Pelvic floor function after gynaecological cancer treatment

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Chapter 6

Reasons for not seeking medical help for severe pelvic floor symptoms: a qualitative study in gynaecological cancer survivors

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Abstract

**Objective** To explore (1) reasons for not seeking help for severe pelvic floor symptoms after gynaecological cancer treatment, (2) the willingness to undergo treatment for these symptoms and (3) to invite suggestions to improve out-patient care.

**Design** Qualitative study using semi-structured interviews.

**Setting** Vulvar, endometrial or cervical cancer survivors treated in the Academic Medical Center, Amsterdam between 1997 and 2007.

**Sample** Purposively selected sample from 138 eligible respondents to pelvic floor related questionnaires, who were severely bothered by symptoms (> 75th percentile of domain sum score of questionnaires) and had not sought medical help.

**Methods** After each semi-structured interview a checklist with reasons for not seeking help was complemented with newly mentioned reasons. The interviews were stopped when data saturation was accomplished, i.e. three consecutive interviewees had not revealed new reasons. The interviews were analysed by two researchers independently.

**Results** Fifteen interviews were conducted. Most reported reasons for not seeking help were that patients found their symptoms bearable in light of their cancer diagnosis and lacked knowledge about possible treatments. Seven patients were willing to undergo treatment. Eleven patients stated that care should be improved, specifically by timely referral to pelvic floor specialists and additional care by oncology nurses.

**Conclusion** There is need for standard attention to adverse effects on pelvic floor function after cancer treatment. This could be realized by quantifying symptoms using questionnaires, standard attention for such symptoms by gynaecological oncologists or oncology nurses and timely referral to pelvic floor specialists of those with bothersome pelvic floor symptoms.
Introduction

There is extensive evidence that treatment for gynaecological malignancies adversely affects pelvic floor function. Patients treated for endometrial, cervical, and vulvar cancer encounter symptoms such as urinary and faecal incontinence, over-active bladder symptoms and constipation. (1-5) Fortunately, a substantial number of these patients survive their malignancy, but as a consequence need to live with the adverse effects of treatment. Studies performed in general female populations have shown that pelvic floor symptoms impair quality of life. (6-8) However, not all women with pelvic floor symptoms visit a doctor for medical help. For instance, less than half of women with stress urinary incontinence seek help. (9-11) This is unfortunate as there are several highly effective treatments for stress incontinence. (12-14) Community-based studies have shown that embarrassment, lack of knowledge about its causes, unfamiliarity with treatment options and presence of concomitant symptoms are reasons for not seeking medical treatment. (15-17)

To the best of our knowledge, no studies have been published that explore help seeking behaviour of gynaecological oncological patients for pelvic floor symptoms. Therefore, we do not know whether their help seeking behaviour differs from that of the general female population. Gynaecological cancer patients routinely visit their gynaecologist and radiotherapist and consequently could easily be referred to a pelvic floor specialist, e.g. uro-gynaecologist, urologist, pelvic physiotherapist, or gastro-enterologist. However, oncological specialists identified bladder and bowel symptoms in only 5 - 15% of gynaecological cancer survivors, whereas 23 to 58% of these women reported severe bladder and bowel symptoms. (18;19) Seeking medical help for pelvic floor symptoms should be encouraged as many conditions can be adequately treated, especially stress urinary incontinence and constipation and to a lesser extent radiation cystitis and proctitis, resulting in better quality of life. (20-27) Insight into the personal factors that impede help seeking behaviour in gynaecological cancer patients is therefore needed. (28)

The primary objective of this qualitative study is to explore patients’ personal reasons for not seeking medical help for bothersome pelvic floor symptoms after treatment for gynaecological malignancy. Secondary objectives are to explore the willingness to undergo treatment for these symptoms and to invite suggestions to improve post-operative out-patient care.

Methods

We conducted a qualitative study administering semi-structured interviews. We obtained approval of the Medical Ethical Committee of the Academic Medical Center (AMC), Amsterdam for conducting this study and patients gave written informed consent for the interview.

Patient selection for the semi-structured interviews was carried out in a three-step procedure. First, we performed a cross-sectional quantitative study in women treated
between 1997 and 2007 for endometrial, cervical, or vulvar cancer in the AMC. Patients were excluded if they were unable to complete a Dutch questionnaire and/or had been treated for metastatic or recurrent disease in the year prior to the study. Patients, fulfilling these in- and exclusion criteria were sent a set of standardized questionnaires on pelvic-floor-related quality of life, containing the Urogenital Distress Inventory (UDI)(29;30) and the Defecatory Distress Inventory (DDI)(31). Both questionnaires incorporate multiple domains. Domain scores are calculated based on the answers to the corresponding questionnaire items. Higher scores represent a higher perceived burden of symptoms.

The second step consisted of selecting those patients who scored over the 75th percentile of the domain sum scores of at least one of the questionnaires, and reported not to have sought specialized help for these symptoms.

Third, to ensure diversity in the group of interviewees, we performed a purposive sampling procedure, i.e. we selected patients on the following pre-defined characteristics: year of treatment, tumour localization, age, parity, presence of co-morbidity, marital status and educational level. (32;33) Sample size was determined by the criterion of data saturation, meaning that when three consecutive patients had not added a new reason for not seeking help, data collection was stopped.

The interviews were conducted by MH, a PhD-student and medical doctor, who was not involved in the treatment of the interviewees. The interviews were audio-recorded. We conducted the interviews by telephone after we had determined the most feasible mode of administration by comparing face-to-face and telephone interviews in a pilot study.

Before starting the interview the researcher ascertained that it was a convenient time and place for the interviewee to be asked medical and intimate questions. Furthermore, the interviewer assured interviewees that the content of the interviews would be kept confidential and no information would be conveyed to their treating physician. The semi-structured interviews started with two questions to confirm the presence and bother of pelvic floor symptoms and whether the patient had not sought medical help for these symptoms, as reported in the questionnaires. When patients reported that their symptoms had disappeared or they had sought help, the interview was stopped. If these questions were endorsed, patients were invited by open non-structured questions to tell about their symptoms and the reasons for not seeking help. After summarizing the information provided by the patients, they were asked if they could think of more reasons for not seeking medical help. After summarizing the information provided by the patients, they were asked if they could think of more reasons for not seeking medical help. If that was the case, the researcher explored and summarized these reasons again, until no further reasons were provided. Subsequently, all interviewees were read aloud a previously designed checklist of possible reasons for not seeking medical help and were asked whether these reasons were applicable to them.

Initially this checklist consisted of 12 reasons for not seeking medical help for pelvic floor symptoms assembled by the authors based on clinical experience and relevant literature. These reasons for not seeking help were categorised into four themes: (1) ‘Pelvic floor symptoms are bearable in the light of the cancer diagnosis’; (2) ‘Specialists did not do anything about symptoms’; (3) ‘Patient is reluctant to go to hospital or physician’; [4]
‘Patient and / or specialists were not aware of existing treatment options’. We finalised each interview with two specific questions asking the patient whether she was willing to undergo treatment for her bothersome pelvic floor symptoms and whether she could provide suggestions on how to improve post-treatment outpatient care concerning pelvic floor symptoms. Additionally, patients were read aloud a checklist consisting of five suggestions how to improve such care and were asked whether they endorsed these suggestions or not.

Analysis started directly after the conductance of each interview. Content analysis of the first four interviews was performed independently by MH and MS, professor in medical psychology, to check the quality of the interviews (e.g. avoidance of inappropriate leading questions, sufficient probing of answers to open questions) and the identification of new reasons. Content analysis of the subsequent interviews was carried out independently by MH and EB, social scientist and PhD student. By using the constant comparative method new reasons for not seeking medical help or suggestions to improve post-treatment out-patient care emerging from each interview were added to the checklists based on negotiated consensus. In the cases that discrepancies occurred the researchers re-read or re-listened to the interview, discussed the content and interpretation until they reached consensus. These resulting extended checklists were used for the subsequent interview. In accordance to this iterative process, each new patient was read aloud more comprehensive checklists, with the exception of the last three respondents whose interviews did not yield new information. Since this indicated that data saturation was accomplished further data collection was stopped.

The first seven interviews were transcribed verbatim. Since analysis was found to be straightforward, transcribing the interviews had no additional value and therefore we analysed the interviews directly from the audio-file.

Results

A total of 853 sets of questionnaires were sent of which 569 were returned, resulting in a response rate of 67%. Of the 139 (24%) patients with a score above the 75th percentile of the UDI domain sum scores, 94 (68%) patients reported not to have sought medical help for their uro-genital symptoms. One-hundred-twenty-five patients (22%) had a score above the 75th percentile of the DDI domain sum scores, of whom 74 (59%) reported not to have sought medical help for defecation symptoms. The overlap of these two groups comprised 30 patients, resulting in 138 eligible patients. The time between questionnaire completion and conductance of the interviews varied from 10 to 12 months. This period was used to enter the questionnaires’ data into a database, developing the checklist, and selecting the patients for the interview. We successively approached 24 patients for the interview, selected by the purposive sampling procedure. Eight patients were found not to be eligible for the interview: four patients told their symptoms had resolved in the meantime, either spontaneously (n=2) and or with conservative treatment (n=2); two patients could not be
tracked down; one patient had deceased and one patient received current treatment for radiation cystitis with hyperbaric oxygen. One eligible patient refused participation due to lack of time. After 15 interviews data saturation was accomplished. Characteristics of the included patients are depicted in Table 1.

The mean duration of the interviews was 27 minutes (range 12 - 39). Twenty-one reasons for not seeking medical help for severe pelvic floor symptoms were added by patients to the initial 12, of which 10 items belong to the first theme ‘Pelvic floor symptoms are bearable in the light of the cancer diagnosis’. One theme was added for not seeking medical help: ‘Patient is self reliant’. The final version of the checklist is shown in Table 2. Theme 1 contains most reasons that were endorsed and most reasons that were added. An example of an original reason that was often endorsed was ‘These symptoms are not as bad as cancer’ which can be illustrated by the following citation of interviewee 9:

‘I was told I am healthy again, so I do not want to complain about these symptoms.’

An example of an added reason is: ‘Although I have severe problems, I do not experience this as suffering’. Interviewee 3 explained it as follows:

<table>
<thead>
<tr>
<th>Interview</th>
<th>Year of treatment</th>
<th>Tumour localisation</th>
<th>Age</th>
<th>Parity</th>
<th>Co-morbity</th>
<th>Marital status</th>
<th>Educational level</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2003</td>
<td>cervix</td>
<td>84</td>
<td>2</td>
<td>Yes</td>
<td>Married</td>
<td>low</td>
</tr>
<tr>
<td>2</td>
<td>1997</td>
<td>endometrium</td>
<td>72</td>
<td>0</td>
<td>Yes</td>
<td>Single</td>
<td>high</td>
</tr>
<tr>
<td>3</td>
<td>1997</td>
<td>cervix</td>
<td>53</td>
<td>0</td>
<td>Yes</td>
<td>Married</td>
<td>high</td>
</tr>
<tr>
<td>4</td>
<td>2001</td>
<td>cervix</td>
<td>48</td>
<td>1</td>
<td>Yes</td>
<td>Living together</td>
<td>low</td>
</tr>
<tr>
<td>5</td>
<td>2005</td>
<td>endometrium</td>
<td>61</td>
<td>2</td>
<td>Yes</td>
<td>Married</td>
<td>low</td>
</tr>
<tr>
<td>6</td>
<td>2006</td>
<td>vulva</td>
<td>85</td>
<td>0</td>
<td>Yes</td>
<td>Single</td>
<td>low</td>
</tr>
<tr>
<td>7</td>
<td>2003</td>
<td>endometrium</td>
<td>69</td>
<td>2</td>
<td>No</td>
<td>Married</td>
<td>low</td>
</tr>
<tr>
<td>8</td>
<td>2005</td>
<td>cervix</td>
<td>43</td>
<td>2</td>
<td>Yes</td>
<td>Divorced</td>
<td>low</td>
</tr>
<tr>
<td>9</td>
<td>2000</td>
<td>endometrium</td>
<td>72</td>
<td>2</td>
<td>Yes</td>
<td>Married</td>
<td>low</td>
</tr>
<tr>
<td>10</td>
<td>2002</td>
<td>cervix</td>
<td>56</td>
<td>1</td>
<td>No</td>
<td>Divorced</td>
<td>high</td>
</tr>
<tr>
<td>11</td>
<td>1998</td>
<td>cervix</td>
<td>39</td>
<td>0</td>
<td>No</td>
<td>Single</td>
<td>low</td>
</tr>
<tr>
<td>12</td>
<td>1998</td>
<td>cervix</td>
<td>55</td>
<td>2</td>
<td>Yes</td>
<td>Married</td>
<td>low</td>
</tr>
<tr>
<td>13</td>
<td>2000</td>
<td>endometrium</td>
<td>73</td>
<td>2</td>
<td>Yes</td>
<td>Married</td>
<td>low</td>
</tr>
<tr>
<td>14</td>
<td>2006</td>
<td>cervix</td>
<td>53</td>
<td>2</td>
<td>No</td>
<td>Married</td>
<td>low</td>
</tr>
<tr>
<td>15</td>
<td>1998</td>
<td>endometrium</td>
<td>75</td>
<td>3</td>
<td>Yes</td>
<td>Divorced</td>
<td>low</td>
</tr>
</tbody>
</table>

I always consider myself lucky that I do not have many complaints, although the urge sometimes hurts so badly.

Theme 2 (‘Specialists did not do anything about the symptoms’) consists of four reasons, of which one was added by an interviewee. Theme 3 (‘Patient is reluctant to go to hospital or physician’) included one original reason and three were added by interviewees. One illustrative reason was ‘Sometimes I am afraid that my symptoms are the result of cancer’. Interviewee 5 expressed this as follows:

‘When my bowel symptoms are very bad and I feel something, I always think: ‘Oh dear’. I always think the cancer will attack again.’

Theme 4 (‘Patient and / or specialists were not aware of possible treatments’) contains six reasons of which 4 were added by interviewees. The original reason, which was endorsed by almost each interviewee was ‘I had no idea that I could undergo treatment for my symptoms’. One of the added reasons was ‘I assumed that when my doctor/specialist thought I had severe symptoms, he/she would refer me to a specialist for these symptoms’. Interviewee 5 commented:

‘I shall hear what the doctor wants with the symptoms.’

Theme 5 (‘Patient is self reliant’) was added in its entirety. We removed the original reason ‘I have adjusted my behaviour in such a way that my symptoms do not bother me so much’ from theme 1 to this theme as it better fitted here. Three reasons were added by interviewees. Patient 7 endorsed the original reason, with the following explanation:

<table>
<thead>
<tr>
<th>Predominant symptom</th>
<th>‘Would you want to undergo medical treatment for your symptoms?’</th>
</tr>
</thead>
<tbody>
<tr>
<td>UI / obstr def</td>
<td>yes</td>
</tr>
<tr>
<td>FI</td>
<td>yes</td>
</tr>
<tr>
<td>OAB / painful bladder</td>
<td>not yet</td>
</tr>
<tr>
<td>UI</td>
<td>not yet</td>
</tr>
<tr>
<td>OAB / FI</td>
<td>no</td>
</tr>
<tr>
<td>OAB / FI</td>
<td>not sure</td>
</tr>
<tr>
<td>UI / constip</td>
<td>yes</td>
</tr>
<tr>
<td>UI</td>
<td>not yet</td>
</tr>
<tr>
<td>OAB / FI</td>
<td>yes</td>
</tr>
<tr>
<td>UI</td>
<td>no</td>
</tr>
<tr>
<td>UI / constip</td>
<td>yes</td>
</tr>
<tr>
<td>UI / obstr voiding</td>
<td>yes</td>
</tr>
<tr>
<td>OAB / UI</td>
<td>yes</td>
</tr>
<tr>
<td>Constip / Fi</td>
<td>no</td>
</tr>
<tr>
<td>UI / FI</td>
<td>not sure</td>
</tr>
</tbody>
</table>
‘I hardly ever leave the house, I resent walking with wet pants.’

At the time of the interview, seven patients were willing to undergo treatment for their pelvic floor symptoms. Two interviewees (6 and 15) could not make a decision about being treated for their pelvic floor symptoms:

‘I will hear from my doctor if something has to be done.’

‘I would not undergo surgery, but anything else: yes!’

Three interviewees (3, 4 and 8) said they considered undergoing treatment in the near future:

‘In the light of getting older and possibly worsening of symptoms, I would consider treatment.’

‘Only when I completely wet myself.’

‘I have my own business; I cannot be away from work.’

Three interviewees (5, 10 and 14) did not want to undergo treatment, for which they provided the following reasons:

‘Because I have other health problems and fear of going to a doctor.’

‘A friend treated for urinary leaking has worse problems than before.’

‘These symptoms are not important enough and I am against taking pills.’

Eleven patients generated suggestions how to improve post-treatment care for pelvic floor dysfunction. In addition to the predefined suggestions, two suggestions were provided by the interviewees (see Table 3). The two most frequently endorsed improvements, seven and eight times respectively, were: ‘There should be timely referral to a pelvic floor specialist when pelvic floor symptoms occur after cancer treatment’ and ‘In addition to care by an oncological specialist, I would have appreciated to discuss side effects of cancer treatment and other discomfort with a (oncology) nurse’.

Table 2: Final version of the checklist with reasons for not seeking help for pelvic floor symptoms (every statement ends with: ‘that is why I did not seek medical help’)

| Theme 1 : Pelvic floor symptoms are bearable in light of the cancer diagnosis |
| Original reasons |
| My symptoms are a logical consequence of treatment |
| My symptoms are a logical consequence of aging |
| These symptoms are not as bad as cancer |
| My symptoms are not as bad as other symptoms I had directly after cancer treatment |
| I am still in follow-up for cancer, that is the reason I do not pay attention to these symptoms |
Added reasons

If these symptoms are the only complaints I have, after having had cancer, I call myself lucky
I had similar symptoms before treatment of cancer, so I am used to them
My symptoms are not as bad as symptoms of other people I know
I have other health problems that are worse than my pelvic floor symptoms
I do not want to be a burden to my family and friends, so I do not mention my symptoms
The symptoms do not occur often
I had been prepared for these symptoms to occur after treatment
Although I have severe problems, I do not experience this as suffering
When I visited the oncological specialist I was so nervous, I forgot to mention my symptoms
It is very difficult to be absent from work or other activities

Theme 2: Specialists did not do anything about the symptoms

Original reasons
My specialist / GP told me my symptoms are a logical consequence of treatment
My specialist / GP told me my symptoms are a logical consequence of aging
I have mentioned my symptoms but the specialist did not react to them

Added reason
My GP or specialist told me that I could not undergo treatment for my symptoms due to other health problems

Theme 3: Patient is reluctant to go to hospital or physician

Original reason
I have become frightened to go to a doctor / to a hospital

Added reasons
Sometimes I am afraid that my symptoms are the result of cancer
I feel embarrassed about my symptoms
I feel embarrassed to go to a doctor for my symptoms and having to get undressed

Theme 4: Patient and / or specialist were not aware of possible treatments

Original reasons
I had no idea that I could undergo treatment for my symptoms
My doctor told me there was nothing to do about the symptoms

Added reasons
I assumed that when my doctor/specialist thought I had severe symptoms, he/she would refer me to a specialist for these symptoms
I think I am the only one with these kind of symptoms
I do not think there is a definitive solution for my symptoms
I do not know where to go for help

Theme 5: Patient is self reliant

Original reason
I have adjusted my behaviour in such a way that my symptoms do not bother me so much

Added reasons
I thought of solutions for my symptoms myself
The symptoms are part of my life / I learned how to live with the symptoms
I am not the type of person to visit a doctor regularly

Legend: In the added theme “Patient is self reliant” an original reason (I have adjusted my behaviour in such a way that my symptoms do not bother me so much) was moved to this theme.
Discussion

In this qualitative study most patients had expected their pelvic floor symptoms to occur as a consequence of the cancer treatment and most patients found their own ways to cope with these symptoms. Moreover, most patients did not seek medical help, because having had cancer overruled the importance of their pelvic floor symptoms. They called themselves lucky if these symptoms were the only complaints they suffered from after cancer treatment. Other remarkable findings are that most patients reported that they had not sought medical help because they were unaware of existing treatment options, with some patients being explicitly told by their oncologist that nothing could be done against such symptoms. However, most patients stated that they were willing to undergo treatment now or in the future if this would be offered and efficacious in their situation. To improve post-treatment outpatient care for pelvic floor dysfunction, the majority of patients would have appreciated consulting a (oncology) nurse to discuss the side effects of the cancer treatment and other topics. Furthermore, many patients recommended timely referral to a pelvic floor specialist when pelvic floor symptoms occur. The two suggestions made by the interviewees were to facilitate contact with other gynaecological cancer survivors and to provide psychological help.

A number of limitations of our study merit attention. The first set of limitations concerns the patient selection. We invited patients who did not seek medical help for bothersome pelvic floor symptoms. The reasons of gynaecological cancer survivors, who did seek medical help, might also be interesting and useful for clinical practice. Furthermore, we identified patients on the basis of their scores on the UDI and DDI, validated questionnaires to assess uro-genital and defecation symptoms. (30; 31) In the absence of empirically based guidelines, we adopted the 75th percentile of the sum scores. This cut-off score appeared to be suitable as all interviewees experienced their pelvic floor symptoms as

Table 3: Suggestions for improving supportive post-treatment care

<table>
<thead>
<tr>
<th>Suggestions</th>
<th>Proposed by</th>
<th>Agreed by</th>
</tr>
</thead>
<tbody>
<tr>
<td>There should be timely referral to a pelvic floor specialist when pelvic floor symptoms occur after cancer treatment</td>
<td>4, 7, 8, 9, 11, 13, 15</td>
<td></td>
</tr>
<tr>
<td>In addition to care by an oncologic specialist, I would have appreciated to discuss side effects of treatment and other discomfort with a (oncology) nurse</td>
<td>4, 5, 7, 8, 9, 10, 11, 15</td>
<td></td>
</tr>
<tr>
<td>Post-treatment care went well, I should have told my symptoms more clearly to my specialist</td>
<td>5, 7, 8, 15</td>
<td></td>
</tr>
<tr>
<td>I should have received more information before cancer treatment about pelvic floor symptoms that could occur or worsen by the treatment</td>
<td>5, 7, 8, 9, 15</td>
<td></td>
</tr>
<tr>
<td>My oncologic specialist should have asked me more specifically about pelvic floor symptoms</td>
<td>8, 9, 15</td>
<td></td>
</tr>
<tr>
<td>Looking back I would have wished contact with other gynaecologic cancer survivors</td>
<td>1</td>
<td>7, 9, 10, 12</td>
</tr>
<tr>
<td>Looking back I would have appreciated psychological help</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

Legend: Suggestions added by patients are shown in italic. The numbers correspond with the numbers of the interviewees in Table 1.
severely bothersome. We aimed at retrieving the primary reasons for not seeking medical help in this group of cancer survivors. We therefore adopted a purposive sampling procedure to ensure heterogeneity of the interviewees. Data saturation was accomplished with 15 patients, a sample size that might be considered quite small for a qualitative study. However, we believe that the sample size was sufficiently large and the sample composition sufficiently heterogenous, as we have succeeded to obtain an exhaustive list of reasons for not seeking medical help. We started each interview with open questions about patients’ help seeking behaviour for pelvic floor symptoms, and used a pre-defined checklist that we expanded on the basis of each subsequent interview. The list of original and added reasons for not seeking medical help from this heterogenous group of gynaecological cancer survivors was extensive showing a great variety. Our results and recommendations may therefore be applicable to all gynaecological cancer survivors, as well as to women who have been treated for other oncological pelvic diseases, e.g. bladder or rectum malignancies.

Second, our secondary research objective was to invite suggestions for post-treatment outpatient care. As we also included interviewees who had already stopped their cancer follow-up we clearly have not collected all possible suggestions for improving outpatient care. Interestingly, even this group of interviewees provided important suggestions.

Third, the use of telephone interviews can be criticised for containing the risk of lack of confidentiality or calling at an inconvenient time. However, we pilot-tested their feasibility and found that they were well accepted by the interviewees. A strength was that the interviews were conducted by a medical doctor, knowledgeable about their treatment and symptoms, but who had no involvement in the treatment of these patients. Moreover, patients were explicitly told that the information provided would be kept confidential and not conveyed to their treating physician. Further, all interviews were analyzed by two persons to enhance the validity of the results.

Our results differ from those found in population based surveys, as our interviewees do not express embarrassment to seek help, do not lack knowledge of the causes of the pelvic floor symptoms, and do not let concomitant symptoms play a role. In the referred population based studies, all the surveys were done with self report questionnaires, whereas we interviewed the patients. These different modes of data collection might explain the different results. However, gynaecological cancer survivors have undergone multiple gynaecological examinations and counselling before cancer treatment and therefore are less embarrassed to go to a gynaecologist and do not lack knowledge about the causes of pelvic floor symptoms. Both groups of women do not seek help because they are unfamiliar with treatment possibilities.

To the best of our knowledge no qualitative study has been conducted on help seeking behaviour for pelvic floor symptoms in gynaecological cancer patients. Patients’ and physicians’ perception of post-treatment morbidity are repeatedly found not to be in accordance. The results of this study suggest that oncologists ask about the side effects of the cancer treatment on the pelvic floor function, but do not seem to
continue asking questions about the impact of those symptoms on patients’ daily life. The oncologists’ reluctance to discuss possible treatment options might be due to lack of knowledge about treatment options for these symptoms in this complicated group of patients. For side effects such as radiation enteritis and cystitis or hypotonic bladder there is no conclusive evidence for curative options. Our interviewees, however, suffered mostly from urinary incontinence, for which good treatment options exist, as recently documented. (26;27) Additionally, there could be a larger role for general practitioners in paying more attention to pelvic floor symptoms and timely referral as part of a ‘shared-care model’ for cancer survivors as suggested by Oeffinger and McCabe. (40)

Conclusion

Most gynaecological cancer patients consider their severe pelvic floor symptoms in the perspective of their previous cancer diagnosis and treatment, as most patients were informed about the consequences of treatment and feel fortunate to be alive. However, most patients would undergo treatment for these symptoms if this was proposed and efficacious. Post-treatment care would be improved if, in addition to the routine oncological checkups by the gynaecological oncologist, an oncology nurse would pay attention to side effects of the cancer treatment on pelvic floor function, and their negative impact on these patients’ quality of life. When gynaecological cancer patients report bothersome pelvic floor symptoms, pelvic-floor-related quality-of-life questionnaires could be used to objectify the symptoms. Subsequent referral to pelvic floor specialists, such as uro-gynaecologists, urologists, gastro-enterologists and pelvic physiotherapists should be considered, although future research has to evaluate whether all existing treatment modalities are equally successful in alleviating pelvic floor symptoms in gynaecological cancer patients.
Reference List


(34) Bowden J. Phenomenographic Research. 1996.


