

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 led 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 translate 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 of 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” comparison⁷ 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 led us to postulate an interesting hypothesis. We hypothesized 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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