-2.8)	1.5 (0.8-2.7)
2	0.9 (0.6-1.4)		4.1 (2.9-5.8)*	2.7 (1.8-4.0)*	2.0 (1.3-3.0)*	1.6 (0.9-2.7)
≥3	0.8 (0.5-1.2)		2.8 (1.8-4.2)*	1.7 (1.1-2.8)*	2.0 (1.1-3.3)*	1.8 (1.0-3.4)*
Educational level						
Primary only (reference)	1.0	1.0	1.0	1.0	1.0	1.0
Secondary or higher	0.5 (0.4-0.8)*	0.6 (0.4-0.9)*	0.6 (0.4-1.0)*	0.9 (0.6-1.3)	0.4 (0.3-0.6)*	0.5 (0.3-0.8)*
BMI						
Underweight < 20 (reference)	1.0	-	1.0	1.0	1.0	1.0
Normal weight 20-<25	0.9 (0.6-1.5)		1.8 (1.2-2.8)*	1.5 (0.9-2.4)	1.1 (0.6-2.0)	1.0 (0.6-1.9)
Overweight 25-<30	1.2 (0.7-2.0)		2.4 (1.5-3.9)*	2.1 (1.3-3.5)*	1.6 (0.9-3.0)	1.5 (0.7-2.8)
Obesitas 30-40	1.6 (0.8-3.1)		2.9 (1.5-5.5)*	2.0 (1.0-4.1)*	2.6 (1.2-5.6)*	1.7 (0.7-3.9)
Severe obesitas >40	1.3 (0.3-7.3)		3.9 (0.8-18.2)	3.3 (0.6-16.7)	-	-
Difficulty emptying bladder						
No (reference)	1.0	1.0	1.0	1.0	1.0	1.0
Yes	3.1 (2.0-4.8)*	3.0 (1.9-4.7)*	2.0 (1.3-3.1)*	2.3 (1.4-3.8)*	3.3 (2.1-5.4)*	3.3 (2.0-5.6)*

† Adjustments were made for age and other factors in the model that showed a significant association in univariate analysis (crude odds ratio's). * p<0.05

The adjusted odds for overactive bladder symptoms was significantly decreased for higher educated women as compared to low educated women and significantly increased for women with obstructive micturition symptoms as compared to those without.

The adjusted odds for stress symptoms was significantly increased for parous women as compared to nulliparous women, for women with obstructive micturition symptoms as compared to those without and increased with increasing weight.

The adjusted odds for urgency symptoms was significantly increased for women who had three or more deliveries as compared to nulliparous women and for women with obstructive micturition symptoms as compared to those without. The adjusted odds for urgency symptoms was significantly decreased for higher educated women as compared to low educated women

Urinary symptoms and quality of life

The results of the ANOVA for the main effects of stress-, urgency- and overactive bladder symptoms and their interactions on the RAND-36 domains are shown in Table 4. Values are expressed as F-values with standardized regression coefficients. The predicted means (not shown) from the ANOVA model showed that all significant F-values indicated a reduction in score, which is consistent with a worse HRQoL. Urge incontinence symptoms only showed a statistical significant reduction of the score on the emotional role limitations. Stress incontinence symptoms showed a significant reduction of the score on the vitality and general health domains. Overactive bladder symptoms were significantly associated with a reduction in score on all RAND-36 domains, the strength of effect being 2 to 15 times that of stress- or urge incontinence. Several significant two-way interactions were found indicating that the effect of the combination of two factors was significantly independent from the effect of each symptoms separately.

Table 4. Effect of stress-, urge incontinence and overactive bladder symptoms on the RAND-36

	RAND-36 domains							
	Physical Function	Social Function	Mental Health	Physical Role limitation	Emotional Role limitation	Vitality	Pain	General health
Co-variate								
Age	2.8	0.1	0.04	2.1	0.4	1.1	3.1	1.7
Main effects								
Urgency symptoms	2.1 (0.05)	1.8 (0.05)	1.1 (0.04)	0.1 (0.01)	4.7 (0.08)*	1.0 (0.04)	1.6 (0.04)	0.01(0.01)
Stress symptoms	1.4 (0.04)	4.0 (0.07)	4.2 (0.07)	0.6 (0.03)	0.8 (0.03)	12.8(0.12)*	0.2 (0.02)	5.6 (0.08)*
Overactive bladder	25.4(0.17)*	13.3 (0.12)*	13.3 (0.12)*	21.2(0.15)*	6.6 (0.09)*	20.9(0.15)*	25.5(0.17)*	17.6(0.14)*
2-way interactions								
Urgency*Stress	0.4	0.2	1.0	0.3	2.5	0.3	0.8	1.0
Urgency*Overactive	0.6	3.8	5.8	5.3	5.4	7.4*	5.9*	13.1*
Stress*Overactive	0.1	5.4	6.8*	0.2	11.5*	5.3	0.4	1.1
3-way interaction	1.0	1.1	0.2	0.4	2.6	2.2	0.1	0.2

ANOVA experimental model. Values expressed as F-values. Standardized regression coefficients in brackets. * $p<0.05$

Table 5. Effect of stress-, urge incontinence and overactive bladder symptoms on the IIQ.

	IIQ domains					
	Total	Social Function	Physical Function	Mobility	Emotional	Embarrassment
Co-variates						
Age	1.6	0.6	0.5	5.4	1.2	0.1
Main effects						
Urgency symptoms	15.5(0.10)*	4.4 (0.10)*	9.9 (0.14)*	6.1 (0.11)*	8.1 (0.13)*	28.8 (0.24)*
Stress symptoms	0.9 (0.04)	1.2 (0.07)	0.5 (0.03)	0.6 (0.03)	0.6 (0.04)	0.5 (0.03)
Overactive bladder	13.4(0.16)*	6.4 (0.12)*	9.2 (0.14)*	24.4 (0.22)*	6.2 (0.11)*	4.9 (0.10)*
2-way interactions						
Urgency*Stress	4.9*	1.6	3.0	3.6	3.6	0.9
Urgency*Overactive	0.5	0.3	0.3	0.2	0.8	0.3
Stress*Overactive	0.1	1.0	1.0	0.1	0.3	0.1
3**-way interaction**	0.5	0.01	0.1	0.1	0.2	1.8

ANOVA experimental model. Values expressed as F-values. Standardized regression coefficients in brackets. * p<0.05

Table 5 shows the ANOVA results for the main effects of stress incontinence, urge incontinence and overactive bladder symptoms and their interactions on the IIQ. Values are expressed as F-values with standardized regression coefficients. The predicted means from the ANOVA model (not shown) showed that all significant F-values indicated a higher score, which is consistent with a worse HRQoL. Both urge incontinence and overactive bladder had a significant negative effect on all domains of the IIQ. The strength of effect for the two symptoms was approximately equal for the social, physical and emotional domains. Symptoms of overactive bladder had twice the effect of urge symptoms on the mobility domain, while the effect of urge incontinence on the embarrassment scale was twice the effect of overactive bladder. The effect of stress incontinence on the IIQ was neglectable.

Discussion

The most important finding of our study was that symptoms of urgency and frequency of voiding (overactive bladder) are reported by one out of four young women, and that these symptoms negatively affect their HRQoL in all its domains. In fact, when measured with a disease-specific HRQoL questionnaire (IIQ), the effect of overactive bladder symptoms on HRQoL is equal to the effect of urge incontinence and much stronger than the effect of stress incontinence. The most profound negative effect of overactive bladder symptoms was recorded on the IIQ mobility domain. Apparently, in the young active female population, limitations in mobility due to urgency or frequency symptoms are especially distressful. The important effect that overactive bladder symptoms have on well-being is further supported by our finding that one out of four women with overactive bladder symptoms reports to be bothered by it. Nevertheless, only 8% of all women with overactive bladder symptoms sought medical help. Another important finding of our study was that there is a clear association between symptoms of difficulty emptying the bladder and stress incontinence, urge incontinence and overactive bladder symptoms. Finally, urge incontinence did not seem to affect HRQoL when measured

with the RAND-36, but proved to be as important as overactive bladder symptoms when measuring HRQoL with the IIQ.
This shows that the IIQ is more sensitive in measuring HRQoL consequences of urinary symptoms than the RAND-36.

In the last two decades, a lot of attention focussed on the prevalence of urinary incontinence and on its impact on quality of life.[1,4,6-9,15-19] Two main problems arise when studying the literature on the prevalence of urinary incontinence. The first problem is the lack of an uniform definition.[20] The second problem is that the prevalence of urinary incontinence in population based studies is probably overestimated. Women with urinary incontinence are probably more likely to respond to a questionnaire asking about these symptoms. These two problems, definition and sample bias, are also the possible limitations of our study.

Like other recent studies, we used a symptom-based definition of stress and urge incontinence, based on the recommendations of the International Continence Society.[4,11] The definition we used for overactive bladder ("a medical condition referring to the symptoms of frequency and urgency, with or without urge incontinence, when appearing in the absence of local pathologic or metabolic factors") is the same as the one recently suggested.[21] In our study design we could not rule out local pathologic factors but we found no differences in diabetes or neurological disease between women with or without symptoms of overactive bladder. Using a symptom based diagnosis of urinary incontinence gives maximal weight to the perception of the severity of the problem by the woman herself. Objective measures, like frequency of incontinence episodes, urodynamic investigations or pad testing, are known to correlate only moderately with reported symptoms and psychosocial consequences.[22,23] Therefore, we believe that an objective diagnosis of urinary incontinence is not a requisite for epidemiologic studies on the consequences of urinary incontinence or overactive bladder symptoms for HRQoL. The differences we recorded between the three different urinary symptoms, both in associated factors as well as in their effect on HRQoL, supports our believe that the selected questions basically identified different groups.

The second possible limitation of our study is the response rate. Although non-responders may have a lower prevalence of symptoms as compared to responders we tried to include as many women without symptoms as possible. This was done by carefully explaining the purpose of our study and the importance of cooperation even if the woman had no urinary symptoms. Nevertheless, results about the prevalence of urinary incontinence and overactive bladder symptoms in all population-based studies have to be interpreted with caution. Our study is no exception to this rule.

A large number of studies that evaluated the consequences of urinary incontinence on quality of life have been performed on selected samples of clinical patients.[1,4,9,15-18] Only a few studies have measured the consequences of urinary incontinence on HRQoL in a random population sample.[6-8] These population studies also showed that women with urge incontinence experienced a worse quality of life as compared to women with stress incontinence. However, these studies used generic HRQoL questionnaires [6,7] or Visual Analog Scales [8] to measure HRQoL, and also did not include symptoms of overactive bladder in analysis. The results therefore present a more global view of the impact of urinary incontinence on HRQoL. As we have shown, results may markedly differ between generic and disease-specific HRQoL questionnaires. With the use of the disease-specific IIQ we were better able to investigate associations between specific symptoms and HRQoL domains, and also better able to study the impact of specific worries (like embarrassment) incontinent women have, than with the RAND-36.

The pathophysiology of "idiopathic" overactive bladder (absence of neurological or metabolic factors) is largely unknown. We found two interesting factors that showed an independent positive association with urge- and overactive bladder symptoms, namely: (1) symptoms of difficulty emptying the bladder and (2) low educational level.
For a better understanding of these findings we first have to consider the pathophysiology of overactive bladder symptoms in children and men.

In children, the concept of dysfunctional voiding, with bladder instabilities and overactivity of the pelvic floor muscles during voiding, is fairly well known.[24] Dysfunctional voiding eventually can result in urodynamically proven diminished bladder volume and bladder compliance, with bladder instabilities and pelvic floor contractions during voiding. It is unclear whether an overactive bladder leads to overactive pelvic floor muscles or whether poor relaxation during voiding may be a learned condition. In men, the relationship between bladder outlet obstruction in benign prostate hypertrophy (BPH) and detrusor instability/urgency is well recognized.[25] There is increasing evidence that bladder outlet obstruction is associated with the development of post-junctional supersensitivity of the detrusor muscle cells, and that this may contribute to the development of detrusor instability. [25] If this bladder outlet obstruction is important in the pathophysiological chain of events for urgency and detrusor instability, it may explain both the findings in children and men. How about women? Our results show that women with overactive bladder and urgency symptoms also often report having difficulty emptying the bladder. This may be due to mechanical obstruction, like a large cystocele, or to difficulties with the relaxation of the pelvic floor during voiding. Since we studied a young population we do not believe that a large proportion of these women had cystoceles. Poor relaxation of the pelvic floor while voiding may simulate the bladder outlet obstruction seen in men with BPH. Like in BPH , long standing bladder outlet obstruction may eventually lead to instabilities and urgency.

Why in this context lower educated women are more likely to report symptoms of overactive bladder and urge symptoms is not clear. If they are more likely to report symptoms anyhow, than one would expect them to also reported more stress incontinence. However, lower educated women did not report significantly more stress symptoms as compared to well educated women. To our knowledge only one other study describes the relationship between the educational level and type and severity of urinary incontinence.[11] It was reported that higher educated women had an increased odds for stress incontinence and on the other hand, severe incontinence was related to a lower educational level. No relationship between urge symptoms and educational level was reported. However, in that particular study, the five scale educational level was fitted into the model as a continuous variable. This may have biassed the results. The same study showed a clear relationship between childhood enuresis and urge symptoms later in life. This suggests that failure to learn to control the bladder in early life is related to a higher degree of failure in later life. This learning process is complex and can be influenced by many intra-personal and environment factors, of which cognitive abilities may be one.

In conclusion, overactive bladder symptoms and symptoms of urinary incontinence are certainly not specific problems of middle-aged or older women. A substantial proportion of young women also experience these symptoms and are bothered by it. Overactive bladder symptoms are as troublesome as urge incontinence and therefore attention should not merely focus on incontinence. Since treatments are available and often non-invasive in character, we believe efforts should be undertaken to inform and educate this age group. The concept of poor relaxation of the pelvic floor causing urgency/detrusor instabilities in young women is far from proven but is interesting and in our opinion warrants further investigation.

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Chapter 4

The effect of childbirth on anal incontinence: a population based, cross-sectional cohort study.

CH van der Vaart, MD, JG van der Bom, MD, PhD, JPWR Roovers, MD, JRJ de Leeuw, PhD,
APM Heintz, MD, PhD.

Introduction

Childbirth has been suggested as an important risk factor for faecal incontinence in women.[1,2] This has been based on the observation that childbirth causes subclinical mechanical damage of the anal sphincter complex and its innervation in approximately one out of three primiparous women.[3,4] However, the association between childbirth and faecal incontinence has not been reported. If childbirth is an important risk factor for faecal incontinence one might expect to find differences in prevalence between parous and nulliparous women. We therefore undertook a population-based, cross-sectional cohort study to examine the effect of parity on flatus and faecal incontinence.

Methods

Study population

A random sample of 3200 women, aged 20-70 years, was obtained from the population registration office of a suburban area in the Netherlands. This sample represents 15% of women in this age group in the selected area. All women were invited to participate in a study on bowel and micturition symptoms. In the accompanying letter care was also taken to encourage women without symptoms to participate. All obtained data were anonymous. A total of 2259 questionnaires (70.6%) were returned. Ninety-one questionnaires were returned because of unknown address and 126 women refused to participate, leaving 2042 (63.8%) fully evaluable women. The study was approved by the local ethics committee.

Measurements

All women received a postal questionnaire in 1999.

Anal incontinence symptoms were measured as follows. Women who replied positively to the question “ do you ever experience involuntary loss of intestinal gas” were considered to have flatus incontinence. Women who replied positively to the questions “do you ever experience involuntary loss of liquid stool” and/or “ do you ever experience involuntary loss of solid stool" were considered to have faecal incontinence. No attempt was made to assess the frequency of loss since we considered any involuntary loss of flatus or faeces to be abnormal.

Besides information on parity, data on possible confounding factors like age, previous hysterectomy, physical functioning and educational level were collected. Physical functioning was measured with the RAND-36.[5] The RAND-36 is a generic quality of life questionnaire that consists of 36 items about functioning on 8 domains: general health, physical functioning, mental health, social functioning, vitality, bodily pain, role limitation because of physical functioning and role-limitation because of emotional functioning. The total score on each domain ranges between 0 (worst) and 100 (best) quality of life. The domain physical functioning was used in our analysis. Data on educational level were dichotomized into primary school only or secondary or higher.

Finally, questions about constipation and urinary incontinence were asked. Since the pathophysiology of faecal incontinence (mechanical and innervation damage of the pelvic floor) is, at least partly, the same as that of urinary incontinence and constipation, the latter two were considered to possibly modify the effect of parity on faecal incontinence. According to international recommendations [6] a woman was considered to have functional constipation if she replied positively to both of the following questions namely: "do you have your bowel movement less than three times a week" and " do you have to strain in more than 25% of time in order to pass your stools". Those women with functional constipation that also answered positively to one of the following questions "do you ever have to remove your feces digitally from your rectum" or "do you have to puss on your vaginal wall in order to have your bowel movement" or "do you experience a sensation of anal blockage when you have your bowel movement" were considered to have outlet constipation.[7,8] Following the recommended ICS definition of different types of urinary incontinence [9] and in concordance with other studies, [10] a woman was considered to have stress-related urinary incontinence if she replied positively to the question "do you experience urine leakage related to physical activity,

coughing or sneezing?"(hereafter referred to as stress incontinence).
A woman was considered to have urgency-related urinary incontinence if she replied positively to the question "do you experience urine leakage related to the feeling of urgency?"(hereafter referred to as urge incontinence).

Statistical analysis

Qualitative parameters are expressed as numbers and percentages and interval parameters are expressed as means with standard deviation (SD). Distributions of qualitative parameters between groups were compared by the Fisher exact test. Students t-test statistics was used to compare interval data between groups. Univariate logistic regression analysis was used to calculate crude odds ratio's (OR) with 95% confidence interval (CI). Multivariate logistic regression was used to obtain adjusted OR with 95% CI for anal incontinence for possible associated factors. In multivariate logistic regression analysis the goodness-of-fit of the model was assessed with the Hosmer-Lemeshow test. Two models were tested. One model explored the effect of possible confounders, the second model also included modification effects. All statistics were performed with the statistical package SPSS 10.0.

Results

Table 1 shows the characteristics of the study population.

Differences between parous and nulliparous women regarding mean age, physical functioning, educational level, anal incontinence, urinary incontinence, constipation and history of hysterectomy are presented in Table 2. Parous women were significantly older, less educated, had a history of hysterectomy, reported urinary stress and urge symptoms and had a lower mean physical functioning score as compared to nulliparous women. No differences were found between groups regarding anal incontinence and constipation.

Table 1 Characteristics of the study population.

Age (years)	46.5 (13.1)
Age distribution	
20-29 years	233 (11.4)
30-39 years	443 (21.6)
40-49 years	465 (22.7)
50-59 years	501 (24.5)
60-70 years	400 (19.8)
Parity	
0	581 (28.5)
1	241 (15.6)
2	708 (27.9)
≥3	512 (14.8)
Mode of delivery	
Spontaneous vaginal only	1144 (78.4)
Cesarean section at least ones	131 (9.0)
Vacuum delivery at least ones	156 (10.7)
Forceps delivery at least ones	83 (5.7)
Perineal trauma	
Episiotomy at least ones	1170 (57.2)
Perineal rupture (any type) at least ones	947 (46.4)
Educational level	
Primary only (low level)	439 (21.5)
Secondary or higher (high level)	1603 (78.5)
Marital status	
Married	1359 (66.6)
Divorced	145 (7.1)
Widow	98 (4.8)
Never been married	440 (21.5)
History of hysterectomy	212 (10.3)

Values are given as mean (SD) or n (%)

Table 2 Comparison of different factors between parous and nulliparous women.

	Nulliparous (n=581)	Parous (n=1461)	Significance level †
Age in years *	38.9 (0.6)	49.4 (0.3)	<0.001
RAND-36			
Physical functioning *	88.3(0.7)	85.7 (0.5)	0.002
Role limitation physical *	77.7 (1.5)	78.8 (0.9)	NS
Anal incontinence ‡			
Flatus incontinence	205 (35.3)	501 (34.3)	NS
Faecal incontinence	44 (7.6)	90 (6.2)	NS
Urinary incontinence ‡			
Stress	159 (27.6)	770 (53.3)	<0.001
Urge	79 (13.7)	372 (25.8)	<0.001
Constipation ‡			
Functional	39 (6.7)	85 (5.8)	NS
Outlet	50 (8.6)	127 (8.7)	NS
Educational level ‡			
Primary only	71 (12.3)	364 (25.1)	<0.001
Secondary or higher	505 (87.7)	1084 (74.9)	
History of hysterectomy ‡	25 (4.3)	184 (12.6)	<0.001

*=Mean (SEM). ‡= numbers(%).

† Fisher exact test for nominal data, Student's t-test for interval variables. Expressed as p-values, NS=Not Significant

Table 3 shows the crude odds ratio's for the three types of anal incontinence for potential associated factors. The odds for faecal incontinence was significantly increased for women with urinary stress or urge symptoms, women older than 60 years, women with outlet constipation, women who had a hysterectomy and lower educated women. The odds for flatus incontinence was significantly increased for women older than 50 years, women with outlet constipation and women with urinary stress or urge symptoms.

Table 3 Crude odds ratio's (95% confidence interval) of types of anal incontinence for potential associated factors.

	Faecal incontinence	**Flatus incontinence**
Parity		
Nulliparous	1.0	1.0
Parous	0.8 (0.6-1.2)	0.9 (0.8-1.2)
Age in 10-years interval		
20-29 (reference)	1.0	1.0
30-39	0.7 (0.4-1.5)	1.0 (0.7-1.4)
40-49	1.1 (0.6-2.1)	1.0 (0.7-1.5)
50-59	1.0 (0.5-1.9)	1.5 (1.1-2.1)*
60-70	1.9 (1.1-3.5)*	1.7 (1.2-2.4)*
Constipation		
No	1.0	1.0
Functional	1.1 (0.5-3.2)	1.2 (0.8-1.7)
Outlet	1.9 (1.1-3.2)*	2.2 (1.6-3.0)*
Urinary incontinence		
Stress-related	2.4 (1.7-3.5)*	1.9 (1.6-2.3)*
Urge-related	2.9 (2.0-4.2)*	2.1 (1.7-2.6)*
Hysterectomy	1.6 (1.0-2.7)*	1.1 (0.8-1.5)
Educational level		
Primary only	1.0	1.0
Secondary or higher	0.6 (0.4-0.9)*	0.9 (0.7-1.1)

* $p<0.05$

All potential confounding factors (significantly associated with both parity and anal incontinence, but not related to the occurrence relation) were entered into a multivariate logistic regression model.

Table 4 shows the crude and adjusted OR with 95%CI for anal incontinence for parity. The effect of childbirth was corrected for age, physical functioning, history of hysterectomy and educational level. Parous women had a statistical significant 37% reduction in odds for faecal incontinence as compared to nulliparous women.

Parous women also had a 17% reduction in odds for flatus incontinence but this did not reach statistical significancy (p=0.09).

Table 4 Adjusted odds ratio's (95% confidence interval) of types of anal incontinence for parity and potential confounders.

Parity	**Flatus incontinence**	**Faecal incontinence**
Parity (parous versus nulliparous), crude	0.94 (0.78-1.17)	0.80 (0.55-1.17)
Adjusted for age	0.80 (0.64-0.99)*	0.65 (0.44-0.96)*
Adjusted for age and hysterectomy	0.80 (0.64-0.99)*	0.64 (0.43-0.95)*
Adjusted for age, hysterectomy and educational level	0.81 (0.65-1.00)	0.61 (0.41-0.92)*
Adjusted for age, hysterectomy, educational level and physical functioning	0.83 (0.66-1.03)	0.63 (0.42-0.95)*

* p<0.05

Finally, the modifying effect of urinary incontinence on the occurrence relation parity - faecal incontinence was assessed. The adjusted odds for faecal incontinence was 0.46 (95%CI 0.28-0.76) for parous women with urinary incontinence as compared to nulliparous women with urinary incontinence. The adjusted odds for faecal incontinence was 0.63 (95%CI 0.30-1.34) for parous women without urinary incontinence as compared to nulliparous women without urinary incontinence.

Discussion

Our data do not support the wide-spread view that childbirth is a risk factor for flatus or faecal incontinence in women. In fact, we found that childbirth reduces the risk of faecal incontinence significantly. This protective effect is most prominent among women who also report urinary incontinence symptoms.

The strength of our study is that we compared the prevalence of anal incontinence between parous and nulliparous women in a population based cohort, and that we adjusted the effect for potential confounders. Our study also has some potential limitations that need to be addressed.

First, because of the design of the study, we were not able to make a definitive diagnosis of anal or urinary incontinence. However, there are no valid tests to confirm faecal incontinence accept for seeing actual loss, which will be seldom feasible even in a clinical settings. One has to rely mainly on self-reported symptoms. For urinary incontinence there are diagnostic tests, like urodynamic testing, available to try to confirm the diagnosis of urinary incontinence. However, urodynamic results often correlate poorly with symptoms, especially urge incontinence.[11,12] Since we adjusted the effect of parity on faecal incontinence for both types of urine loss, and found no major differences, a definitive diagnosis of the type of urinary incontinence would not have altered our results. Secondly, we were not informed about the severity of faecal incontinence. If parous women, although having a reduced prevalence of overall faecal incontinence, had more severe faecal incontinence this could have it's implications for clinical practice. However, we also found reduced odds of flatus incontinence for parous women. Flatus incontinence can be regarded as a symptom of less severe damage of the continence mechanism.

Why is childbirth so commonly stated to be a major risk factor for faecal incontinence? If true, such a statement should be supported by epidemiological data as well as supportive data on a well-defined pathophysiological pathway.

Epidemiological studies on the prevalence of faecal incontinence in the general population are scarce.[13-15] Two large community-based studies on the prevalence of anal incontinence are widely quoted. Nelson and co-workers, examining a population sample ≥18 years old, found that the age-adjusted odds for women to have anal incontinence was 1.5 times that of men.[14] However, the definition of anal incontinence included involuntary loss of gas and data were collected from "the most knowledgeable member of the household" on the continence status of the other members of the household. The latter might not have been an appropriate way to identify an embarrassing condition like faecal incontinence. Drossman and co-workers studied a random sample of men and women aged 15 years or older. They did not demonstrate any difference in prevalence between men and women.[15] Faecal incontinence (defined as involuntary loss of faecal material) was reported by 7.7% of females and 7.9% of males. The prevalence increased with ageing. Our reported prevalence of faecal incontinence is the same as in this study. Unfortunately, both the Nelson and Drossman studies did not control their data on women for parity. That faecal incontinence is not limited to women is further supported by the observation that in the elderly, male gender is an independent risk factor for faecal incontinence.[16,17] The only epidemiological data on the relationship between parity and faecal incontinence comes from studies that report on the new development of faecal incontinence after delivery.[3,4,18-21] However, these studies 1) often assess the presence of faecal incontinence symptoms in the first nine months after delivery, 2) usually find that observed anal sphincter damage does not produce symptoms in the majority of women, 3) are performed on selected samples, and 4) do not adjust their data for potential confounders. The long-term relationship between childbirth and anal incontinence was studied by Ryhammer and co-workers.[22] They identified that multiple vaginal deliveries increase the risk of permanent incontinence of flatus and urinary incontinence, but not for faecal incontinence. This study also did not address the issue of confounding and data were not compared to nulliparous women.

The major body of evidence that childbirth is the major risk factor of faecal incontinence seems to be derived from the observation that childbirth can cause mechanical and innervation damage of the anal sphincter complex.[3,4,23-25] Major anal sphincter lacerations (third and fourth degree) will induce faecal incontinence directly and not all women will achieve continence after repair of these defects.[26-28] However, these third and fourth degree lacerations occur in approximately 1% of deliveries in countries were posterolateral episiotomies are preferred over median episiotomies.[28,29]

The long-term consequences of major anal sphincter lacerations are unclear. At 30-year follow-up, the prevalence of faecal incontinence was equal among women who had a third or fourth degree anal sphincter laceration and women who had delivered by a cesarean section.[30] This suggests that other factors play an important role in the development of faecal incontinence.

With the introduction of anal endosonography it became clear that approximately one-third of primipara will have subclinical damage of the anal sphincter complex.[3,4] However, only a minority of women with subclinical anal sphincter damage will have anal incontinence symptoms, predominantly flatus incontinence.[3] It was postulated that further damage in consecutive pregnancies may expose women with subclinical anal sphincter damage to a higher risk of faecal incontinence later in life. This was supported by the results of a recent study in which it was demonstrated that anal sphincter damage occurred in 34% of primipara, of whom 42% developed faecal incontinence after a second delivery.[4] This would implicate that approximately 15% of multipara would have faecal incontinence. Because the presence of faecal incontinence symptoms was assessed within 6 to 12 weeks after delivery the results may have been seriously biased. Two-third of women who had an abnormal prolonged pudendal nerve terminal motor latency (PNTML), as indicator of innervation damage to the anal sphincter, at six weeks after delivery fully recovered at six months.[25] Therefore women who have symptoms early after delivery may not have symptoms in longer follow-up. As with major lacerations, the long term consequences of subclinical anal sphincter damage are questionable. Perimenopausal parous women were shown to have the same anal canal maximum resting and squeezing pressure as nulliparous women.[31] A finding one would not have expected knowing that at least one out of three parous women had suffered subclinical anal sphincter damage.

Anal continence is the result of a complex interaction between anal sphincter function, rectal sensitivity and adaptation, stool structure, cognitive and physical functioning.[32-36] It is therefore obvious that studying the consequences of childbirth in such a complex system, other potential risk factors for faecal incontinence have to be accounted for. Since we cannot reliably assume that the distribution of these factors will be equal among parous and nulliparous women, careful assessment of possible confounders is obligatory when studying risk factors for faecal incontinence.

The exact contribution of all these factors to the continence mechanism is still poorly understood and therefore our finding that childbirth has a protective effect on the development of faecal incontinence has to be interpreted with caution. A hypothetical explanation for this finding is that parous women are better able to adjust their rectum to distension. Poor adjustment has been shown to occur in faecal incontinent patients with normal anal canal pressures.[33] The observation that rectoceles are more common in parous as compared to nulliparous women may explain this better adjustment to distension. Data to support this hypothesis are not available.

In conclusion, the need to identify risk factors for third or fourth degree anal sphincter lacerations remains obvious. However, whether childbirth-related subclinical anal sphincter damage has a long-term effect on the anal continence mechanism is highly questionable. The results of our study indicate that there are probably more important factors than childbirth involved in the pathophysiology of faecal incontinence in women. Our findings do not support recommendations to change obstetrical practice in women with subclinical anal sphincter lesion in their consecutive pregnancies.

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Chapter 5

Differences in urinary incontinence symptoms between women scheduled for hysterectomy and women who are not.

CH van der Vaart, MD, JPWR Roovers, MD, JG van der Bom , MD, PhD, JRJ de Leeuw, PhD and APM Heintz, MD, PhD

Introduction

There is a contradiction between the reported long term (increased risk) and short term (relieve of symptoms) effect of hysterectomy on urinary incontinence[1,2] A recently published meta-analysis concluded that hysterectomy increases the odds of having urinary incontinence later in life.[1] In contrast, hysterectomy has been reported to relieve urinary incontinence symptoms in up to 75% of women at two years follow-up.[2] This is surprisingly high for a surgical procedure that is not designed to treat incontinence. Several hypothesis for this finding can be generated. First, symptoms leading to hysterectomy, like an enlarged uterus or endometriosis, may be associated with the development of urinary incontinence. As a consequence, eliminating these causal factors may relieve urinary incontinence. If this hypothesis is to be true, one might expect that the prevalence of urinary incontinence is higher in women scheduled for hysterectomy as compared to women that are not. Secondly, hysterectomy may not decrease the prevalence of urinary incontinence but improve the perception of it as a problem. This hypothesis is supported by the fact that the prevalence of depression and anxiety in women scheduled for hysterectomy is high (up to 62% for depression and 65% for anxiety).[2,3] Under these circumstances of mood disorders, the perception of the severity of co-existing symptoms may be altered.

A specific problem in studies on the consequences of hysterectomy is that no adequate distinction is made between stress incontinence (urinary incontinence related to physical activity or sudden increase in abdominal pressure) and urge incontinence (urinary incontinence related to feeling of urgency). Since the pathophysiological mechanism for these two types of urinary incontinence differs[4,5], different effects of hysterectomy on each type may be anticipated.

In conclusion, it is very well possible that women scheduled for hysterectomy differ from those who are not with regard to the prevalence, type and bothersomeness of urinary incontinence. Without proper adjustment for these differences, one cannot reliably study the short and long term consequences of hysterectomy on urinary incontinence.

We performed a study to compare the prevalence, type and bothersomeness of urinary incontinence between women that were candidate for hysterectomy and women that are not.

Methods

Study population

The study population consists of two samples of women.

The first sample is a random population sample of 3200 women, between 20 and 75 years of age, that was obtained from the population registration office of a suburban area in the central part of the Netherlands in 1999. These women were invited to participate in a study on the prevalence and consequences of urogenital and defecation symptoms in the female community. All women received a questionnaire with an accompanying letter explaining the purpose of the study. Care was taken to encourage women without any symptoms to participate. A reminder was sent after four weeks to all women. Data collection was anonymous. Two-thousand forty-two women responded (63.8%). The representiveness of the sample was tested by comparing the two extremes of a single general health perception question (excellent and very poor) between the study sample and age-adjusted data from the nationwide Dutch Central Bureau of Statistics. Both groups were similar (excellent health 24.1 versus 24.0 percent and very poor health 2.3 versus 2.6 percent). To select a non-gynecological population a total of 222 women (10.8%) who had a hysterectomy or reported menstrual bleeding problems were excluded from this sample, finally leaving 1831 women (non-hysterectomy group).

The second sample consists of 414 women who were scheduled for hysterectomy (pre-hysterectomy group) for benign, non-prolapse conditions (bleeding problems, dysmenorrhoea, chronic abdominal pain, severe cervical dysplasia and mechanical problems related to uterine fibroids). They represent 90% of the 460 women that were eligible for this study (46 women (10%) refused to participate). Women were obtained from thirteen hospitals throughout the Netherlands, both teaching and non-teaching, that participated in this study. Besides hysterectomy, no additional surgical interventions were performed.

Study design

The community sample received a self-administered questionnaire in the second half of 1999. All women in the pre-hysterectomy sample received the same questionnaire between April 1999 and June 2000, one to three months prior to surgery. The study was approved by the local ethics committee with the restriction not to contact non-responders.

For every woman data on age, parity and educational level were collected.

Urogenital symptoms were measured with the Urogenital Distress Inventory (UDI).[6] The UDI consists of 19 items and each item measures if a *symptom* is present and the amount of bother the woman experiences from that symptom. The latter is measured on a four-point Likert scale ranging from not at all to greatly which was dichotomized in the analysis into: not bothersome (not at all, slightly) and bothersome (moderate, greatly). Following the recommended ICS definition of different types of UI [7] and in concordance with other epidemiological studies [8,9], we selected two questions from the UDI. The question "do you experience urine leakage related to physical activity, coughing or sneezing?" was used as an indicator for stress-related incontinence (hereafter known as stress incontinence) and "do you experience urine leakage related to the feeling of urgency?" as an indicator for urgency-related incontinence (hereafter known as urge incontinence). Overall UI was defined as having answered positively to one or both of these questions.

Women with stress incontinence who were not at all or slightly bothered by it were regarded as not having bothersome stress incontinence (no-bothersome stress incontinence). Bothersome stress incontinence was defined as reporting moderately or greatly bother by the symptom (bothersome stress incontinence). The same dichotomization was performed to separate bothersome from no-bothersome urge incontinence

In addition, the indication for hysterectomy was obtained from the medical record for the pre-hysterectomy group.

Statistical analysis

Logistic regression was used to obtain odds ratio's (OR) with 95% confidence interval (CI) for the type and bothersomeness of urinary incontinence for hysterectomy (pre- or non-hysterectomy). A multi-variate logistic regression analysis was used to adjust the odds ratio for the following potential prognostic variables: age, parity (nulliparae versus primi/multipara) and educational level (primary versus secondary/higher). A two-tailed Student's *t* test was used to compare interval data. All statistics were performed with SPSS 10.0.

Results

Characteristics of the study groups

Women scheduled for hysterectomy had their surgery planned for the following indications. Sixty-nine percent had bleeding problems, 13% lower abdominal pain, 8% dysmenorrhoea, 7% mechanical problems due to uterine fibroids and 3% had severe cervical dysplasia.

The characteristics of both study groups are presented in Table 1. Pre-hysterectomy women were statistically significant lower educated (OR 2.4, 95%CI 1.9 - 3.0) and more often parous (OR 2.3, 95%CI 1.7-3.1) as compared to non-hysterectomy women. There was no statistically significant difference in mean age.

Associations between hysterectomy and urinary incontinence

The distribution of the type and severity of urinary incontinence are presented in Table 2. The prevalence of overall urinary incontinence, stress incontinence and urge incontinence were similar in both groups. In contrast, bothersome stress incontinence (OR 6.7, 95%CI 4.7-9.4) and bothersome urge incontinence (OR 17.0, 95% CI 9.8-29.8) were statistically significant more often reported by pre-hysterectomy incontinent women as compared to the non-hysterectomy incontinent women.

Table 1. Characteristics of women from the community sample and women scheduled for hysterectomy.

	Non-hysterectomy (n=1831)	**Pre-hysterectomy** (n=411)	**Significance level**
Demography			
Age (years)	45.2 (0.3)	44.4 (0.3)	NS*
Education level			
Primary only	363 (19.7)	152 (36.8)	<0.0001†
Secondary or higher	1468 (80.3)	259 (63.2)	
Parity			
0	556 (30.4)	65 (15.8)	<0.0001†
1	219 (12.0)	54 (13.1)	
2	624 (34.0)	189 (46.0)	
≥3	432 (23.6)	103 (25.1)	

* Student's t-test, † Fisher exact test, two-tailed. NS = not significant

Values are numbers (%) or means (standard error of mean)

Table 2. Type and severity of urinary incontinence in relation to hysterectomy.

	Non-hysterectomy (n=1831)	**Pre-hysterectomy** (n=411)	**Significance level**
Urinary incontinence			
Urine incontinent (UI)	902 (49.3)	204 (49.1)	NS
Stress incontinence	812 (44.7)	187 (45.5)	NS
Bothersome stress incontinence	128/812 (15.7)	104/187 (55.4)	<0.0001*
Urge incontinence	375 (20.5)	87 (21.1)	NS
Bothersome urge incontinence	45/375 (11.9)	61/87 (69.8)	<0.0001*

* Fisher exact test, two-tailed

Values are numbers (%)

Parity, educational level and age in relation with urinary incontinence

The association between parity and educational level and type and severity of urinary incontinence symptoms are shown in Table 3 and Table 4. Parous women reported significantly more often urinary incontinence, both stress and urge, as compared to nulliparous women. Among women with urinary incontinence, parous women were statistical significantly more likely to experience bothersome symptoms, both stress and urge, as compared to nulliparous women.

Lower educated women reported statistically significant more often urge incontinence, but not stress symptoms, as compared to higher educated women. Among women with urinary incontinence, lower educated women were statistically significant more likely to experience bothersome symptoms, both stress and urge, as compared to higher educated women.

The age of women with urinary incontinence, both stress and urge, was statistically significant higher as compared to women without urinary incontinence. Among women with urinary incontinence, no statistically significant differences in age were observed between women with bothersome and no-bothersome stress or urge incontinence. (Data not shown)

Multivariate analysis

As the prevalence of urinary incontinence symptoms was not significantly different between pre- and non-hysterectomy women, we only performed a logistic regression analysis to evaluate the risk for bothersome urinary incontinence (Table 5). Adjustment for parity and educational level did not substantially changed the odds for bothersome stress- or urge incontinence for pre-hysterectomy women as compared to non-hysterectomy women. Age was not included in the model as it was not significantly associated with hysterectomy or bothersome urinary incontinence.

Table 3. The relationship of parity and educational level with stress and urge urinary incontinence symptoms.

	Number	Stress incontinence	Urge incontinence
Parity			
Nulliparous	621	173 (27.9)	85 (13.7)
Parous	1621	826 (51.0)*	377 (23.3)*
Educational level			
Primary only	515	242 (47.0)	135 (26.2)*
Secondary/higher	1727	765 (44.3)	322 (18.7)

Values are numbers (%). * Two-sided Fisher's exact test p<0.01

Table 4. The relationship of parity and educational level with bothersome stress and urge urinary incontinence symptoms.

	Bothersome stress incontinence		Bothersome urge incontinence	
Parity	n		n	
Nulliparous	173	22 (12.7)	84	9 (10.7)
Parous	826	210 (25.4)*	378	97 (25.7)*
Educational level	n		n	
Primary only	236	76 (32.2)*	132	38 (28.9)*
Secondary/higher	763	153 (20.1)	330	65 (19.7)

Values are numbers (%). * Two-sided Fisher's exact test p<0.01

Table 5. Crude and adjusted odds ratio's (OR) with 95% Confidence Interval (CI) of bothersome stress- and urge incontinence for hysterectomy.

	Bothersome stress incontinence	Bothersome urge incontinence
Hysterectomy†		
Crude	6.7 (4.7 - 9.4)	17.0 (9.8 - 29.8)
Adjusted for parity	6.5 (4.6 - 9.2)	16.2 (9.2 - 28.3)
Adjusted for parity and educational level	6.3 (4.5 - 9.0)	14.6 (8.3 - 25.7)

† Odds ratio's for pre-hysterectomy versus non-hysterectomy groups.
All OR's significant at p<0.001

Discussion

We found that women who are scheduled for hysterectomy do not have a higher prevalence of stress- or urgency urinary incontinence symptoms as compared to women who are not scheduled for hysterectomy. However, when asking women with urinary incontinence about their perception of its severity, pre-hysterectomy women report much more often to be bothered by it as compared to non-hysterectomy women. This increased bothersomeness is more profound for urge incontinence symptoms than for stress incontinence symptoms. In addition, women with a low educational level were more likely to undergo a hysterectomy and experience urinary incontinence as bothersome as compared to higher educated women.

Apart from the fact that we compared urinary incontinence symptoms between pre-hysterectomy and non-hysterectomy women our study has two important strengths. First, we discriminated symptoms of urge from stress urinary incontinence. This is of importance since these two types of urinary incontinence have a different pathophysiological background. Secondly, we included the woman's own perception of severity of her incontinence by asking how bothersome she experienced her incontinence to be. This approach provides an estimate of perceived severity of the incontinence from the patients point of view, regardless the actual amount or frequency of urine loss.

There are several possible limitations to our study that need to be addressed.

One of the concerns is that the difference in response rate between the community group (63.8%) and pre-hysterectomy group (90%) could have affected our results. Although we explicitly encouraged women without any symptoms from the community sample to participate, the reported prevalence of urinary incontinence in this group might be overestimated. However, the reported prevalence of urinary incontinence in our study is in agreement with recent studies with higher response rates (up to 84%) that used the same definition for urinary incontinence. [8,9] Furthermore, it is stated that samples based on voluntary responses tend to overrepresent people with strong opinions, most often negative opinions.[10] This would indicate that the prevalence of bothersome urinary incontinence is more likely to be overreported by the community sample than underreported.

Therefore, the true differences we found in bothersome urinary incontinence between pre-hysterectomy and the community sample may even be greater than we have reported. Another concern is that population based studies do not allow objective demonstration of urinary incontinence. We therefore cannot conclude that we measured stress or urge incontinence. Apart from the discussion if urodynamics can be regarded as the golden standard in the diagnosis of urinary incontinence, our study was designed to measure incontinence as a symptom. From this symptom-based point of view our results have to be interpreted. However, since we found substantial differences between the effects of stress and urge incontinence symptoms, we believe that our two questions indeed identified women with different types of urinary incontinence.

Hysterectomy, after caesarean section the second most performed operation in women, has been related to UI in later life.[1] Prospective studies on the sequella of hysterectomy that also include information on urinary incontinence are scarce.[2,11-15] The results, ranging between an increase in incontinence and improvement of incontinence, are difficult to compare between studies. Some studies have limited power and report on differences between urge and stress incontinence without mentioning the definitions used.[14,15] Other studies do not distinguish stress from urge urinary incontinence symptoms, use different definitions for the severity of incontinence, do not present results based on intention to treat (between 10.5 and 18% drop-outs) and perform additional surgical procedures for urinary incontinence without adjusting their results for it. [2,11,13] Our results show that, with regard to bothersome urinary incontinence symptoms, women scheduled for hysterectomy differ from those who are not. These differences have to be accounted for when analysing short and long term consequences of hysterectomy on urinary incontinence.

The differences in experienced bother between pre- and non-hysterectomy women may be explained by several hypothesis. First, candidates for hysterectomy may have larger volumes of urine loss or more frequent incontinence episodes. A comparative quantitative assessment of the amount of urine loss and frequency of incontinence episodes between women scheduled for hysterectomy and a control group has not been performed.

Since in our study no information on the frequency or volume of urine loss was available we can only speculate about its effect on bothersomeness. However, if bothersome UI would have presented itself in terms of frequent and large amounts of urine loss, it would have been conceivable that the gynaecologist would have noticed this and would have proposed additional treatment. Another hypothesis to explain the increased bothersomeness is that mood disorders among women scheduled for hysterectomy affect their perceived severity of co-morbidity. It is known that women scheduled for hysterectomy have an increased incidence of psychologic morbidity (especially depression and anxiety) as compared to the general population [3,11,16] Furthermore, anxious women presented themselves with complaints of UI at significantly smaller volumes of urine (measured with a 48-hour pad test) as compared to non-anxious women.[17] Thus, the high prevalence of mood disorders among women scheduled for hysterectomy may be responsible for reporting UI as troublesome, even at small volumes of loss.

One of the most interesting findings of our study is the relationship between educational level, hysterectomy and bothersome urinary incontinence. Low educated women are significantly more likely to experience urinary incontinence as bothersome as compared to higher educated women and are at increased risk for having a hysterectomy. Low educated women are also known to report transient and persistent health-related limitations [18] more often as compared to higher educated women. This implicates that at the same objective severity of symptoms, low educated women are probably more likely to experience these symptoms as bothersome as compared to higher educated women, resulting in more help-seeking behaviour. Seeking medical attention predisposes women to undergo diagnostic and therapeutic procedures, like hysterectomy. It is unlikely that educational level itself will affect the objective severity of menstrual bleeding problems or urinary incontinence. Therefore, we believe that other factors than the objective severity of problems are responsible for the increase in perceived worries about symptoms in low educated women.

For pre-hysterectomy women, we found that the odds for bothersome stress incontinence was considerably smaller than the odds for bothersome urgency symptoms (6.3 versus 14.6). Several explanations for this phenomenon can be given. First, stress and urge incontinence are different diseases.[18,19] Secondly, urge incontinence has been show to have significantly more negative consequences on quality of life as compared to stress incontinence, and is therefore considered to be a more bothersome disorder.[19,20] Thirdly, symptoms of depression were shown to be associated with idiopathic urge incontinence and not with stress incontinence.[21] If depression is indeed associated with a worse perception of the severity of symptoms and also related to an increased risk of urge urinary incontinence, this may explain our findings. Finally, the sample of women with urge symptoms was smaller in number than the sample of women with stress incontinence symptoms. This is reflected in a larger 95% confidence interval of the odds ratio of bothersome urge incontinence for hysterectomy. Since the 95% confidence intervals between bothersome stress- and bothersome urgency symptoms overlap (4.5-9.0, versus 8.3-25.7) the differences may be coincidental.

In conclusion, women scheduled for hysterectomy do not report urinary incontinence more often than women who are not. This indicates that the hypothesis of a causal relationship between the symptoms leading to hysterectomy and urinary incontinence is unlikely. However, the type and bothersomeness of urinary incontinence differs significantly between incontinent pre-hysterectomy and non-hysterectomy women. This indicates that these factors, together with parity and educational level have to be considered in assessing the consequences of hysterectomy on urinary incontinence. The markedly increased odds of bothersome urinary incontinence for pre-hysterectomy women supports our hypothesis that these women have a different perception of the severity of their urinary incontinence as compared to non-hysterectomy women. One of the factors of importance in this different perception may well be the educational level or other factors related to socioeconomic status. Whether improved health after hysterectomy changes the perceived worries about urinary incontinence is still unclear but deserves further attention.

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Chapter 6

Hysterectomy: A risk factor for urinary incontinence?

CH van der Vaart, MD, JG van der Bom, MD, PhD, JRJ de Leeuw, PhD, JPWR Roovers, MD,
and APM Heintz, MD, PhD

Introduction

The lifetime risk for women over 60 years of age to have a hysterectomy is approximately 25%.[1,2] Although hysterectomy is an effective procedure for curing a number of gynecologic diseases, it has been associated with the development of changes in urinary function, especially urinary incontinence (UI).[3-5] Recently it was suggested that practitioners should discuss the possibility of an increased likelihood of urinary incontinence later in life with women planned for hysterectomy.[3]

For urinary incontinence, a distinction is made between symptoms of urine leakage related to increase in abdominal pressure (stress incontinence) and urine leakage related to a feeling of urgency (urge incontinence). The pathophysiology of these two types of incontinence is believed to be different. Stress incontinence has been related to poor pressure transmission to the urethra due to hypermobility of the bladder neck or insufficient closure function of the urethra itself. Urge incontinence is related to involuntary detrusor contractions or hyperreflexia. These differences suggest that different factors cause different types of urinary incontinence. Therefore, it may be expected that effects of hysterectomy on stress incontinence and urge incontinence differ.

The nature of urinary incontinence (stress-related or urgency-related) has been associated with the impact that women experience from incontinence on their quality of life. Urge incontinence appeared to adversely affect quality of life more than symptoms of stress incontinence. [6,7] Nevertheless, the majority of women with urinary incontinence report not to be bothered by it at all. Therefore, information on the severity of urinary incontinence, reflected as a high degree of bother, is also of importance in the assessment of the consequences of hysterectomy on urinary incontinence.

The primary objective of the present study was to examine whether hysterectomy is an independent risk factor for stress-related and for urgency-related urinary incontinence. In addition we evaluated whether hysterectomy is associated with bothersome incontinence symptoms.

Methods

Study population

The study population consists of a random population sample of 2322 women, between 35 and 75 years of age. This sample was obtained from the population registration office of a suburban area in the central part of the Netherlands in 1999. These women were invited to participate in a study on the prevalence and consequences of urogenital and defaecatory symptoms in the female community. All women received a questionnaire with an accompanying letter explaining the purpose of the study. Care was taken to encourage women without any symptoms to participate, emphasizing the importance to compare their situation with women with symptoms. All women received a reminding letter after four weeks. Sixteen-hundred and eighty-nine questionnaires were returned (72.2%). Twenty-nine questionnaires were returned because the women had moved and 34 women refused to participate, leaving 1626 fully evaluable women (70.0%). In this sample 1417 women (87%) had no history of hysterectomy and 209 had a history of hysterectomy (13%). All hysterectomies were performed for non-malignant conditions.

Measurements

All women received a self-administered questionnaire in 1999. The study was approved by the local ethics committee, with the restriction that contacting non-responders was not allowed.

The questionnaire consists of 162 items about urogenital symptoms, defaecatory symptoms, quality of life, depressive symptoms, health-locus of control and coping strategies. For the present study we used the data from the following items and scales.

For every woman data on age, parity, history of urinary incontinence surgery and educational level were collected. Educational level was included since a low educational level has been related to an increased risk of having a hysterectomy and to report transient and persistent health-related limitations as compared to a higher educational level.[1,8] Educational level was dichotomized into primary only and secondary/higher level.

Urogenital symptoms were measured with the Urogenital Distress Inventory (UDI).[9] The UDI consists of 19 items and each item measures whether a *symptom* is present and the amount of bother the woman experiences from that symptom. The latter is measured on a four-point Likert scale ranging from not at all to greatly. Following the recommended International Continence Society definition of different types of UI [10] and in concordance with other studies, [11,12] we selected two questions from the UDI. A woman was considered to have stress urinary incontinence if she replied positively to the question "do you experience urine leakage related to physical activity, coughing or sneezing?" A woman was considered to have urge urinary incontinence if she replied positively to the question "do you experience urine leakage related to a feeling of urgency?". Overall urinary incontinence was defined as having stress and/or urge urinary incontinence. Bothersome stress incontinence was defined as reporting moderately or greatly bother by the symptom. Women without stress incontinence and women with stress incontinence who were not at all or slightly bothered by it were regarded as not having bothersome stress incontinence. The same dichotomization was performed to separate bothersome from not-bothersome urge incontinence.

Statistical analysis

Logistic regression was used to obtain odds ratio's (OR) with 95% confidence interval (CI) of the type and bothersomeness of urinary incontinence for hysterectomy. A multi-variate logistic regression analysis was used to adjust the odds ratio for hysterectomy for urinary incontinence symptoms. The variables age, parity (nulliparae versus primi/multiparae) and educational level (primary versus secondary/higher) were entered one at a time into the model. All statistics were performed with SPSS 10.0.

Results

Characteristics of women with or without a hysterectomy

Table I shows the characteristics of the non-hysterectomy and hysterectomy groups. Women with a history of hysterectomy were older, had a lower educational level, were more often parous and more often had a history of urinary incontinence surgery.

Table 1. Characteristics of the non-hysterectomy and hysterectomy groups.

	Non-hysterectomy (n=1417)	**Hysterectomy** (n=209)	**P-value**
Age in years	50.3 (10.0)	57.4 (7.6)	<0.001 *
Education level			
Primary only	321 (22.7)	78 (36.7)	<0.001†
Secondary or higher	1096 (77.3)	131 (63.3)	
Parity			
0	290 (20.5)	25 (11.7)	<0.001†
≥1	1127 (79.5)	184 (88.3)	
History of urinary incontinence surgery	16 (1.1)	20 (9.6)	<0.001†

Values are numbers (%) or means (standard deviation)

* Student's t-test, † Fisher exact-test

Effects of hysterectomy on urinary incontinence

Table 2 shows the prevalence of the different types of urinary incontinence among women with and without a history of hysterectomy. Overall urinary incontinence (stress symptoms and/or urgency symptoms) was reported by 64.0% (133/209) of women with a history of hysterectomy and by 55.1% (781/1417) of women without a history of hysterectomy (OR 1.4, 95% CI 1.1 - 1.9). After adjustment for age, parity and educational level, the odds for "overall" urinary incontinence for women with a history of hysterectomy was 1.4 (95% CI 1.0 - 1.9) as compared to women without a history of hysterectomy.

As it has been suggested that age is an important modifier of the effect of hysterectomy, a separate analysis was performed for women younger than 60 years (n=1226) and 60 years or over (n=400). Eighty-nine women (24.0%) of 60 years or over and 114 (9.5%) women younger than 60 years had a hysterectomy. Among women with a history of hysterectomy aged 60 years and over, the odds for urinary incontinence was increased by 60 percent (OR 1.6, 95%CI 1.0 - 2.6, p=0.07) as compared to women without a history of hysterectomy. Among women with a hysterectomy younger than 60 years of age, the odds for urinary incontinence was 1.3 (95%CI, 0.9 - 2.0, p=0.22) as compared to women without a history of hysterectomy.

Table 2. Prevalence of urinary incontinence among women with and without a history of hysterectomy.

	Non-hysterectomy (n=1417)	**Hysterectomy** (n=209)	**P-value**
Symptoms			
Urinary incontinence (overall)	781 (55.1)	133 (64.0)	<0.01
Stress incontinence	716 (50.5)	118 (57.0)	NS
Bothersome stress incontinence	120 (8.5)	23 (11.1)	NS
Urge incontinence	320 (22.6)	80 (38.3)	<0.0001
Bothersome urge incontinence	44 (3.1)	21 (9.7)	<0.0001

Values are numbers (%). Stress- and urge incontinence not mutually exclusive.

Fisher exact test. NS = Not significant

Table 3. Crude and adjusted odds ratio's (95% confidence interval) for urinary incontinence for women with and without a history of hysterectomy.

	Urinary incontinence			
	Stress	Bothersome stress	Urge	Bothersome urge
Hysterectomy				
Crude	1.3 (0.9 - 1.8)	1.4 (0.8 - 2.2)	2.1 (1.6 - 2.9)*	3.4 (1.9 - 5.9)*
Adjusted for age	1.3 (0.9 - 1.8)	1.2 (0.7 - 2.0)	1.9 (1.4 - 2.7)*	2.7 (1.5 - 4.7)*
Adjusted for age and parity	1.2 (0.9 - 1.6)	1.2 (0.7 - 1.9)	1.9 (1.4 - 2.7)*	2.7 (1.5 - 4.7)*
Adjusted for age, parity and educational level	1.2 (0.9 - 1.6)	1.2 (0.7 - 1.8)	1.9 (1.4 - 2.6)*	2.6 (1.4 - 4.4)*

* $p < 0.05$

Table 3 shows the crude and adjusted odds ratio's of stress symptoms, bothersome stress symptoms, urgency symptoms and bothersome urgency symptoms urinary incontinence for hysterectomy. After adjustment for age, parity and educational level, both the odds for stress incontinence and bothersome stress incontinence for women with a history of hysterectomy decreased to 1.2. Especially adjustment for parity decreased the odds. The odds for urge- and bothersome urge incontinence symptoms for women with a history of hysterectomy decreased slightly after adjustment but were still highly significant. In this model increasing age caused the greatest reduction in odds ratio.

Again, a separate analysis was performed for women younger and older than 60 years of age. Table 4 shows the crude and adjusted odds ratio's for urinary incontinence for women with a history of hysterectomy in the two age groups. The crude and adjusted odds for both urge- and bothersome urge incontinence symptoms for women with a history of hysterectomy are significantly increased in both age groups. The crude and adjusted odds of both stress- and bothersome stress incontinence symptoms for women with a history of hysterectomy are not significantly increased in the age groups.

Table 4. Crude and adjusted odds ratio's (95% confidence interval) for urinary incontinence for women with compared to women without a history of hysterectomy, according to age < 60 years and ≥60 years.

	Age	
	< 60 YEARS (n=1226)	≥60 YEARS (n=400)
Urinary incontinence		
Stress		
Crude	1.3 (0.9 - 1.9)	1.5 (0.9 - 2.4)
Adjusted ‡	1.1 (0.8 - 1.7)	1.4 (0.8 - 2.2)
Bothersome stress		
Crude	1.5 (0.8 - 2.7)	1.1 (0.5 - 2.5)
Adjusted ‡	1.2 (0.7 - 2.3)	1.1 (0.5 - 2.5)
Urge		
Crude	2.2 (1.5 - 3.2)*	2.2 (1.3 - 3.6)*
Adjusted ‡	1.7 (1.1 - 2.5)*	2.2 (1.3 - 3.6)*
Bothersome urge		
Crude	3.6 (1.8 - 7.3)*	2.7 (1.1 - 6.7)*
Adjusted ‡	2.5 (1.2 - 5.2)*	2.7 (1.1 - 6.8)*

* $p < 0.05$

‡ Adjustments were made for age, parity and educational level

The effect of parity and educational level on urinary incontinence

In addition to our main findings regarding the consequences of hysterectomy on urinary incontinence, we separately examined the effect of parity and educational level on urinary incontinence symptoms. Parous women were more likely to have stress incontinence symptoms (55.2% versus 34.8%, OR 2.31, 95%CI 1.78 - 2.98) and urge incontinence symptoms (26.6% versus 16.5%, OR 1.84, 95%CI 1.33 - 2.55) as compared to nulliparous women. Lower educated women reported more urge incontinence symptoms (30.4% versus 22.8%, OR 1.47, 95%CI 1.14 - 1.89) but not stress incontinence symptoms as compared to higher educated women.

Discussion

Our findings show that hysterectomy is associated with an increased risk of urge incontinence and bothersome urge incontinence symptoms, but not with stress- or bothersome stress incontinence symptoms, independent of age, parity and educational level. This finding did not markedly differ for women younger or older than 60 years. Additional findings were that parity was associated with both stress- and urge incontinence symptoms and a low educational level was associated with urge-, but not with stress incontinence symptoms.

A strength of our study is that we separated symptoms of urine leakage related to physical activity or increased abdominal pressure from those related to sensations of urgency. Differentiating these two types of urinary incontinence is of clinical importance for the individual patient since the consequences of having stress or urge incontinence symptoms for well-being are different. A second strength is that we included the perceived severity (bothersomeness) of urinary incontinence into our analysis. The degree of bothersomeness has been related to the frequency of urine loss.[11] Women with weekly occurring urine loss reported to be significantly more bothered by it than women who reported infrequent (less than once a week) urine loss. When counseling women about the sequella of hysterectomy, women may respond differently to an increased risk of having infrequent, not-bothersome urinary incontinence as compared to an increased risk of frequent urine loss that is reported by other women to affect their well-being. A final strength is that we used a random population based cross-sectional study design in which the prevalence of urinary incontinence was assessed with standardized questions independent of age, parity and history of hysterectomy.

Our study also has several potential limitations that need to be addressed. First, we did not objectively demonstrate urine leakage, which is a requirement for a sign-based definition of urinary incontinence. Urodynamic investigation is necessary to make a condition-based diagnosis of stress or urge incontinence, but whether it has to be considered as the 'golden standard' is debatable. There is a considerable difference between patients' self-reported symptoms and actual findings from routine office urodynamic testing.[13] However, 40 to 84% of patients who complained of urge urinary incontinence and that did not have unstable bladder contractions on office urodynamics, were shown to have bladder instabilities during ambulatory urodynamics.[14] Furthermore, with the use of ambulatory urodynamics, several studies have shown that more than 40% of continent subjects have unstable bladder contractions.[15] Whatever the value of urodynamics may be in establishing urinary incontinence as a condition, the objective of our study was to assess urinary incontinence as a symptom. We therefore carefully defined urinary incontinence as stress- or urge incontinence symptoms from a symptom-based definition point of view.

Secondly, overweight, as measured with the Body Mass Index (BMI), has been related to an increased odds of having urinary incontinence. [16] It has been associated with stress incontinence and urge incontinence.[12] Women after hysterectomy are reported to have a higher BMI as compared to controls.[17] This is probably due to weight gain after hysterectomy, which starts early after surgery, and not to pre-existing overweight.[18] Therefore, overweight does not appear to be a risk factor for having a hysterectomy and therefore cannot be considered to be an important confounder. In our study population information on BMI was not available and therefore we were unable to correct our results for this possible modifying factor.

The association we found between hysterectomy and overall urinary incontinence is similar to that of a recent meta-analysis on the subject.[3] Although it has been reported that urgency symptoms have a greater negative impact on quality of life as compared to stress symptoms, [6,7] few studies report on differences between urge and stress incontinence after hysterectomy.[12,19-24] However, the heterogeneity of these studies limit overall interpretation. Some studies are limited by sample-size [19,21], do not state the questions used to distinguish stress from urge incontinence [19] and have a remarkable low prevalence of hysterectomy (6.3% in women aged 30-59 years) [23]. All but one study did not adjusted for age and parity. The study by Kuh and co-workers adjusted their results for age, parity and educational level.[12] This study reports increased adjusted odds (odds ratio 1.3, 95%CI 0.93 - 2.0) of urge incontinence after hysterectomy. The association between hysterectomy and stress incontinence was not reported. However, the domain of this study was 48-year old women and therefore the results cannot be well compared to ours.

Why hysterectomy is a risk factor for urgency symptoms is not clear. The cause of detrusor instability is not fully understood but has been related to innervation problems of the detrusor muscle. Development of post-junctional supersensitivity of the detrusor muscle seems to play an essential role.[25] Partial denervation of the detrusor appears to be the mechanism responsible for this post-junctional supersensitivity. During hysterectomy blunt dissection of the bladder from the uterus and cervix may damage a major part of the detrusor innervation, and division of the cardinal ligaments may also damage the main branches of the pelvic plexus.[26] On the other hand, stress incontinence seems to be related to changes in the function of structures (like the pubo-urethral ligaments, pubococcygeus muscle and suburethral vaginal wall) closely related to the urethra.[27] It is unlikely that hysterectomy causes direct damage to these structures. At six months after hysterectomy no changes in urethral length and maximal closure pressure were detected as compared to pre-hysterectomy values.[28] However, bladder sensitivity had increased significantly. Therefore, it seems plausible that hysterectomy is more likely to be related to the development of urge incontinence symptoms instead of stress incontinence symptoms.

In conclusion, although hysterectomy itself is very effective for resolving uterine bleeding problems, our results show that patients have increased odds of urge- and bothersome urge incontinence symptoms after hysterectomy. This should be discussed with the individual patient and weighted against the expected beneficial effects of hysterectomy.

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Chapter 7

The effect of coping strategies on Health-related quality of life in women with symptoms of pelvic floor dysfunction.

CH van der Vaart, MD, JRJ de Leeuw, PhD, JPWR Roovers, MD, APM Heintz, MD, PhD

Introduction

Symptoms of pelvic floor dysfunction, like urinary incontinence, obstructive micturition, overactive bladder, faecal incontinence, constipation and genital prolapse are common in the general adult female population. The prevalence of urinary incontinence has been reported to be between 14 and 71.4%.[1-4] Faecal incontinence occurs in 7% and constipation in 10-20% of otherwise healthy women.[5-7] All of these symptoms may occur in combination[8] and are often without prospect of complete recovery and have a relatively long duration. In this context these symptoms of pelvic floor dysfunction can be regarded as chronic disorders that may have long-term consequences on Health-related Quality of Life (HRQoL) of those affected. Indeed, many women with symptoms of pelvic floor dysfunction report to be bothered by their symptoms and were shown to have a reduction in HRQoL.[9-11]

The concept of HRQoL gives maximum weight to the subjective perception of the severity of the problem for individual women. It is intuitively clear that the impact of symptoms on HRQoL is not only related to the objective severity of the disorder but also to the individual's response to the situation. For instance, only a small proportion of women who have self-reported bothersome urinary incontinence seek professional help.[12,13] These differences in help-seeking behaviour may well be related to the way women handle or cope with problems of pelvic floor dysfunction.

Coping is a psychological construct that refers to the way in which people respond and behave in the response to stressful events. [14,15] It has been subject of investigation in psychologic research for the last two decades. Although the concept of coping is complex some basic "meta-strategies" of coping have been identified. These involve emotion-oriented versus problem-oriented [14] and passive or avoiding versus active or approaching [15] ways of coping. Problem-oriented or active ways of coping are usually considered to be better ways of coping than emotional-oriented or passive ways of coping.[16] However, which coping style is more accurate is also determined by the situation it is applied in. For instance, in situations that are unresolvable (like terminal cancer) emotional-oriented coping strategies may be more appropriate than problem-oriented coping strategies.

In women with pelvic floor dysfunction, the role of coping strategies in the adaptation to these symptoms has received little attention. Although there is an increasing interest in measuring HRQoL in these women it has not been properly recognized that HRQoL may not only be influenced by the severity of the symptoms but also by different coping strategies. Information about the effect of coping strategies on HRQoL can be of clinical importance. The effectiveness of interventions, when measured in terms of changes in HRQoL, may seriously be biassed if the effect of coping strategies (positively or negatively) on HRQoL are not accounted for. In this case, the same objective cure of symptoms may lead to different improvements in HRQoL, obscuring the effect of treatment itself.

Therefore, the aim of our study was to measure the effect of different coping strategies on HRQoL in women with symptoms of pelvic floor dysfunction.

Methods

Study population

The study population consists of a random population sample of 3200 women, between 20 and 70 years of age, that was obtained from the population registration office of a suburban area in the central part of the Netherlands. These women were invited to participate in a study on the prevalence and consequences of urogenital and defecation symptoms in the female community. All women received a questionnaire with an accompanying letter explaining the purpose of the study. Care was taken to encourage women without any symptoms of pelvic floor dysfunction to participate in the study, emphasizing the importance of their cooperation to compare their situation with that of women with symptoms. A reminder was send after four weeks to all women. All data collected were anonymous. Two-thousand forty-two women responded (63.8%).

Study design

All women received a 162-item, self-administered questionnaire in 1999. The study was approved by the local ethics committee, with the restriction that contacting non-responders after the reminding letter was not allowed.

Data on age and educational level were collected. In analysis, the educational level was dichotomized into primary only and secondary or higher.

Symptoms of pelvic floor dysfunction were measured with the Urogenital Distress Inventory (UDI)[17] and the Defecation Distress Inventory (DDI).The UDI consists of 19 items and each item measures if a *symptom* is present and the amount of bother the woman experiences from that symptom. The latter is measured on a four-point Likert scale ranging from not at all to greatly. The original UDI consists of three domains; stress incontinence symptoms, irritative symptoms and obstructive symptoms. The score of each domain ranges from 0 to 100, a high score representing more or more bothersome complaints. We translated the UDI and tested it's psychometric qualities. We identified five instead of three domains namely; urinary incontinence, overactive bladder symptoms, obstructive micturition, genital prolapse and pain/discomfort.(Chapter 2) A total UDI score is computed by taking the sum of the five domains (range 0 - 500). The DDI consists of 15 items about symptoms related to obstructive defecation, constipation, faecal incontinence and painful defecation. It was developed in our Center to be used for measuring anorectal symptoms in women presenting with symptoms of pelvic floor dysfunction. The content validity of the DDI was ensured by literature review and interviews with three experts in the field from the Department of Surgery and Obstetrics/Gynecology from the University Medical Center Utrecht, the Netherlands.

A structured interview of the 15 selected items was held with 20 female patients to account for face validity. The layout of the items was exactly comparable to that of the UDI. Factor analysis, using a principal axis factoring model with varimax rotation, showed four distinct domains (constipation, faecal incontinence, painful defecation and incontinence for gas). Cronbachs' alpha[18], as a measurement of internal consistency of these domains, ranged between 0.71 - 0.78. Like the UDI, the score of the domains ranges from 0 to 100 and the DDI total score ranges from 0 to 400. In the analysis the total score of the UDI and DDI were added together and transformed into one 'pelvic floor distress' (PFD) scale, with a score ranging from 0 to 100. Again, a high score implicates more or more bothersome symptoms.

Health-related quality of life was measured in three ways. First, two questions were used to obtain a general quality of life score. The questions were: "How would you rate your overall health during the last week?" and "How would you rate your quality of life during the last week". Answers were obtained on a 6-point Likert scale ranging from extremely bad to excellent. The mean value of these two questions was transformed into a single score ranging from 0 (extremely bad) to 100 (excellent). Secondly, a disease specific quality of life score for pelvic floor disorders was obtained. We used the Incontinence Impact Questionnaire (IIQ) as a disease-specific quality of life questionnaire. The IIQ that was developed to be used in combination with the UDI.[17] The original IIQ consists of 30 items about the impact of urogenital symptoms on four aspects of quality of life: physical functioning, emotional functioning, travel and social functioning. A high score on the IIQ domains indicates that the person's well-being on that particular domain is negatively affected. Factor analysis (principal axis factoring with varimax rotation) of our translation of the IIQ identified a fifth factor that contains 4 items about embarrassment. Cronbachs' alpha for the five domains ranged from 0.83 (embarrassment) to 0.93 (mobility). The total IIQ score (sum of all five domains) was used in analysis. Finally, general emotional well-being was assessed with the Center for Epidemiologic Studies - Depression scale (CES-D) [19]. This questionnaire consists of 20 items and has been developed for research in the non-psychiatric population. A Dutch translation has been validated [20]. The total score ranges from 0 to 60. In this study the total CES-D score was used as an indication for depressive symptomatology.

Coping strategies were measured with 22 items originating from the Ways of Coping Checklist (WCC) and the Utrecht Coping List (UCL).[21,22] The reason for this selection was that we considered the WCC and the UCL to assess coping strategies in general.

We were especially interested in disease-specific coping aspects of women with symptoms of pelvic floor dysfunction and therefore made a selection we thought would fit this purpose. A factor analysis (principal axis factoring with varimax rotation) on these 22 items resulted in the following coping strategies: Planful and rational actions (4 items, Cronbachs' alpha=0.82), Distancing (4 items, Cronbachs' alpha=0.76), Self-blame (2 items, Cronbachs' alpha=0.63), Wishful thinking (3 items, Cronbachs' alpha=0.75), Emotion expression/seeking social support (3 items, Cronbachs' alpha=0.85), Seeking distraction (2 items, Cronbachs' alpha=0.62) and Avoidance (3 items, Cronbachs' alpha=0.63). The items of each subscale are presented in the appendix. For each coping strategy a score ranging from 0 to 100 was obtained. A higher score indicating a more extensive use of that the coping strategy.

Statistical analysis

Stepwise linear regression analyses were used to determine which variables can be used to predict generic HRQoL, disease-specific HRQoL(IIQ) and depressive symptoms (CES-D). Squared multiple correlations were calculated after each entry of a new factor into the model. All variables were entered in one block. Factors included as independent variables in the models were age, educational level, PFD total score and coping strategies.

Standardized regression coefficients were calculated for each variable that explained a significant proportion of the different HRQoL scale variations. This allowed us to study the strength and direction of the effect.

All data analysis were performed with the statistical package SPSS 10.0.

Results

The baseline characteristics of the study population are presented in Table 1. Only 9.5% of the women did not report any symptoms on the UDI and DDI. Of the remaining 1848 women a total of 1057 (57.2%) answered the questions of the IIQ and coping. From the group of women with 1 to 5 positive symptoms on the UDI and DDI, 36.8% answered the IIQ and coping questions. For the group of women with 6 to 10 positive symptoms this was 69.3%, for the group of women with 11 to 15 positive symptoms 86.1%, and for the group of women with more than 15 symptoms 98.9%.

Table 1 Characteristics of the study population.

Age (years)	46.5 (13.1)
Age distribution	
20-29 years	233 (11.4)
30-39 years	443 (21.6)
40-49 years	465 (22.7)
50-59 years	501 (24.5)
60-70 years	400 (19.8)
Parity	
0	581 (28.5)
1	241 (15.6)
2	708 (27.9)
≥3	512 (14.8)
Educational level	
Primary only (low level)	439 (21.5)
Secondary or higher (high level)	1603 (78.5)
Marital status	
Married	1359 (66.6)
Divorced	145 (7.1)
Widow	98 (4.8)
Never been married	440 (21.5)
Positive symptoms on UDI and DDI	
0	194 (9.5)
1-5	925 (45.3)
6-10	586 (28.7)
11-15	249 (12.2)
>15	88 (4.3)

Values are expressed as means (SD) or numbers (%)

The results of the stepwise linear regression analyses are presented in Table 2, 3 and 4. Table 2 shows the results for the disease-specific HRQoL as measured with the IIQ.

The PFD score explained the largest proportion (33%) of the total variance (42%) of the model. The coping strategies Avoidance, Wishful thinking, Seeking distraction, Planful/rational actions and Distancing explained an additional 8 % of the total variance of the IIQ.

The strength and direction of the effect of coping strategies on the IIQ score are shown in Table 2. The educational level explained the final 1% of the total explained variance of the IIQ.

Table 2. Factors associated with the Incontinence Impact Questionnaire total score.

	Standardized regression coefficient	R Square
Pelvic floor distress score	0.453	0.33
Avoidance*	0.152	0.38
Wishful thinking*	0.134	0.39
Educational level	-0.094	0.40
Distraction*	0.127	0.41
Planful/rational action*	-0.080	0.42
Distancing*	-0.066	0.42

Stepwise linear regression analysis. Only factors significantly ($p<0.05$) associated are shown

* Coping strategy

Table 3. Factors associated with General HRQoL.

	Standardized regression coefficient	R Square
Pelvic floor distress score	-0.264	0.10
Wishful thinking*	-0.214	0.12
Planful/rational action*	0.149	0.14

Stepwise linear regression analysis. Only factors significantly ($p<0.05$) associated are shown

* Coping strategy

In Table 3 the results for the general HRQoL score are shown.

A total of 14% of the variance of the general HRQoL was explained by the model. Ten percent was explained by the PFD and an additional 4% by two coping strategies. Note the strength of effect of the two coping strategies and the PFD and also the difference in direction of the effect between the coping strategies Wishful thinking and Planful actions.

Table 4. Factors associated with the CES-D total score.

	Standardized regression coefficient	R Square
Pelvic floor distress score	0.279	0.10
Age	-0.180	0.12
Seeking distraction*	0.106	0.14
Self-blame*	0.068	0.14
Emotional expression/seeking support*	-0.110	0.15
Wishful thinking*	0.086	0.15

Stepwise linear regression. Only factors significantly ($p<0.05$) associated are shown

* Coping strategy

Finally, in Table 4 the results for depressive symptoms are shown. Again, the largest proportion of variance was explained by the PFD (10%) and only 3% by coping strategies. Age explained 2 % of variance. Again, notice the direction and strength of effect of the different coping strategies on depressive symptoms.

The association between coping strategies and educational level is shown in Table 5. Lower educated women more extensively used Avoidance coping as compared to higher educated women. The opposite is true for the coping strategy Planful rational actions.

Table 5. Educational level and coping strategies in women with pelvic floor dysfunction.

	Low educated n=218	**Higher educated** n=839	**P-value***
Planful and rational actions	55.0 (1.7)	61.7 (0.8)	0.0001
Emotion expression/seeking social support	44.6 (1.6)	48.1 (0.8)	0.05
Distancing	43.0 (1.9)	44.6 (0.9)	NS
Wishful thinking	50.0 (1.4)	47.1 (0.7)	0.05
Avoidance	41.0 (1.4)	35.8 (0.6)	0.001
Distraction	45.1 (1.5)	46.2 (0.8)	NS
Self-blame	36.8 (1.4)	36.8 (0.7)	NS

Values are mean (standard error of mean)

* Students T-test. P-values adjusted for unequal variances when appropriate.

Discussion

Our study shows that, when measuring HRQoL in women with symptoms of pelvic floor dysfunction, the severity score of these symptoms (PFD score) explained most of the variance in HRQoL, regardless if this is expressed in general, disease-specific or emotional terms. Coping strategies explained a reasonable extra proportion of the variance of the IIQ (8%) but only a small proportion of the variance of the RAND-36 or depressive symptoms (CES-D). When using a generic HRQoL outcome measure, the strength of the negative effect of the severity of pelvic floor symptoms (PFD score) is the same as the strength of the negative effect of the coping strategy Wishful thinking, and almost twice the strength of the positive effect of the coping strategy Planful/rational actions. This implicates that women with the same PFD score may have a marked difference in generic HRQoL score, depending on the strength and direction of the coping strategies they apply to the situation. Without knowledge about these coping strategies, the true effect of pelvic floor symptoms on generic quality of life is difficult to express. The same is true for the assessment of HRQoL with an disease-specific instrument like the IIQ. Of the total 42% of explained variance in the model, approximately 8% is explained by coping strategies. When looking at the direction of the effects (positive or negative), women who more express the coping strategies Planful/rational actions and Distancing will have a lower IIQ score (better HRQoL!) as compared to women in whom these strategies are less expressed.

The concept of coping is a complex one and there is a lot of discussion about which factors determine coping strategies and what the effects of coping strategies on well-being are.[23] Although there are several definitions for coping, the most commonly used is the one by Lazarus and co-workers who describe coping as "constantly changing cognitive and behavioural efforts to manage the specific external and internal demands that are appraised as taxing or exceeding the resources of the person".[16] Several important issues are incorporated in this definition. First, "constantly changing" implies that coping strategies are flexible. Depending on the nature, severity and stage of the disease coping strategies may differ. Life-threatening diseases, such as cancer or heart diseases, call for a more problem oriented coping strategy as compared to non life-threatening diseases like diabetes that do not cause the same amount of alarm.[23] With progression of disease, for instance the progression of breast cancer, coping strategies have been reported to change from problem-oriented to more emotional-oriented.[24] Our results show that there is a clinical and statistical significant positive correlation between increasing severity of symptoms (Higher IIQ score) and emotion-oriented avoiding coping strategies (Avoidance and Wishful thinking). However, this does not mean these emotion-oriented, avoiding coping strategies in severe pelvic floor dysfunction have to be always interpreted as inadequate ways of coping. If the situation is appraised as one in which nothing useful can be done to change the situation, rational problem-solving efforts can be counterproductive and emotion-oriented or avoiding coping strategies may be the best choice. [25-27] A second important issue in the definition of coping by Lazarus and co-workers is that it emphasises the importance of personal resources. This has lead some researchers to explore the relationship between coping strategies and personality characteristics. Coping strategies postulated to be functional were shown to be linked to personal qualities that are widely regarded as beneficial (like optimism and self-esteem) and inversely associated with less beneficial qualities (pessimism).[28,29] We did not measure personality characteristics but we were informed about the educational level of the women. We showed that low educated women more frequently used Avoidance coping strategy as compared to higher educated women. The opposite was found for the coping strategy Planful rational actions, which was more expressed in higher educated women. Besides, a nearly significant difference was found in the coping strategies Wishful thinking (more expressed in lower educated women) and Emotion expression/seeking social support (more expressed in higher educated women). Apparently a low educational level predisposes to the use of avoiding, emotion-oriented coping strategies in women with pelvic floor dysfunction. Since we have shown that these coping strategies have a negative effect on HRQoL, lower educated women are more likely to experience greater negative impact of pelvic floor symptoms on their quality of life. We could clearly demonstrate this effect with the disease-specific IIQ, but not with a generic HRQoL questionnaire or depressive symptoms. However, these findings have to be interpreted carefully because we also showed that the strength of effect of beneficial coping strategies ("Planful rational actions" and "Distancing") was almost half that of non-beneficial coping strategies ("Avoidance" and "Wishful thinking"). This implicates that the value of coping in women with pelvic floor dysfunction is not so much in raising the level of well-being but in the prevention of a worse situation. This difference between the strength of effect of beneficial and non-beneficial coping strategies has been reported before.[30]

A point of concern of our study is the fact that only 57.2% of women with at least one PFD symptom present answered the questions of the IIQ. There was a clear relationship between the number of reported symptoms on the PFD and the willingness to fill in the IIQ questionnaire. We believe that women with few symptoms were less likely to feel bothered by these symptoms and therefore decided to skip the IIQ questions in the questionnaire. However, since the IIQ is intended to measure bothersomeness of pelvic floor dysfunction on different aspects of HRQoL we do not believe that our results are effected by the response rate.

In this study we could clarify which coping strategies are most helpful in women with pelvic floor dysfunction in the general female community. The next question would be whether the use of more beneficial coping strategies can be encouraged in women with pelvic floor dysfunction symptoms. Clearly, our study design (random, anonymous, population sample) was not suitable to answer such a question. However, it is most likely that the flexible use of coping strategies in different situations by the same individuals makes it possible to encourage the use of specific strategies in specific situations. Recently, a study by van Dulman and co-workers demonstrated that cognitive-behavioural therapy for irritable bowel syndrome increased the number of successful coping strategies and decreased patient's avoidance behaviour.[31] Although the beneficial effect of behavioural therapy in urinary incontinence is well established[32], it has not been evaluated how much of the success can be contributed to changing coping strategies.

In conclusion, the effects of coping strategies on HRQoL in women with symptoms of pelvic floor dysfunction can be substantial, especially when HRQoL is measured in general terms. If these effects of coping strategies are not accounted for in treatment outcome analysis, the true value of the effect of the intervention may be obscured. This can be especially bothersome in non-randomised studies that compare the effectiveness of different treatments. Low educated women with pelvic floor symptoms more frequently use emotion-oriented, passive coping strategies as compared to higher educated women. These coping strategies were shown to be positively correlated with a worse HRQoL. Therefore, screening for coping strategies and educational level can be of importance in selecting women with pelvic floor dysfunction that may benefit from behavioural therapy. This may be especially true for women with relatively mild objective symptoms.

Appendix. Questions used in the assessment of coping strategies with corresponding scale

Planful and rational actions

I think about how to handle the problem

I take direct action to get around the problem

I concentrate my efforts in doing something about it

I prepare myself for new situations in order not to get into problems

Expression of emotion/seeking social support

I try to get advise about what to do from someone I trust

I talk to someone about how I feel

I discuss my feelings with someone

Distancing

I accept that this has happened and that it can't be changed

I learn to live with it

I just wait and see what will happen

I accept the reality of the fact that it has happened

Wishful thinking

I feel unhappy because I can't get around the problem

I wish the problem was over

I wish I could have prevented what has happened

Avoidance

I try to avoid situations that can get me into trouble

I try to avoid contact with people who are unaware of my problems

I avoid social contacts

Distraction

I try to get distraction

I try to think about other things not related to the problem

Self-blame

I blame myself for what has happened

I criticize myself

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Chapter 8

The relationship between ways of coping with pelvic floor dysfunction and help-seeking behaviour in adult women.

CH van der Vaart, MD, JRJ de Leeuw, PhD, JPWR Roovers, MD, APM Heintz, MD, PhD

Introduction

Symptoms of pelvic floor dysfunction, like urinary incontinence, genital prolapse, constipation and anal incontinence are common in the adult female population. Urinary incontinence has a reported prevalence between 14-71.5% and constipation is reported by 10-20 % of the female population.[1-6] Although these symptoms are common, it has been reported that approximately seventy percent of women with moderate to substantial complaints of urinary incontinence or bowel dysfunction do not seek professional help.[7-9] Much of the delay in help-seeking has been attributed to feelings of embarrassment about the symptoms [10] but it is also reasonable to assume that the objective severity of the symptoms is related to it. However, the psychosocial impact of urinary incontinence only moderately correlates with the objective severity of symptoms.[11] Therefore, women may present themselves to their physician with complaints that cannot be objectively demonstrated.

The way people respond to the consequences of specific diseases is not only related to the type and severity of the disease itself but also to their individual ability to cope with the situation and the degree to which they perceive control about it. Coping and locus of control are important factors involved in the individual's response to stress. Coping refers to the way in which people respond and behave in response to a stressful event.[12] The role of coping in adjustment to several chronic diseases has been well assessed.[13-15] Important distinctions in ways of coping are problem-oriented versus emotion-oriented coping, and passive or avoiding versus active or approaching ways of coping.

Locus of control refers to the beliefs which people have that the cause or course of a specific event (illness) is controlled by internal (personal) or external (situational/accidental, powerful others) elements.[16] When studying the consequences of pelvic floor dysfunction it is unclear why some women seek medical attention for relatively mild symptoms while others, despite reporting severe bothersome symptoms, decide not te seek help. The way women cope with their symptoms and/or perceive control about them may give an explanation for this difference. The role of coping and locus of control in this process of adjustment to pelvic floor symptoms has received little attention.

The aim of this study is to analyse differences in coping and locus of control between women who seek help for symptoms of pelvic floor dysfunction and those who do not.

Method

Study population

The study population consisted of two samples of women. First, a random population sample of 3200 women, between 20 and 70 years of age, was obtained from the population registration office of a suburban area in the central part of the Netherlands. These women were invited to participate in a study on the prevalence and consequences of urogenital and defecation symptoms in the female community. All women received a questionnaire with an accompanying letter explaining the purpose of the study. Care was taken to encourage women without any symptoms of pelvic floor dysfunction to participate in the study, emphasizing the importance of their cooperation to compare their situation with that of women with symptoms. A reminder was send after four weeks to all women. All data collected were anonymous. Two-thousand forty-three women responded (63.8%). The second sample consisted of 109 consecutive women who visited the gynaecological outpatient clinic of the University Medical Center Utrecht, the Netherlands. These women all presented with symptoms of pelvic floor dysfunction.

Study design

All women received a 162-item, self-administered questionnaire in 1999. The study was approved by the local ethics committee.

Data on age and educational level were collected. In analysis, the educational level was dichotomized into primary only and secondary or higher.

Symptoms of pelvic floor dysfunction were measured with the Urogenital Distress Inventory (UDI)[17] and the Defecation Distress Inventory (DDI).The UDI consists of 19 items and each item measures if a *symptom* is present and the amount of bother the woman experiences from that symptom. The latter is measured on a four-point Likert scale ranging from not at all to greatly. The original UDI consists of three domains; a stress, irritative and obstructive scale. The score of each scale ranges from 0 to 100, a high score representing more or more bothersome complaints. We translated the UDI and tested it's psychometric qualities. We identified five instead of three domains namely; urinary incontinence, overactive bladder symptoms, obstructive micturition, genital prolapse and pain/discomfort.(Chapter 2) A total UDI score is computed by taking the sum of the five domains (range 0 - 500). The DDI consists of 15 items about symptoms related to obstructive defecation, constipation, faecal incontinence and painful defecation. It was developed in our Center to be used for measuring anorectal symptoms in women presenting with symptoms of pelvic floor dysfunction. The content validity of the DDI was ensured by literature review and interviews with three experts in the field from the Department of Surgery and Obstetrics/Gynaecology from the University Medical Center Utrecht, the Netherlands. A structured interview of the 15 selected items was held with 20 female patients. The lay-out of the items was exactly comparable to that of the UDI. Factor analysis, using a principal axis factoring model with varimax rotation, showed four distinct domains (constipation, faecal incontinence, painful defecation and incontinence for gas). Cronbachs' alpha of these domains ranged between 0.71 - 0.78. Like the UDI, the score of the domains ranges from 0 to100 and the DDI total score ranges from 0 to 400. In the analysis the total score of the UDI and DDI were added together and transformed into a single Pelvic Floor Distress' (PFD) scale, with a score ranging from 0 to100. Again, a high score indicates more or more bothersome symptoms.

Health-related quality of life was measured in three ways. First, two questions were used to obtain a general quality of life score. The questions were: "How would you rate your overall health during the last week?" and "How would you rate your quality of life during the last week". Answers were obtained on a 6-point Likert scale ranging from extremely bad (=1) to excellent (=6). The mean value of these two questions was transformed into a single score ranging from 0 (extremely bad) to 100 (excellent). Secondly, a disease specific quality of life score for pelvic floor disorders was obtained. We used the Incontinence Impact Questionnaire to measure this disease-specific quality of life. The IIQ was developed to be used in combination with the UDI.[17] The original IIQ consists of 30 items about the impact of urogenital symptoms on four aspects of quality of life: physical functioning, emotion functioning, travel and social functioning. The score on each IIQ domain ranges from 0 to 100. A high score on the IIQ domains indicates that the person's well-being on that particular domain is negatively affected. Factor analysis (principal axis factoring with varimax rotation) of our translation of the IIQ identified a fifth factor that contains 4 items about embarrassment. Cronbachs' alpha for our five domains ranged from 0.83 (embarrassment) to 0.93 (mobility). The total IIQ score (sum of all five domains, range 0 - 500) was used in analysis. Finally, emotion well-being was assessed with the Center for Epidemiologic Studies - Depression scale (CES-D). [18] This questionnaire consists of 20 items and has been developed for research in the non-psychiatric population. A Dutch translation has been validated.[19] The total score ranges from 0 to 60. In our study the total score of the CES-D was used as an indication for depressive symptomatology.

Coping strategies were measured with 22 items originating from the Ways of Coping Checklist (WCC) and the Utrecht Coping List (UCL).[21,22] The reason for this selection was that we considered the WCC and the UCL to assess coping strategies in general. We were especially interested in disease-specific coping aspects of women with symptoms of pelvic floor dysfunction and therefore made a selection we thought would fit this purpose. A factor analysis (principal axis factoring with varimax rotation) on these 22 items resulted in the following coping strategies: Planful and rational actions (4 items, Cronbachs' alpha=0.82), Distancing (4 items, Cronbachs' alpha=0.76), Self-blame (2 items, Cronbachs' alpha=0.63), Wishful thinking (3 items, Cronbachs' alpha=0.75), Emotion expression/seeking social support (3 items, Cronbachs' alpha=0.85), Seeking distraction (2 items, Cronbachs' alpha=0.62) and Avoidance (3 items, Cronbachs' alpha=0.63). The items of each subscale are presented in the appendix. For each coping strategy a score ranging from 0 to 100 was obtained. A higher score indicating a more extensive use of that the coping strategy.

Finally, 18 questions about locus of control were used to analyze internal control over both the cause and course of the disease, control attributed to powerful others and control attributed to coincidental factors.[22] For each scale a score from 0 to 100 was computed. A high score indicated that the specific locus of control was more expressed.

By definition, all women from the clinical sample had at least one symptom on the PFD scale. These women will be referred to as clinical cases (CLCA). Women from the community sample were considered to be a representative of the community cases (COCA) if they replied positively to at least one question of the PFD scale.

Statistical analysis

Bivariate correlations for nominal data were calculated using two-sided Fisher exact test. For univariate comparison of interval data a Students t-test was used. Since there was a significant difference in mean age between clinical and community cases, comparisons of interval data between these groups were adjusted for age in an ANOVA model with age as a co-variate. The following comparisons were made. First, we compared the whole group of CLCA and COCA. Secondly, since we were interested in the influence of coping strategies on help-seeking behaviour in women with mild symptoms and in women with severe symptoms, we used the two extremes (1st and 4th quartile) of the PFD to perform separate analyses. Because of the differences in group size we tested the equality of variances between groups with Levene's statistics. If the Levene test was significant we adjusted the significance level for these unequal variances. All statistics were performed with SPSS 10.0.

Results

Only 9.5% of women from the community sample reported no symptoms on the UDI and DDI. Of the remaining 1848 women a total of 1057 (57.2%) answered the questions of the IIQ, coping and locus of control. These women are the community cases (COCA). All 109 women from the clinical population answered the IIQ, coping and locus of control questions. Table 1 shows the characteristics of the COCA and CLCA.

CLCA were significantly older and lower educated as compared to the COCA.

Table 1 Characteristics of community and clinical cases.

	Community cases (n=1057)	**Clinical cases** (n=109)
Age	45.8 (1.1)	54.7 (0.4)*
Educational level		
Primary	217 (20.5)	44 (40.8)*
Secondary or higher	840 (79.5)	65 (59.2)
PFD score	10.9 (0.3)	19.8 (1.2)*
PFD 1^e quartile (< 9.87)	582 (55.1)	25 (22.1)
PFD 2^e quartile (9.87 - 17.47)	275 (26.0)	27 (25.0)
PFD 3^e quartile (17.48 - 25.97)	134 (12.7)	28 (26.0)
PFD 4^e quartile (> 25.97)	66 (6.3)	29 (27.5)

Values are numbers (%) or means (standard error of mean)

Fisher exact for nominal data, Students t-test for interval data. * $p<0.05$

Differences between all COCA and CLCA are presented in Table 2. In this analysis age was used as a covariate. Educational level (primary only=0 and secondary/higher=1) was entered as continuous variable. All coping strategies except distancing were more frequently used by CLCA as compared to COCA. CLCA significantly more often attributed the locus of control of their symptoms to powerful others, reported a worse general and disease-specific quality of life and were lower educated as compared to COCA.

Differences between COCA and CLCA with mild symptoms (PFD score < 9.87) on coping, locus of control, well-being and educational level are presented in Table 3. Values are expressed as age-adjusted means. CLCA presenting themselves with mild symptoms significantly expressed more Emotion expression/Seeking support and Wishful Thinking coping strategies as compared to COCA. CLCA also had a statistical significantly higher IIQ score (worse quality of life) and lower educational level as compared to COCA. No differences were found in locus of control and general HRQoL and depressive symptoms.

Table 2 Differences in ways of coping, locus of control and well-being between community and clinical cases.

	Community cases (n=1057)	**Clinical cases** (n=109)	**P-value†**
Ways of coping			
Distancing	44.4 (0.8)	44.6 (2.5)	NS
Emotion expression/seeking support	47.4 (0.8)	62.4 (2.2)	0.005
Seeking distraction	46.1 (0.7)	58.4 (2.2)	0.005
Planful rational actions	60.4 (0.7)	72.6 (1.4)	0.005
Wishful thinking	47.8 (0.6)	62.1 (1.7)	0.005
Self-blame	37.1 (0.6)	43.5 (2.0)	0.005
Avoidance	37.0 (0.6)	43.0 (1.8)	0.005
Locus of control			
External (powerful others)	74.1 (0.2)	75.3 (0.6)	0.05
External (coincidental)	77.0 (0.2)	76.5 (0.6)	NS
Internal control	80.3 (0.2)	80.0 (0.5)	NS
General Quality of Life	73.0 (0.6)	65.7 (1.9)	0.005
Incontinence Impact Questionnaire	29.6 (1.6)	96.2 (8.3)	0.005
CES-D total score	15.8 (0.2)	16.0 (0.7)	NS
Educational level	0.79 (0.01)	0.66 (0.05)	0.005

† ANOVA with age as covariate. Values are expressed as adjusted means (standard error). Significance level adjusted for unequal variances when Levene's test for equality of variances was significant ($p<0.05$). NS=not significant

Table 3 Differences in ways of coping, locus of control and well-being between community and clinical cases with a low Pelvic Floor Distress score (<9.87).

	Community cases (n=582)	**Clinical cases** (n=25)	**P-value†**
Ways of coping			
Distancing	40.2 (1.2)	39.8 (5.0)	NS
Emotion expression/seeking support	46.0 (1.1)	61.1 (5.0)	0.05
Seeking distraction	42.2 (1.0)	45.9 (4.3)	NS
Planful rational actions	57.4 (1.1)	63.7 (3.3)	NS
Wishful thinking	41.9 (0.8)	55.5 (3.7)	0.005
Self-blame	33.9 (0.8)	39.7 (4.5)	NS
Avoidance	33.2 (0.7)	38.2 (3.1)	NS
Locus of control			
External (powerful others)	73.6 (0.2)	75.2 (1.1)	NS
External (coincidental)	76.8 (0.2)	75.9 (0.9)	NS
Internal control	80.6 (0.2)	81.1 (1.0)	NS
General Quality of Life	76.7 (0.8)	75.4 (2.8)	NS
Incontinence Impact Questionnaire	12.7 (1.1)	35.9 (8.5)	0.005
CES-D total score	14.7 (0.2)	14.5 (1.4)	NS
Educational level	0.84 (0.01)	0.66 (0.10)	0.05

† ANOVA with age as covariate. Values are expressed as adjusted means (standard error). Significance level adjusted for unequal variances when Levene's test for equality of variances was significant ($p<0.05$). NS=not significant

Table 4 Differences in ways of coping, locus of control and well-being between community and clinical cases with a high Pelvic Floor Distress score (> 25.98).

	Community cases (n=66)	**Clinical cases** (n=29)	**P-value***
Ways of coping			
Distancing	56.4 (2.7)	50.7 (4.8)	NS
Emotion expression/seeking support	46.5 (2.8)	59.8 (4.0)	0.05
Seeking distraction	63.2 (2.7)	66.8 (4.1)	NS
Planful rational actions	65.7 (2.5)	79.3 (2.7)	0.005
Wishful thinking	64.0 (2.2)	68.4 (3.8)	NS
Self-blame	46.8 (3.2)	45.0 (4.4)	NS
Avoidance	52.4 (2.8)	49.0 (4.2)	NS
Locus of control			
External (powerful others)	76.6 (0.8)	77.0 (1.1)	NS
External (coincidental)	77.9 (0.7)	76.4 (1.1)	NS
Internal control	79.1 (0.7)	79.9 (1.0)	NS
General Quality of Life	59.4 (2.7)	50.7 (3.7)	NS
Incontinence Impact Questionnaire	123.2 (13.5)	145.5 (19.2)	NS
CES-D total score	20.8 (0.9)	18.0 (1.3)	NS
Educational level	0.61 (0.06)	0.58 (0.1)	NS

† ANOVA with age as covariate. Values are expressed as adjusted means (standard error). Significance level adjusted for unequal variances when Levene's test for equality of variances was significant ($p<0.05$). NS=not significant

Differences between COCA and CLCA with severe symptoms (PFD score > 25.97) on coping, locus of control, well-being and educational level are presented in Table 4. Values are expressed as age-adjusted means. CLCA with severe symptoms significantly expressed more Emotion expression/Seeking support and Planful rational actions coping strategies as compared to COCA. No other statistical significant differences were found.

Discussion

Our study shows that women who seek help for symptoms of pelvic floor dysfunction differ in their coping strategies from women who do not. These differences are also related to the severity of pelvic floor symptoms. Women who present themselves with mild symptoms clearly use more emotion-oriented and passive coping strategies as compared to women with the same severity of symptoms who do not seek help. CLCA with mild symptoms also report a worse HRQoL as is expressed by a significantly higher IIQ score as compared to COCA. In contrast, women who present themselves with severe symptoms of pelvic floor dysfunction apply more problem oriented, active coping strategies as compared to women with comparable symptoms who do not seek help. In contrast to women with mild symptoms, the IIQ scores of COCA and CLCA with severe symptoms did not differ. This indicates that the experienced impact on HRQoL of these severe symptoms of pelvic floor dysfunction is equally high in COCA as in CLCA. Not seeking help for severe symptoms was related to a trend to have more depressive symptoms ($p=0.08$). Apparently, more passive and emotion-oriented coping strategies predispose women with symptoms of pelvic floor dysfunction to early help-seeking behaviour and less use of problem-oriented, active coping strategies predisposes women to avoid help-seeking, regardless the severity of their problems.

By some investigator, coping is not considered to be a stable personality characteristic but rather as a dynamic process.[23] Although certain coping strategies have been linked to certain personality characteristics [24,25], coping strategies may change within a person depending on the type and severity of the stressful event they are used in. Therefore, it is not possible to consider some coping strategies as "good" and other strategies as "bad". As we have shown in Chapter 7, emotion-oriented and passive coping strategies have a significant positive correlation with a reduction in well-being and problem-oriented, active coping strategies improve quality of life. Therefore, women with symptoms of pelvic floor dysfunction may benefit from active, problem-oriented coping strategies.

Another important finding of our study is the effect of educational level on help-seeking behaviour. In our overall study population, low educated women are significantly more likely to present themselves with symptoms of pelvic floor dysfunction, independent of age, coping strategies and PFD score, as compared to higher educated women. However, the positive correlation between educational level and help-seeking behaviour is valid for women with mild symptoms but not for women with severe symptoms. In this last group, help-seeking behaviour does not depend on educational level. This information is of importance since it implicates that low educated women have an increased risk of undergoing diagnostic procedures and invasive treatments for pelvic floor dysfunction at relatively low symptom levels. Although this relationship between educational level and help-seeking behaviour has not been established in patients with pelvic floor dysfunction symptoms, such a relationship is known to exist, for instance for hysterectomy.[26] Low educated women have an increased risk of hysterectomy as compared to higher educated women, where it is unlikely that the objective severity of bleeding problems is related to educational level. Our results show that there is a association between a low educational level and emotion-oriented, passive coping strategies, but we cannot conclude that the educational level is a determinant of certain coping strategies.

We believe that our findings may have important consequences for clinical practice. Clinicians should be aware that it is not only the type and objective severity of symptoms of pelvic floor dysfunction that will determine whether women seek professional help or not. The way they cope with these problems independently affects the help-seeking process. We therefore believe that, in addition to obtaining patient's history and performing physical examination, it is useful to obtain a PFD score and assess coping strategies in women with pelvic floor dysfunction. From a clinical point of view, this may lead to early psychological assessment of these women and provide the basis for adding behavioural treatment to the standard treatment. Behavioural therapy has been successful in both urinary incontinence as well as irritable bowel disease.[27,28] In irritable bowel disease, improvement of symptoms were shown to be positively related to the use of a larger use of beneficial coping strategies.[27] For urinary incontinence it has not yet been established how much of the beneficial effect can be attributed to changing coping strategies.

One of the potential limitations of our study is the fact that there are no widely accepted and valid coping questionnaires.[29] Moreover, coping questionnaires like the Ways of coping checklist and Utrecht Coping List usually assess coping strategies in general.[12,24] Since it is well recognized that the use of coping strategies will have different implications in different diseases, one has to determine a priori which coping strategies may be of importance for the research question. This will often implicate that researchers use combinations of questions from different questionnaires. Although this probably will improve the questionnaires validity for a particular disease or situation, comparing the results of different studies may be difficult if there is no international consensus. Therefore, at this point it seems wise to describe study results in terms of "metastrategies" like emotion-oriented versus problem-oriented or active versus passive coping strategies rather than in more detailed strategies. We found an acceptable to good internal consistency of the different coping scales of our questionnaire. When expressed in metastrategies, we could demonstrate important differences between COCA and CLCA. We therefore believe that our questionnaire could be the basis for further investigations in women with pelvic floor dysfunction.

The second possible limitation of our study is the fact that only 57% of COCA (women with at least one PFD symptom) answered the IIQ and coping questions. It is possible that our results are affected by this sample bias. However, studies with this kind of voluntary responses are known to overrepresent people with strong, most negative opinions.[30] We found a linear relationship between the numbers of symptoms on the PFD and the willingness to answer the IIQ and coping questions (data shown in Chapter 7). Therefore, if there was a selection, this would have been in favour of women with more bothersome pelvic floor dysfunction. If all COCA would have answered the IIQ, the difference between CLCA and COCA most likely would have been even more pronounced.

We conclude that coping strategies do affect help-seeking behaviour in women with pelvic floor dysfunction. It may predispose certain women with mild symptoms to seek help for their symptoms of pelvic floor dysfunction and receive invasive diagnostic or therapeutic procedures. On the other hand it may delay help-seeking in certain women who, on the basis of the severity of the symptoms, could benefit from treatment.

Gynaecologists, urologists, gastroenterologists, colorectal surgeons and primary health care workers should be aware of the potential role of coping strategies in the perception of the severity of symptoms of pelvic floor dysfunction. This awareness may lead to therapeutic strategies that include psychological evaluation and treatment if indicated. The beneficial effect of such a strategy needs to be investigated in future studies.

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Chapter 9

General discussion

In this thesis, several questions regarding the risk factors, consequences and help-seeking behaviour for symptoms of pelvic floor dysfunction in women were addressed. We started by pointing out the necessity to include measurements of quality of life in determining the severity of symptoms of pelvic floor dysfunction.

Health-related Quality of Life (HRQoL) instruments and pelvic floor dysfunction

When setting the outline for this thesis, it was clear that a valid questionnaire to measure disease-specific HRQoL in women with symptoms of pelvic floor dysfunction was not available in the Dutch language. We found that there are two major problems with all currently available disease-specific HRQoL questionnaires for pelvic floor dysfunction. First, there is no world-wide consensus about which of the available instruments has the best properties and should be used. [1] This has resulted in an increasing amount of different questionnaires that are all usually considered as "valid" by the authors. However, this has lead to the opposite of what was initially intended, namely: the improvement of comparability of research and treatment data worldwide. Secondly, all currently available questionnaires were developed in relatively small and highly selective populations. [2-6] Therefore, if these instruments are used in large epidemiological surveys their results may be difficult to interpret. We decided to translated the Urogenital Distress Inventory (UDI) and Incontinence Impact Questionnaire (IIQ). In our opinion, the questions that were used in the original UDI and IIQ had good face validity, which means that they addressed the symptoms and problems that are commonly mentioned by women with urogenital symptoms well. After translation, we took the opportunity to test the psychometric qualities of the UDI and IIQ in a random population based cross-sectional sample of adult women as well as in a selected population of women presenting themselves with urogenital complaints to the gynaecologic outpatient clinic of the University Medical Center Utrecht. This approach has two important strengths. First, the use a random sample of women between 20 and 70 years of age, without any pre-selection criteria, implicates that the results of our studies with the UDI/IIQ can be generalized to the average population of adult women. Secondly, since there is no "golden standard" for different symptoms of pelvic floor dysfunction it is advocated to use a "known-group" comparison[7] to assess the criterion validity of a questionnaire measuring symptoms of pelvic floor dysfunction. In our study this was done by comparing the data from the clinical cases ("known group") with women from the population sample who reported symptoms of pelvic floor dysfunction (community cases). Regarding factor analysis, we identified the following five domains in the UDI namely: urinary incontinence, overactive bladder, obstructive micturition, pain/discomfort and genital prolapse (Chapter 2). The items of these domains showed a good discriminatory validity, which means that the individual items correlated poorly with the other scales. Furthermore, these domains appear to be clinically sound and are reliable. A weakness in the design of the original UDI is the fact that factor analysis revealed several items that had a high correlation with more than one domain, indicating a suboptimal discriminatory validity. The reason why this observation did not result in the adjustment of the original three-scale construction of the UDI is unclear. When evaluating the IIQ, we showed that, in addition to the 4 domains of the original IIQ, our factor analysis revealed a fifth domain with four items about embarrassment. In literature, embarrassment has been identified as one of the factors that makes women refrain from seeking medical attention for urinary incontinence. We found the UDI urinary incontinence scale to have the highest positive correlation with the IIQ embarrassment domain. Therefore, the inclusion of the embarrassment domain appears to enhance the clinical quality of the IIQ in assessing HRQoL.

Since the IIQ is a disease-specific HRQoL questionnaire, we expected it to be more sensitive for the impact of symptoms of pelvic floor dysfunction as compared to the generic RAND-36 questionnaire. Our study supported this hypothesis in several ways. First, we showed that the UDI domain scores correlated much better with the IIQ domain scores as compared to the generic RAND-36 domain scores (Chapter 2). Secondly, we demonstrated that the IIQ was much more sensitive than the RAND-36 in distinguishing the effect of different urinary symptoms on HRQoL (Chapter 3). Finally, we analysed the effect of different coping strategies on generic and disease-specific HRQoL (Chapter 7).

The strength of the effect of the symptoms of pelvic floor dysfunction and several coping strategies on generic HRQoL, as measured with the RAND-36, was equal. However, the strength of effect of symptoms of pelvic floor dysfunction on the IIQ was 3-times that of the coping strategies. This clearly indicates that the effect of symptoms of pelvic floor dysfunction on HRQoL are better expressed in the IIQ as compared to the RAND-36. This also implicates that the IIQ is probably more sensitive to changes in symptoms of pelvic floor dysfunction as compared to the RAND-36.

Since we were interested in both urinary and defecation symptoms, we decided that a questionnaire about bowel habits in relation to functioning of the pelvic floor had to be included in our analysis. At the onset of this thesis, such a questionnaire was not available. Therefore, we decided to develop the Defecation Distress Inventory (DDI). However, since at our gynecological outpatient clinic women often present with urogenital symptoms instead of defecation symptoms, we were unable to test the psychometric qualities as extensively as we did with the UDI. Factor analysis of the DDI that was used in our population survey showed the following four domains namely: faecal incontinence, flatus incontinence, constipation and painful defecation. These domains showed good internal consistency and appear clinically sound.

Regarding the psychometric qualities of our version of the UDI, IIQ and DDI, we conclude that these instruments are easy to use, disease-specific, reliable and clinically sound. Therefore, we recommend to use the domains we identified in the UDI/IIQ for future studies. With the addition of the DDI to the UDI/IIQ, information about overall Pelvic Floor Dysfunction (PFD) can be obtained. The sensitivity to change of the UDI, IIQ and DDI is currently tested at our institute.

Symptoms of pelvic floor dysfunction: Risk factors and Health-related Quality of Life

When setting the outline for this thesis, it was clear that several questions regarding the prevalence and potential risk factors for different symptoms of pelvic floor dysfunction were already extensively addressed. [8-11] However, there were several important clinical questions for which data were scarce or inconclusive.

First, the prevalence and risk factors for urinary incontinence are commonly assessed in middle-aged or older women. Information about the prevalence and these risk factors in young women is scarce. Furthermore, most authors do not separate urinary incontinence related to a feeling of urgency (urge incontinence) from that of urinary incontinence related to physical activity or coughing/sneezing (stress incontinence). Such a distinction should be made because both types of urinary incontinence represent different pathophysiological entities and have different consequences on HRQoL.[12-15] We showed that symptoms of stress incontinence occur in approximately 40%, and symptoms of urge incontinence in approximately 15% of young women aged 20-45 years. Secondly, symptoms of overactive bladder (urinary frequency and urgency) are increasingly becoming the subject of investigation.[16] We reported that overactive bladder symptoms occur in one out of four young women (Chapter 3). The observation that obstructive micturition was independently associated with symptoms of overactive bladder and urge incontinence has lead us to postulate an interesting hypothesis. We hypothized that symptoms of overactive bladder in young women are related to longstanding poor pelvic floor relaxation during micturition. This poor pelvic floor relaxation produces the same effects on bladder functioning as the bladder outlet obstruction seen in men with Benign Prostate Hypertrophy and in children with dysfunctional voiding. In the latter two groups, bladder outlet obstruction eventually triggers detrusor hyperactivity.[15] This hypothesis should be subject of future investigation since it may have important implications for prevention and treatment of overactive bladder symptoms in women.

The consequences of symptoms of overactive bladder for HRQoL were striking. Symptoms of overactive bladder were significantly related to a reduction in HRQoL, both measured with the IIQ as well as with the RAND-36. Urge incontinence symptoms had a comparable negative effect on the IIQ as symptoms of overactive bladder but did not show a significant effect on the RAND-36. The reason for the difference in reported effect of overactive bladder and urge incontinence on the RAND-36 may be the following. We showed that the strength of effect of symptoms of overactive bladder and urge incontinence were different on two IIQ domains. Symptoms of overactive bladder had a greater negative effect on the IIQ mobility domain as compared to symptoms of urge incontinence. The opposite was true for the IIQ embarrassment domain. Since the IIQ mobility domain showed a higher correlation (0.24-0.46) with the RAND-36 domains than the IIQ embarrassment domain (0.16-0.28), symptoms of overactive bladder, by reducing mobility, have a greater effect on the RAND-36 domain scores as compared to urge incontinence.

With regard to risk factors for pelvic floor dysfunction, the effect of childbirth on faecal incontinence was the second important issue we addressed in this thesis. Solely based on the observation that childbirth causes occult anal sphincter damage in one out of three women, it was postulated that childbirth is the major risk factor for faecal incontinence.[17,18] However, this view is not supported by epidemiological data. Unfortunately, some authors have already suggested that obstetrical practice in consecutive pregnancies should be altered in women with occult anal sphincter damage after first delivery.[19] The facts that the pathophysiology of faecal incontinence is multi factorial and that epidemiological studies showed that faecal incontinence is as common in men as in women, somehow have stayed out of the discussion.[20,21] In our large random population sample, we showed that there is no difference in prevalence of faecal incontinence between parous and nulliparous women (Chapter 4). This implicates that childbirth is not a major factor in the pathophysiology of faecal incontinence in women. Therefore, we do not support recommendations to change obstetrical practice that are solely based on ultrasound investigations of the anal sphincter.

Besides childbirth, hysterectomy is the second most common gynecological life event in women.[22,23] Approximately one out of four women, aged 60 years or older, will have had a hysterectomy. A recent review on this subject showed that, in women aged 60 years or older, the odds for urinary incontinence was significantly increased for women with a history of hysterectomy as compared to women without.[24] In contrast, studies that evaluated the short-term consequences of hysterectomy showed a high “cure” rate of hysterectomy of pre-existing urinary incontinence.[25,26] However, it is unclear if the characteristics of women scheduled for hysterectomy differ from those who are not. If so, and if these characteristics are also related to urinary incontinence, they may be important confounders in the analysis of the concurrence of hysterectomy and urinary incontinence. We demonstrated that women scheduled for hysterectomy did not have an increased prevalence of urinary incontinence as compared to women who are not (Chapter 5). However, when urinary incontinence is present, women scheduled for hysterectomy are much more bothered by it. We postulate that the "cure" of urinary incontinence after hysterectomy, reported to be as high as 75%, could be very well due to a change in perception of urinary incontinence as a problem. A study to analyse this hypothesis is currently being performed. In addition to the study on women scheduled for hysterectomy, we also studied the long-term consequences of urinary incontinence. In our random population-based sample, we demonstrated that hysterectomy increased the long-term risk for symptoms of urinary urge incontinence but not for stress incontinence. This effect was already demonstrated in women younger than 60 years. Since hysterectomy is more likely to damage the bladder innervation and less likely to damage the urethral support system our findings appear logical. When counselling patients on the sequella of hysterectomy, information about the increased risk for urinary urge incontinence should be provided. Especially since urge incontinence has a stronger negative effect on HRQoL as compared to stress incontinence. This was clearly demonstrated in several studies and this thesis (Chapter 3).[12-14]

Sociodemographic / psychological factors and the pelvic floor

The final research question of this thesis was about the influence of sociodemographic factors, coping and locus of control on HRQoL and help-seeking behaviour in women with symptoms of pelvic floor dysfunction.

In our study we demonstrated that active, problem-oriented coping strategies are beneficial in women with symptoms of pelvic floor dysfunction. Women with symptoms of pelvic floor dysfunction who used more emotion-oriented and avoiding coping strategies reported a significant reduction in HRQoL as compared to women with more problem-oriented, active coping strategies. We also demonstrated that women with pelvic floor dysfunction who applied more emotion-oriented or passive coping strategies were more likely to present themselves to their physician with relatively mild symptoms. Because of this, these women are at an increased risk of undergoing diagnostic or therapeutic interventions that are probably not justified as far as the objective severity of illness is concerned.

Throughout this thesis, we found a remarkable influence of educational level on the presence and impact of different symptoms of pelvic floor dysfunction. As compared to women with a higher educational level, women with a low educational level were statistical significantly more likely to;

1. Report symptoms of overactive bladder and urinary urge incontinence;
2. Report faecal incontinence;
3. Have an increased risk of being scheduled for or having had a hysterectomy;
4. Use more emotion-oriented or passive/avoiding coping strategies;
5. Present themselves with relatively mild symptoms of pelvic floor dysfunction.

The possible consequences of different educational levels should be kept in mind by clinicians who treat patients with symptoms of pelvic floor dysfunction. Efforts should be undertaken to develop diagnostic models that include psychosocial screening for the initial evaluation of women with pelvic floor dysfunction. This may lead to early detection of women in whom a more comprehensive psychological evaluation is useful before initializing treatments that may be invasive in character. A nice example that supports the necessity for such an approach is the study by Kjerulff and co-workers on the effectiveness of hysterectomy.[25] In this study, the main risk factor for an adverse outcome of hysterectomy was having depressive symptoms before surgery. Early recognition and treatment of this factor may have improved outcome.

Based on the data of this thesis, the following hypothesis on the relationship between educational level and pelvic floor dysfunction is postulated. In case of pelvic floor dysfunction, a low educational level predisposes women to predominantly use emotion-oriented and avoiding coping strategies (Chapter 7). These coping strategies will enhance the negative effect of symptoms of pelvic floor dysfunction on HRQoL. As a consequence, this impairment of HRQoL may influence help-seeking behaviour, especially at low symptom severity levels (Chapter 8). By seeking medical attention more often, low educated women are more at risk to undergo invasive diagnostic and therapeutic interventions as compared to higher educated women. The reason for this difference in coping strategies between low and higher educated women is unclear. Interestingly, in a few recent studies the association between socio-economic status, depression, urinary urge incontinence and the serotonergic response was evaluated. Serotonin is one of the neurotransmitters of which a low activity is positively associated with symptoms of depression and bladder hyperactivity.[26] Furthermore, a blunted serotonin response was associated with a lower socioeconomic status.[27] Our study demonstrated that a low educational level was positively correlated with symptoms of overactive bladder and urge incontinence. Both these symptoms were shown to be significantly associated with a reduced emotional well-being as measured with the IIQ. Therefore, subnormal serotonin activity may be the common denominator of the association between educational level, overactive bladder and depression.

Recommendations for clinical practice

This thesis has shown that symptoms of pelvic floor dysfunction are very common among adult women.

With regard to urinary symptoms, physicians should be aware that symptoms of overactive bladder (frequency and urgency), with or without urinary incontinence, affect HRQoL in all its dimensions in young women. Especially the reduction in mobility can be of importance in this otherwise physical healthy population. We believe that symptoms of pelvic floor dysfunction should be asked for in women who complain of a reduction in well-being that cannot be contributed to other factors.

With regard to faecal incontinence the message is clear. Our data do not support the wide spread believe that childbirth is the major risk factor for developing faecal incontinence in women. Nevertheless, identifying and avoiding risk factors that are related to third or fourth degree anal sphincter rupture remains obvious.

With regard to the consequences of hysterectomy, we provided substantial evidence that the risk of urgency-related urinary incontinence after hysterectomy is increased. Therefore, women undergoing hysterectomy should be counselled about this increased risk.

Both primary care physicians as well as medical specialists should be aware that the reason why women seek help for symptoms of pelvic floor dysfunction is not only determined by the objective severity of the symptoms, but also for a substantial part by the way they cope with it. The latter is also related to educational level. In practice, obtaining a severity score of symptoms, for instance with the UDI, may identify women with relatively mild symptoms. Especially in these women, the use of invasive diagnostic and therapeutic procedures should be well-considered and for some women additional psychological evaluation and treatment may be of great benefit. For a more precise determination of which women are most likely to benefit from such a strategy, further research is indicated. Finally, primary healthcare workers should be aware that depressive symptoms may be related to severe symptoms of pelvic floor dysfunction. Depending on the most expressed coping strategy, some of these women with severe symptoms of pelvic floor dysfunction may refrain from seeking help. Since for most of the symptoms of pelvic floor dysfunction non-invasive treatments are available (physiotherapy, behavioural therapy, sanitary pads), noticing these symptoms and provide adequate treatment may improve both physical and emotional health in these women.

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Summary

This thesis comprises several studies on symptoms of pelvic floor dysfunction in adult women. These symptoms are known to have a high prevalence in adult women and are often experienced as bothersome. Therefore, efforts should be made to identify risk factors for different symptoms of pelvic floor dysfunction and the consequences of these symptoms on quality of life should be studied. The studies of this thesis were all performed in a large cohort of both clinical patients and women randomly selected from the community. This implies that the results and recommendations of the thesis can be applied in general as well as in specialised clinical practice. The main purpose of this study was to investigate the prevalence, risk factors, consequences and factors associated with help-seeking behaviour of different symptoms of pelvic floor dysfunction.

In **Chapter 1** the research questions of this thesis are introduced. It was pointed out that symptoms of pelvic floor dysfunction, like urinary incontinence, urinary frequency and urgency, genital prolapse and faecal incontinence are frequently reported by adult women. The literature regarding the consequences of two major life events in women, eg childbirth and hysterectomy, on different symptoms of pelvic floor dysfunction is discussed. The concept of Health-related Quality of Life (HRQOL) is pointed out and the advantages and disadvantages of different types of HRQOL questionnaires are discussed. Finally, to study the interaction between symptoms of pelvic floor dysfunction, HRQOL and help-seeking behaviour in women, we assessed coping strategies and locus of control. The concepts of coping and locus of control are discussed briefly.

In **Chapter 2** we describe the results of a study on the prevalence of urogenital symptoms (with the exclusion of defaecation symptoms) and the psychometric qualities of the Dutch version of the Urogenital Distress Inventory (UDI) and the Incontinence Impact Questionnaire (IIQ). In a community-based, cross-sectional cohort study we showed that four out of five adult women have at least one symptom of pelvic floor dysfunction. We found a moderate to good positive correlation between the UDI en IIQ scores. This indicates that more or more severe symptoms was associated with a worse quality of life.

Factor analysis of the UDI showed that it consists of five domains. These five domains each contain items that are clinically sound and reliable. Factor analysis of the IIQ showed that, in addition to the original four domains, a fifth factor with four items about embarrassment was extracted. Since women with urinary incontinence often report that they are embarrassed by their incontinence, the inclusion of such a domain in a disease-specific HRQOL questionnaire on urogenital symptoms is essential. For future research we recommend the use of our version of the UDI and IIQ.

In **Chapter 3** the results are presented of a study on the prevalence, risk factors and consequences of stress- and urge urinary incontinence and symptoms of overactive bladder in a community based, cross-sectional cohort of young women. One out of four women reported symptoms of overactive bladder. These symptoms have the same negative consequences on HRQOL as urge incontinence. The prevalence of stress incontinence was as high as 40% but this symptom did not seem to bother women much. These results indicate that identifying and treating symptoms of overactive bladder in young women may significantly improve their quality of life.

One of the most important factors that was significantly associated with all three types of urinary symptoms was obstructive micturition. We postulated that long-standing poor relaxation of the pelvic floor during voiding may induce urgency and urge incontinence in women. Since symptoms of overactive bladder are common among women and have a negative effect on HRQoL, this hypothesis should be tested in future research.

In **Chapter 4** we assessed the prevalence of flatus and faecal incontinence in a community-based cross-sectional cohort study. We aimed at identifying whether childbirth is a risk factor for flatus and faecal incontinence as is commonly stated in literature. Our results, the first in its kind, show that there is no evidence for a causal relationship between childbirth and faecal incontinence. Applying interventions aimed at the prevention of third and fourth degree anal sphincter ruptures remains undisputed. However, changing clinical practice in women with occult anal sphincter damage after first delivery in their consecutive pregnancies does not seem to be justified.

In **Chapter 5** we compared the prevalence and severity of stress- and urge urinary incontinence in women scheduled for hysterectomy with women from a random community sample who were not scheduled for hysterectomy . We did not demonstrate a difference in prevalence between these two groups. This indicates that symptoms that are the reason for performing a hysterectomy are not associated with urinary incontinence. However, if urinary incontinence is present, women scheduled for hysterectomy are significantly more bothered by it as compared to women from the community sample. Apparently, the perception of the severity of urinary incontinence is influenced by the fact that a woman is scheduled for hysterectomy. Therefore, we speculate that hysterectomy may not cure incontinence but it may influence the perception of it as a problem. This hypothesis is currently subject of investigation at our institute.

In **Chapter 6** we assessed the long-term consequences of hysterectomy on urinary incontinence in a population based, cross-sectional cohort study. In contrast with other studies, we distinguished symptoms of stress incontinence from symptoms of urge incontinence. This is essential since these two types of urinary incontinence represent different pathophysiological entities. We showed that hysterectomy increases the risk for urge incontinence but not for stress incontinence. Especially since urge incontinence negatively affects HRQOL, we recommend that women should be informed about this long-term consequence of hysterectomy.

In **Chapter 7** we studied the effect of different coping strategies on HRQOL in women with symptoms of pelvic floor dysfunction extracted from a population based, cross-sectional cohort sample. Health-related Quality of Life was assessed with a generic (RAND-36) and a disease-specific questionnaire (IIQ). Depressive symptoms were assessed with the Center of Epidemiological Studies - Depression scale (CES-D). We showed that, at the same level of symptom severity, women who more frequently used emotion-oriented and passive coping strategies reported a significantly worse HRQOL as compared to women who applied more problem-oriented, active coping strategies.

Our findings implicate that physicians have to be aware that the way women cope with their symptoms of pelvic floor dysfunction; (1) affects their perceived HRQOL; (2) is associated with depressive symptoms and; (3) may influence their help-seeking behaviour. This awareness may identify women who are in need of treatment but do not report their symptoms voluntarily and, on the opposite, women who ask for treatment at low symptom severity level.

In **Chapter 8** we examined which factors are related to help-seeking behaviour in women with symptoms of pelvic floor dysfunction. To do so, we compared clinical cases with women from a random population sample with symptoms of pelvic floor dysfunction (community cases).

First, we analysed differences between clinical cases and community cases with mild symptoms of pelvic floor dysfunction. We found that clinical cases with mild symptoms expressed more passive coping strategies as compared to community cases. Secondly, we analysed differences between clinical cases and community cases with severe symptoms of pelvic floor dysfunction. Clinical cases with severe symptoms of pelvic floor dysfunction expressed more problem-oriented, active coping strategies as compared to community cases.

In addition, we found that lower educated women significantly more often presented themselves with mild symptoms at our clinic as compared to higher educated women. This implicates that these women have an increased risk of undergoing diagnostic and therapeutic procedures at low symptom severity levels.

Chapter 9 contains the general discussion in which the answers to the research questions are discussed in more detail and recommendations for clinical practice are pointed out.

Samenvatting

In dit proefschrift werden de resultaten beschreven van studies die zijn verricht bij volwassen vrouwen met symptomen van bekkenbodem dysfunctie. Deze symptomen komen frequent voor en kunnen de kwaliteit van leven negatief beïnvloeden. Het is daarom van belang risicofactoren voor het ontstaan van deze symptomen te identificeren en de gevolgen op de kwaliteit van leven in detail te onderzoeken. Het onderzoek werd verricht onder vrouwen uit de populatie en vrouwen die zich met klachten bij de gynaecoloog meldden. Dit impliceert dat de resultaten en aanbevelingen van deze studie voor zowel huisartsen als gynaecologen van belang kunnen zijn.

In **Hoofdstuk 1** introduceren wij de onderzoeksvragen aan de hand van literatuuronderzoek. Symptomen als urine incontinentie, overactieve blaas, genitale prolaps en anale incontinentie worden frequent gemeld door volwassen vrouwen. Gegevens die bekend zijn over de gevolgen van de baring en hysterectomie, twee belangrijke gebeurtenissen in het leven van de vrouw, worden gepresenteerd. Het begrip " Aan de gezondheid gerelateerde kwaliteit van leven" (Health-related Quality of Life = HRQoL) wordt geïntroduceerd en de voor- en nadelen van verschillende soorten van meetinstrumenten (generiek of ziekte-specifiek) worden uiteengezet. Bij het bestuderen van de associaties tussen de ernst van de symptomen van bekkenbodem dysfunctie, de gevolgen ervan op de HRQoL en hulp-zoek gedrag wordt van de begrippen Coping en Locus of Control gebruik gemaakt. De concepten Coping en Locus of Control worden toegelicht.

In **Hoofdstuk 2** worden de resultaten van een studie naar de prevalentie en consequenties van urogenitale klachten bij vrouwen uit een aselecte steekproef uit de bevolking gepresenteerd. In deze studie werd gebruik gemaakt van de Urogenital Distress Inventory (UDI) en de Incontinence Impact Questionnaire (IIQ). De UDI meet welke urogenitale symptomen aanwezig zijn en hoe hinderlijk het symptoom is. De IIQ meet de gevolgen van urogenitale symptomen op de diverse aspecten van de HRQoL. Tachtig procent van de vrouwen meldde in ieder geval één urogenitaal symptoom. Er werd een redelijk tot goede positieve correlatie gevonden tussen de UDI en de IIQ score, hetgeen impliceert dat meerdere of ernstige urogenitale symptomen gepaard gaan met een slechtere kwaliteit van leven. De psychometrische kwaliteiten van de Nederlandstalige versie van de UDI en IIQ bleken bevredigend tot goed. Factor analyse van de UDI liet zien dat deze uit vijf klinisch relevante domeinen bestaat. Uit het onderzoek van onze versie van de IIQ bleek dat er, naast de originele vier domeinen, een vijfde domein bestaat met items over schaamte. Veel vrouwen met urine incontinentie geven aan dat schaamte een belangrijke belemmerende factor is bij het aangaan van sociale contacten en in hun motivatie om hulp te zoeken. Een dergelijke schaal lijkt daarom essentieel als onderdeel van een ziekte-specifieke HRQoL vragenlijst voor urogenitale symptomen. Onze versie van de UDI en IIQ wordt daarom aanbevolen om te gebruiken in toekomstig onderzoek naar het voorkomen van urogenital symptomen en de effectiviteit van behandelingen.

In **Hoofdstuk 3** werden de prevalentie, risicofactoren en consequenties van stress- en urge incontinentie en van symptomen van een overactieve blaas onderzocht. Hiervoor werd een aselecte steekproef uit de populatie van jonge vrouwen gebruikt. Aangetoond werd dat één op de vier vrouwen symptomen van een overactieve blaas heeft. Tevens werd aangetoond dat symptomen van een overactieve blaas en urge incontinentie significante negatieve gevolgen hebben voor de kwaliteit van leven. De prevalentie van stress incontinentie is het hoogst (40%) maar dit symptoom wordt door de meeste vrouwen niet als hinderlijk ervaren. Een opvallende bevinding is dat symptomen van een obstructieve mictie met name zijn gerelateerd aan urge incontinentie en symptomen van een overactieve blaas. Naar aanleiding van de resultaten van deze studie wordt de hypothese gepostuleerd dat langdurige onvolledige relaxatie van de bekkenbodem tijdens de mictie bij vrouwen aanleiding kan geven tot het ontstaan van onwillekeurige detrusor contracties. Gezien de hoge prevalentie van symptomen van overactieve blaas en de negatieve gevolgen ervan op de HRQoL dient deze hypothese nader te worden onderzocht.

In **Hoofdstuk 4** werd onderzocht of er een associatie bestaat tussen de baring en anale incontinentie. In een aselecte steekproef uit de bevolking van vrouwen tussen de 20 en 70 jaar werd de prevalentie van flatus en faecale incontinentie vergeleken tussen vrouwen die wel (para) en vrouwen die geen kinderen hebben gebaart (nullipara). Er werd geen verschil gevonden tussen para en nullipara hetgeen impliceert dat andere factoren dan de baring verantwoordelijk zijn voor het ontstaan van faecale incontinentie. Desalniettemin blijven obstetrische interventies gericht op het voorkomen van complete anale sphincter rupturen zinvol. Echter, het aanpassen van het obstetrisch beleid bij een tweede zwangerschap van vrouwen die een verborgen sphincter defect hebben na een eerste partus (zoals regelmatig wordt gesuggereerd in diverse studies) lijkt niet gerechtvaardigd.

In **Hoofdstuk 5** werd de prevalentie en ernst van urine incontinentie vergeleken tussen vrouwen die op de wachtlijst staan voor een hysterectomie (klinische populatie) en gezonde vrouwen uit de bevolking. Er werd geen verschil gevonden in prevalentie van urine incontinentie, zowel van het stress als van het urge type, tussen de twee groepen. Dit suggereert dat de klachten en afwijkingen die de aanleiding zijn voor het verrichten van een hysterectomie, niet van invloed zijn op de prevalentie van urine incontinentie. Echter, als urine incontinentie symptomen aanwezig waren, had de klinische populatie daar veel meer hinder van in vergelijking met vrouwen uit de steekproef uit de populatie. Klaarblijkelijk wordt de perceptie van urine incontinentie als zijnde hinderlijk, beïnvloed door het feit dat er andere gynaecologische klachten zijn waarvoor een hysterectomie noodzakelijk is. Wij veronderstellen dat het in de literatuur vermelde percentage patiënten waarvan de symptomen van urine incontinentie na hysterectomie verdwijnen(75%!), mogelijk veroorzaakt wordt door een veranderde perceptie van de urine incontinentie. Deze hypothese is thans onderwerp van studie in onze kliniek.

In **Hoofdstuk 6** zijn de lange termijn consequenties van de hysterectomie op het ontstaan van urine incontinentie onderzocht. Aangezien de pathofysiologie van stress- en urge incontinentie verschillend is, werd het effect van beide vormen van urine incontinentie onderzocht. Aangetoond werd dat een hysterectomie het risico op het ontstaan van urge incontinentie verhoogd maar niet het ontstaan van stress incontinentie.

Met name gezien het feit dat urge incontinentie de kwaliteit van leven negatief beïnvloed, dient deze bevinding meegenomen te moeten worden in de counseling van patiënten die een hysterectomie ondergaan.

In **Hoofdstuk 7** werd het effect van verschillende coping strategieën op de ervaren kwaliteit van leven gemeten bij vrouwen met symptomen van bekkenbodem dysfunctie uit een aselecte steekproef uit de bevolking. Kwaliteit van leven werd gemeten met een generieke (RAND-36) en een ziekte-specifieke vragenlijst (IIQ). Depressieve symptomen werden gemeten met de Center of Epidemiological Studies-Depression scale (CES-D). Vrouwen die vaker gebruik maakten van emotie-gerichte en passieve coping strategieën hadden, bij dezelfde symptomen, een significant slechtere kwaliteit van leven en rapporteerden meer depressieve symptomen in vergelijking met vrouwen die meer probleem-gerichte en actieve coping strategieën toepasten. Zowel de huisarts als medisch specialist dient zich ervan bewust te zijn dat de ervaren hinder van een klacht niet alleen wordt bepaald door de ernst ervan, maar ook door de wijze waarop vrouwen met de klacht omgaan. Indien de patiënt onvoldoende in staat is om efficiënte coping strategieën toe te passen kan dit het hulp-zoek gedrag en de vraag om interventies beïnvloeden.

In **Hoofdstuk 8** werd onderzocht welke factoren een rol spelen in het hulp-zoek gedrag van vrouwen met symptomen van bekkenbodem dysfunctie. Een klinische populatie vrouwen werd vergeleken met vrouwen uit de bevolking met klachten van bekkenbodem functie stoornissen maar die daarvoor geen hulp zochten. Op basis van de UDI score werden vrouwen geselecteerd met milde symptomen en vrouwen met ernstige symptomen. Vrouwen die hulp zochten voor milde symptomen maakten meer gebruik van emotie-gerichte, passieve coping strategieën in vergelijking met vrouwen uit de populatie met een vergelijkbare UDI score. Tevens waren zij significant vaker laag opgeleid. Vrouwen die hulp zochten bij ernstige symptomen maakten meer gebruik van probleem-gerichte, actieve coping strategieën in vergelijking met vrouwen uit de populatie met een vergelijkbare UDI score. Er bestond een tendens dat vrouwen uit de populatie met ernstige symptomen meer depressieve symptomen hadden in vergelijking met vrouwen met ernstige symptomen die wel hulp hadden gezocht.

Deze bevindingen hebben implicaties voor zowel de huisarts als de medisch specialist. Vrouwen die hulp zoeken voor milde symptomen lopen het risico invasieve diagnostische procedures en interventies te ondergaan die niet gerechtvaardigd zijn op basis van de ernst van het symptoom. Aan de andere kant zijn er vrouwen met ernstige klachten die, waarschijnlijk mede door het onvoldoende gebruik van efficiënte coping strategieën, geen hulp zoeken en een daarmee een verhoogd risico lopen op depressieve klachten.

Hoofdstuk 9 bevat de generale discussie waarin de antwoorden op de onderzoeksvragen in detail worden besproken en aanbevelingen worden gegeven voor de dagelijkse praktijk.

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Dit proefschrift markeert het einde van een intensieve periode van wetenschappelijke vorming en vormt de basis voor toekomstige research. In het hele proces zijn een aantal mensen van speciaal belang geweest.

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Speciaal dank ik...
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Curriculum vitae

De auteur van dit proefschrift werd op 26 mei 1960 geboren te Amsterdam. Hij volgde zijn middelbare schoolopleiding aan de Scholengemeenschap Amsterdam-Oost, alwaar hij in 1978 het VWO diploma behaalde. In datzelfde jaar werd begonnen met de studie Geneeskunde aan de Vrije Universiteit te Amsterdam. In januari 1986 behaalde hij het artsexamen en werkte vervolgens van maart tot september als arts-assistent op de afdeling gynaecologie van het Andreas Ziekenhuis te Amsterdam. Van januari 1987 tot april 1990 werkte hij als arts-assistent interne geneeskunde, chirurgie en gynaecologie in het Medisch Centrum Leeuwarden, locatie Bonifatius hospitaal. In de periode april 1990 tot april 1996 volgde hij de specialisatie opleiding verloskunde/gynaecologie in de cluster Groningen (opleiders Prof.dr. J.G. Aalders, Dr. F. Engel en Dr. W.A. Brouwer). Van april 1996 tot oktober 1996 werkte hij als waarnemend gynaecoloog in het Medisch Centrum Leeuwarden locatie Zuid. Vanaf oktober 1997 is hij werkzaam als staflid gynaecologie in het Universitair Medisch Centrum Utrecht (hoofd Prof. dr. A.P.M. Heintz) met als aandachtsgebied de urogynaecologie en bekkenbodem chirurgie.

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