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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