

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 its 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 its 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 its 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 figure 1.

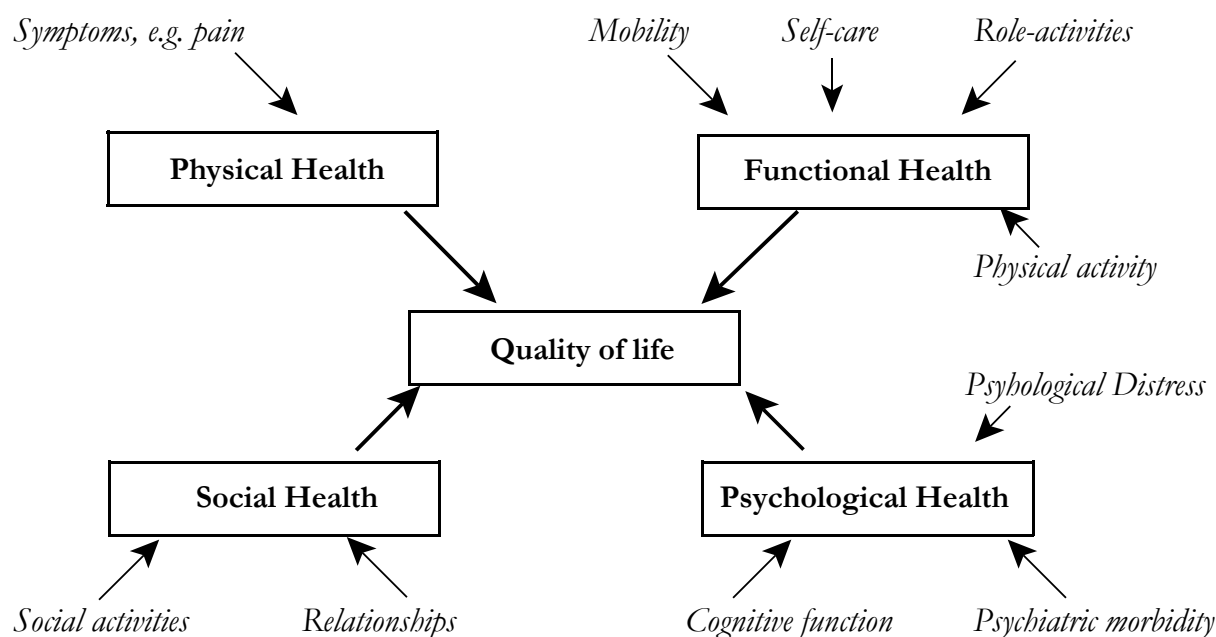


Figure 1. Interactions in Quality of Life models. From MacDonagh 1996.¹⁷

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 its 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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