

Development of the Breast Cancer Survivors Symptom Checklist for Use in Follow-Up Multidisciplinary Appointments

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Background: Breast cancer survivors are primarily followed up to monitor the effectiveness of treatment and complications and to detect recurrences. Many breast cancer survivors may experience prolonged adverse physical and psychological effects, which should also be addressed at follow-ups. The objective of this study was to develop a brief symptom assessment tool for breast cancer survivors to be used as a guideline for the survivors and all health care professionals conducting the routine follow-up. The second objective was to describe the women's individual experiences with follow-ups.

Methods: A literature review, a focus group of 6 healthcare professionals using a nominal group technique process, and the experience and feedback via qualitative interviews with 16 breast cancer survivors was used to develop the Breast Cancer Survivors Symptom Assessment Checklist (BCS-SC).

Results: The BCS-SC consists of a set of 13 symptoms/burdens and one question. On a scale from 0 (no symptom) to 10 (worst imaginable), survivors indicated the extent to which they experience each symptom. All survivors perceived the annual follow-ups as important, but none prepared for them. Eight of the 16 survivors reported that they had 2 or more of the symptoms/burdens listed in the BCS-SC. However, only one of the survivors had mentioned her symptom to the doctor at follow-up.

Conclusion: The BCS-SC is a comprehensive assessment tool for symptoms/burdens that are common among breast cancer survivors and can aid efforts to optimize their follow-up. Furthermore, the BCS-SC allows for a more patient-initiated and focused consultation, leading to more patient-centered quality care.

Keywords: breast cancer, checklist, personalized approach, survivorship, symptoms assessment tool

Introduction

Due to advances in early detection, treatment, and follow-up care, relative 5-year survival rates in Norway are currently estimated at 92%.¹ Breast cancer patients are followed up annually for 10 years. The follow-ups include evaluation of any ongoing treatment, side effects, and disease status and detection of recurrence; information is also provided.² The breast cancer patients survival rate has increased dramatically in recent decades, therefore quality of life (QoL) has become a major focus in research and clinical practice. The type of follow-up the survivors receive may affect their level of reassurance and have an impact on their QoL. It has been suggested that worsening QoL might be related to worsened prognosis and an increase in the risk of recurrence.³

Over the past decades, research has shown that breast cancer and its treatment have a significant emotional and social impact on patients,⁴ their QoL^{5,6} as well as their capacity for work.⁷⁻⁹ Many survivors experience prolonged adverse physical, cognitive, and psychological effects.^{4,10,11} Furthermore, survivors may experience multiple symptoms concurrently, which compounds the impact on functions in daily life, yet these symptoms often remain underdiagnosed and untreated because the

patient's report of symptom severity is rarely part of routine cancer care and validated symptom assessment tools are not readily available to clinicians.¹² Some brief symptom inventories exist that allow for simple and rapid documentation of multiple patient-reported symptoms at the same time.¹³ However, not all symptoms screened by these instruments are relevant for breast cancer survivors and some symptoms that are relevant, are not covered. Therefore, based on previous symptom assessment tools, research, clinical experience, and patient involvement, we decided to develop an assessment tool for breast cancer survivors to be used at routine follow-ups. Effective care for breast cancer patients after treatment depends on recognition of the patients' psychosocial as well as physical needs.^{14,15} Better assessment is a prelude to successful treatment of symptoms.

The aim of the present study was (1) to develop a brief symptom assessment tool that provides an adequate summation of symptoms/burdens described by breast cancer survivors, (2) to describe women's individual experiences with follow-up consultations without the aid of an assessment tool.

Materials and Methods

A focus group of 6 healthcare professionals (oncology nurses, clinical nurse specialist) with expertise in breast cancer symptom management was convened. First, the group conducted a search of the literature to identify existing symptom assessment scales for cancer symptoms using PubMed, CINAHL, and Cochrane Library databases. MeSH terms (eg, "checklist", "assessment tool", "breast cancer") were combined with keywords (eg, "follow-up", "treatment", "late effects", "symptoms", "survivorship"). All search results were scanned for possible relevant content based on titles and abstracts. Next, the optimal properties of a symptom screening tool for breast cancer survivors and symptom assessment scales were identified and evaluated. A nominal group technique (NGT) was used to identify the most important symptoms for inclusion. NGT is a process that is designed to promote group participation in identifying problems, generating solutions, and decision-making. The structure of NGT has 5 stages: introduction, idea generation, sharing ideas, group discussion, voting. It helps groups to make fast and informed decisions, taking everyone's opinion into account.¹⁶ The NGT resulted in a final ranking of items according to the sum of votes from all participants. A consensus approach in face-to-face discussion was then implemented to produce an initial draft of the checklist we named the Breast Cancer Survivors Symptom Checklist (BCS-SC).

The next step was to involve the breast cancer consumers to assess the checklist. Before their follow-up appointment, patients were asked if they were willing to be interviewed immediately after the follow-up at the hospital. The follow-ups were conducted without the use of the BCS-SC. One-to-one semi-structured interviews were conducted with 16 patients to explore their experiences and perceptions of follow-up. The interviews lasted from 30 to 45 minutes. A semi-structure interview guide was developed. The following questions were included:

- How have you been since treatment was completed?
- Did you receive information regarding the possibility of experiencing late side effects?
- At the last consultation, after treatment was complete, did the doctor talk about getting back to work?
- Did the doctor talk about the importance of adherence with regard to endocrine therapy?
- Do you prepare for your annual follow-up (eg, write down questions, you want to ask the doctor)?
- How important are these annual follow-ups for you?

After the interview, the patient was asked to fill out and assess the BCS-SC, with the interviewer present. The following topics were covered: views and feasibility of using the BCS-SC during routine follow-up, were any symptoms or ailments missing, presentation of the data on a one-page sheet, usefulness, length of time to fill out the BCS-SC. If the patient scored 4 or more on an item(s), they were asked if they had mentioned that particular symptom(s) to the doctor. Finally, patients were asked if they thought that the BCS-SC would be a helpful tool for the annual follow-ups.

Data Analysis

Descriptive statistics are presented as means, standard deviations (SD), and frequencies where appropriate. The interviews were conducted, audio-taped, and transcribed verbatim by the first author. The interviews were analyzed using

thematic analysis in 6 steps: familiarization, coding, generating themes, reviewing themes, defining and naming themes. The transcripts were carefully reviewed independently by 2 researchers to identify categories, which were then compared and a set of core themes was derived.¹⁷

Results

The focus group and the interviews both contributed to the development of the BCS-SC.

Results from the Focus Group

The focus group found that the optimal properties for a breast cancer survivor symptoms screening tool were: (1) capture of both physical and psychosocial symptoms; 2) minimal burden for the respondent, (3) focus on subjective types of symptoms rather than objective symptoms, and (4) focus on the severity of symptoms.

The 2 most suitable screening tools found were the M.D. Anderson Symptom Inventory (MDASI), which includes 13 cancer-related symptoms that are common for most cancers,¹⁸ and the Edmonton Symptom Assessment System (ESAS), which was developed to assist in the assessment of 9 symptoms that are common in palliative care.¹⁹ However, the group concluded that not all symptoms screened by the ESAS or MDASI are relevant for breast cancer survivors and many symptoms are not covered.

The NGT process resulted in identification of 13 symptoms/burdens. The symptoms were fatigue, pain, problems sleeping, body image, menopausal burdens/symptoms, sexuality, weight gain, lymphedema, cognitive functioning, and emotional distress. The burdens were social network, work situation, financial. In addition, one question was added and possibility to add symptoms/burdens that were not on the checklist was included (Table 1).

The group had a significant dialogue on social network, work situation, and finances. The health professionals cannot provide assistance with these items, but can make suggestions or refer to other professionals that may be of help. Because these items were viewed as important for the individual's QoL, and this view is supported by research,^{20–22} the consensus of the group was to retain them.

Table 1 The Breast Cancer Survivors Symptom Checklist

In order for you to get the best possible benefit from follow-up consultation, we want you to fill out and take this form with you. This form lists some of the symptoms/ailments one may experience due to the treatment for breast cancer. We want you to put a circle around the number that best describes how you have been in the last week. The scale goes from 0 = no ailments/symptoms to 10 = worst imaginable											
Fatigue	0	1	2	3	4	5	6	7	8	9	10
Pain	0	1	2	3	4	5	6	7	8	9	10
Sleeping problems	0	1	2	3	4	5	6	7	8	9	10
Altered body image	0	1	2	3	4	5	6	7	8	9	10
Menopausal problems	0	1	2	3	4	5	6	7	8	9	10
Sexuality	0	1	2	3	4	5	6	7	8	9	10
Weight gain	0	1	2	3	4	5	6	7	8	9	10
Lymphedema	0	1	2	3	4	5	6	7	8	9	10
Concentration/memory	0	1	2	3	4	5	6	7	8	9	10
Worried/anxiety/depression	0	1	2	3	4	5	6	7	8	9	10
Social network	0	1	2	3	4	5	6	7	8	9	10
Work situation	0	1	2	3	4	5	6	7	8	9	10
Financial	0	1	2	3	4	5	6	7	8	9	10
Taken everything into consideration, how are you feeling today?											
	0	1	2	3	4	5	6	7	8	9	10
Anything else (you may use the back of this sheet)											

The group decided to adapt the layout of the ESAS, using a visual analog scale from 0 (no burden/symptom) to 10 (worst imaginable). A score of 4 or more for pain was considered to have an impact on daily life;²³ for all other items, a score of 5 or more was considered to have an impact on daily life and as a threshold level for medical intervention.²⁴

A short introduction was formulated as a heading for the BCS-SC. The respondents were asked to indicate the extent to which they experienced each symptom/burden listed on the BCS-SC. The time frame used was “now”.

Results from Patient Interviews

Demographic and medical data of the patients are shown in Table 2. Three patients had their first-annual follow-up, 2 their second, 3 their fourth, 4 their fifth, 1 her eighth, and 3 their tenth.

How Have You Been Since Your Treatment Was Completed?

The women's illness experiences varied, but most reported that they felt fine when interviewed. However, several of the participants had experienced physical and psychological symptoms, burdens, or worries.

“My pain due to arthritis worsened after treatment”. [Participant 1]

“I have had my ups and downs. I have some control, but then everything gets black...ups and downs.” [Participant 7]

“In the beginning I had lots of pain due to the expanding prosthesis, but then it was changed to a permanent prosthesis. I have less pain now”. [Participant 16]

I had both breasts removed, one due to cancer and the other prophylactically and both were reconstructed. I am pleased that the doctor listened to my worries. I have no genetic defect, but breast cancer is hereditary in my family. [Participant 2]

“The first year was very bad, I was sick, not good at all, but since then I have been fine.” [Participant 13]

“It has gone smoothly, no traumatic treatment...but I always feel some tension at follow-ups.” [Participant 12]

Did You Receive Information Regarding the Possibility of Experiencing Late Side Effects?

In general, most believed that they had received good information. The information regarding side effects was mostly related to the possibility of experiencing pain due to endocrine treatment. Only a few patients had been informed about side effects or late effects due to the treatment. A couple expressed that they had the opportunities to get the information they needed.

“Most of the information was regarding side effects of the tablets I have to use.” [Participant 5]

Table 2 Demographic and Medical Data (N = 16)

Age (years)	
Mean (SD)	60 (7.4)
Range	49–72
Have more than 12 years of education	14 (85.7)
Are married/cohabitate	8 (50.0)
Have children	11 (68.8)
Type of surgery	
BCT + SN	9 (56.3)
BCT + AD	0 (0.0)
Mastectomy + SN	3 (18.8)
Mastectomy + SN + PR	3 (18.8)
Mastectomy + AD	1 (6.2)
Had received adjuvant therapy	
Chemotherapy	7 (43.80)
Radiation therapy	12 (75.0)
Endocrine therapy	8 (50.0)
Had recurrence	4 (25.0)

Note: Values are number (%) except where indicated otherwise.

Abbreviations: BCT, breast-conserving surgery; SN, sentinel node; PR, primary breast reconstruction; AD, axillary dissection.

“I was informed that some have more pain than others...” [Participant 7]

There were so many doctors...I encountered many doctors when receiving chemotherapy... they seemed more occupied with blood results and they like...so no...not much information [Participant 8]

We got some explanations, but I think in some cases they can be afraid to say too much, so it is up to each person to read, find out for themselves...but I did receive some information. [Participant 9]

At the Last Consultation After the Treatment Was Complete Did the Doctor Talk to You About Getting Back to Work?

Some women were working during treatment, and others started working when they finished the treatment. Some could not remember if the doctors had talked about getting back to work; 2 confirmed that was talked about.

“Yes, we talked about how I felt and how to proceed” [Participant 10]

“Yes we had a dialogue all the time. I went back to work, but am retired now.” [Participant 14]

“Yes we probably did...I cannot remember...but I did get the information I wanted.” [Participant 12]

Did the Doctor Talk About the Importance of Adherence with Regard to Endocrine Therapy?

Six participants had received anti-hormone treatment. Some said that the doctor emphasized the importance of adherence, and others could not remember if the doctor had mentioned it.

Yes, but it did not go well. I contacted the doctor and was encouraged to try 3 months more, but in the end it was horrible. I got depressed, developed anxiety, and had trouble sleeping, had pain in my joints. I contacted my doctor ...I told her I had to stop taking them and she understood, but said I could start with them again at any time. [Participant 7]

I am finished taking the tablets, but I took them all the years I should because I knew how important they were, but there were many side effects....yes especially mood swings and I was in such a bad mood. [Participant 13]

Do You Prepare for Your Annual Follow-Up? (Eg, Write Down Questions You Wanted to Ask the Doctor)

Most women did not prepare for the follow-up checks, but said that they had discussed what they wanted. Topics that were raised by the participants included concerns about feeling pain in the operated area, the risk of experiencing relapse, why they experienced pain all over their body, and the results from the mammography.

“Yes I think about what I want to ask. I experience pain at times, and I asked about the pain.” [Participant 10]

“Yes I do, I ask about why I experience pain in the operating area...what the risks for relapse are....why I ache all over my body.” [Participant 14]

“She (the doctor) was very informative, she took her time, yes it is often the case that when they (doctors) start talking about things, questions may arise.” [Participant 5]

How Important are These Annual Follow-Up for You?

All women perceived the follow-ups as important and reassuring. Most preferred follow-ups at the hospital instead with their general practitioner (GP), because they experienced that the hospital took the follow-ups more seriously.

The first 5 years I went to follow-ups at the hospital, but later follow-ups were with the GP. I received appointments for mammography every year, but neither the GP nor I knew who requisitioned it or who received the results. The GP finally found out that it was the hospital that had requisitioned the mammography and received the results. I would have preferred to have all my follow-ups at the hospital. Now I had my last follow-up at the hospital. [Participant 11]

“I think the follow-ups are very good, but I prefer having them at the hospital. I do not think the GP takes them seriously.” [Participant 6]

“I feel secure that any relapse will be detected early and it is good to have regular communication with the hospital.” [Participant 5]

I am happy I can continue to have my follow-ups at the hospital. After 5 years one is supposed to go to the GP, but my GP does not even know that I have had the operation. [Participant 13]

Results from the Patients' Assessment of the BCS-SC

The patients questioned what was meant by the time frame “now”. The time frame was therefore changed to “during the last week”. One woman thought there should be one item for “fear of recurrence”. However, the others thought that the item “feeling blue/worried/anxiety” covered fear of recurrence. The patients were asked which term should be used: “fatigue or tired/exhausted”. They all agreed that the term fatigue should be used. All of the patients considered the BCS-SC easy to understand and use. The final version of the BCS-SC is presented in Table 1.

Table 3 presents the BCS-SC scores for the individual women and the most persisting symptoms/burdens were fatigue and sleeping problems, followed by sexuality, concentration/memory. Four of the 16 women answered “all things considered, they did not feel good today”.

Women who had scored 4 or more on any of the BCS-SC items were asked if they had discussed this topic with the doctor during the follow-up consultation. Participant 5 scored had scored more than 5 on several symptoms/problems (fatigue, sleeping problems, and concentration/memory). When asked if she had mentioned these to the doctor at follow-up she answered:

No maybe my sleeping problems are due to my age. I don't know if my poor memory is due to my age or treatment...no I did not mention it...Yes I mentioned that I was tired...fatigue...because that has to do with the tablets...they take your energy away.... [Participant 5]

The patients were asked if they thought that the BCS-SC would be a helpful tool for the annuals follow-ups. All patients thought the BCS-SC was helpful and that it was wise to use it. Filling out the BCS-SC made them think and prepare for the follow-up. Some mentioned that the BCS-SC probably also was a good working tool for the doctor and made it easier for them as well.

“Yes.I definitely think it can be helpful before follow-ups...I because...yes ...the point about sexuality....I had not thought about it...but I could have asked ...” [Participant 7]

Absolutely wise – it's much easier...yes...such a form makes it easier...it's not easy to remember everything on a busy day...it's probably easier for the doctor also as a work tool... [Participant 13]

Table 3 The Breast Cancer Survivors Symptom Checklist Scores for the 16 Women

BCS-SC	0	1	2	3	4	5	6	7	8	9	10	Sum
Fatigue	2	3	2	1	0	2	4	1	1	0	0	8
Pain	8	1	1	3	1	1	1	0	0	0	0	3
Sleeping problems	4	2	0	2	1	3	2	1	1	0	1	8
Altered body image	4	3	2	3	2	0	0	0	0	1	1	2
Menopausal problems	6	2	2	4	0	1	0	0	0	0	1	2
Sexuality	8	2	2	0	0	0	1	1	0	1	1	4
Weight gain	8	2	1	2	0	2	0	1	0	0	0	3
Lymphedema	15	1	0	0	0	0	0	0	0	0	0	0
Concentration/memory	4	1	4	1	2	1	0	2	0	1	0	4
Worried/anxiety/depression	4	4	3	2	2	0	0	1	0	0	1	2
Social network	12	0	2	1	0	0	0	0	1	0	0	1
Work situation	11	0	2	0	0	2	1	0	0	0	0	3
Financial	12	1	0	1	0	0	1	0	0	0	1	2
Feeling today	5	4	2	0	1	0	1	2	0	0	1	4

Notes: No symptom/burden = 0 and worst imaginable = 10. Sum = the total number that scored at cut-off or above. Cut-off was set at 4 for pain and 5 for all the other items.

The final version of the BCS-SC after the patients had given their feedback was presented to 2 breast cancer surgeons for their feedback. Based on both patients' and surgeons' feedback, the BCS-SC was finalized.

Discussion

The Breast Cancer Survivors Symptom Checklist

We develop the BCS-SC assessment tool for breast cancer survivors for use as a guideline for survivors and all health care professionals conducting routine follow-ups. The final version of the checklist consists of a set of 13 symptoms/burdens, and one question. The patients are asked to indicate the extent to which they experience each symptom/burden on a scale from 0 (no symptom/burden) to 10 (worst imaginable). The time frame used was in the last week. The content of this checklist is based on a review of the literature, clinical experiences, an NGT process, feedback from breast cancer surgeons and patients regarding the usability and validity. In view of the rigorous development process, we believe that the checklist is a comprehensive assessment tool for symptoms/burdens that are common among breast cancer survivors and can aid efforts to optimize their follow-up.

Patients' Experience of Follow-Ups

Most of the patients believed that they had received good information, but not all were informed regarding possible side effects or late effects. This finding is similar to previous findings that breast cancer survivors often express unmet needs for information on the effects of cancer treatment, emotional distress, and lifestyle changes.¹²

When one considers the increase in the incidence of breast cancer, the age at time of diagnosis, and the decrease in mortality, the return to work issue is important. Thus, this should be a topic that is routinely addressed at follow-ups, and factors that could get in the way of return to work or ease it should be discussed. A systematic research and meta-analysis including studies from Europa and Asia found that the overall rate of return to work was 57%.²⁵ In the present study, some of the patients worked during their treatment, whereas others started to work after treatment was completed. However, few could remember if the doctor had talked about getting back to work at follow-ups.

The experience of the illness varied among the breast cancer survivors. Most said that they did not experience any problems. Thus, it was interesting to note that half of the survivors reported that they had 2 or more of the symptoms/burdens listed in the BCS-SC. This is consistent with previous research that shows cancer survivors may experience symptoms/burdens related to cancer and its treatments years after the treatment has been completed.^{6,26,27} There is evidence that indicates that the psychological needs of cancer survivors often go underdiagnosed during routine medical follow-up.²⁸

The most persisting symptoms/burdens found in the present study were fatigue and insomnia, followed by sexuality, concentration/memory. These are the same as found previously to be the most persisting symptoms/burdens experienced by survivors.^{8,26,29} However, although many of the survivors in the present study experienced symptoms/burdens, they did not discuss these with the doctors at follow-up.

The primary goal of follow-up after breast cancer treatment is to detect recurrences or second primary breast cancer and to monitor side effects related to treatment.² Concern for long-term QoL and psychological adjustment of cancer survivors has increased because improved treatments have resulted in a growing population of cancer survivors in Norway.¹ However, it appears that both the women and the doctors are mostly concerned regarding the results of mammography or other tests. Monitoring side effects is an important issue of the follow-up, but our experience is that when doctors ask patients if they want to discuss anything or how they are feeling, most patients say that they feel fine and have nothing to discuss. A reason for not addressing other issues could be that the participants were unaware that breast cancer follow-up care extends beyond surveillance for recurrence.

Adjuvant hormonal therapy is important in the treatment of receptor-positive breast cancer. However, non-adherence rate to hormonal treatment is estimated to be between 30% and 60%.^{30–32} In the present study, only 1 in 6 women said that the doctor had emphasized the importance of adherence. The BCS-SC lists the most prominent side effects of adjuvant hormonal treatment. Thus, we propose that the BCS-SC could contribute to remind the doctors to inquire about the adherence to endocrine therapy.

All the survivors in the present study perceived the annual follow-ups as important and reassuring. They preferred follow-ups at the hospital instead of with the GP because they experienced that the hospital took the follow-ups more seriously. This is similar to previous findings regarding patients' follow-up preference with cancer-related specialists.³³ In addition, it has been found that patients are more positive about nurse practitioner-led follow-up than GP-led-follow-up.³⁴ It appears that patients valued the expertise of specialists in hospital settings more than GPs.

Breast Cancer Survivors' Assessment of the BCS-SC

None of the survivors had prepared for their follow-up consultation, even though they all perceived them as important. However, when asked if the BCS-SC could be a helpful tool for the annual follow-ups, all answered yes. They argued that if they had received and filled in the checklist before their follow-up, they would be better prepared. Furthermore, the BCS-SC would insure that the symptoms/burdens they experienced would be discussed. They reported that the BCS-SC was brief and easy to fill out. Furthermore, some also commented that the BCS-SC would be a helpful tool for the doctors at follow-up.

Clinical Implications

There has been a paradigm change from reactive to predictive, preventive, and personalized medicine, which has been declared as an essential transformation of the overall health care approach to benefit the patient and society at large.³⁵ This implies that follow-ups should also be personalized. Thus, the BCS-SC may be considered a cost-effective tool to individualize follow-ups and provide tailored care to improve the patient's health outcome and QoL. The BCS-SC is simple and quick to administer. It supports subjective decision-making in resource-limited settings or primary care, and may improve outcomes. We propose that all breast cancer survivors should fill out the BCS-SC routinely before their follow-up at the hospital or with the GP. Including the patient's BCS-SC score in the follow-up routinely would help to elicit patient concerns and allow discussion of issues that could otherwise be missed.

Strengths and Limitations

The development of the BCS-SC was based on a literature review, clinical experience and patient input. Limitations of the literature review include the possibility of missing articles and errant evidence interpretation. The use of the qualitative analysis technique utilized may be prone to biases of subjective interpretation. In addition, there may have been a bias in the types of patients who agreed to participate, and the sample size for the study was small. Thus, this study should be viewed as a small-scale preliminary study. Future research with a larger sample is needed to better evaluate the feasibility and validity of the BCS-SC. In addition, it remains uncertain as to which scores on the BCS-SC (except pain) comprise the optimal cut-off to determine symptom severity for breast cancer survivors. Further research should explore the optimal cut-off for each BCS-SC item to determine symptom/burden severity. Future research could also investigate the doctors' evaluation of the utility of the BCS-SC.

Conclusion

The BCS-SC appears to be a promising brief screening tool for symptoms/burdens and could be incorporated into routine follow-ups for breast cancer survivors. This would help to elicit patient concerns and allow discussion of issues that could otherwise be missed. This can improve clinician-patient communication and symptom management, as well as provide the opportunity for multi-professional support and more personalized follow-up. This is supportive of the paradigm change from reactive medicine to predictive, preventive, and personalized medicine.

Abbreviations

BCS-SC, the Breast Cancer Survivors Symptom Assessment Checklist; ESAS, the Edmonton Symptom Assessment System; GP, general practitioner; NGT, nominal group technique; MDASI, the M.D. Anderson Symptom Inventory; SD, standard deviation.

Data Sharing Statement

The data (interview transcripts) reported in this paper are not publicly available, because the participants did not consent to public data sharing. The quantitative data are available upon reasonable request from the corresponding author after permission from the Hospital's Privacy Officer has been obtained.

Ethical Approval and Informed Consent

This study was conducted in accordance with the Declaration of Helsinki and approved by The Regional Committee for Medical and Health Research Ethics South East Norway (REC 2014/730) and the Data Inspectorate, Oslo University Hospital. All participants received oral information on the purpose of the study. They were informed that the interview would be taped and that all data would be de-identified. All participants were required to review the consent form before signing. All participants gave their written informed consent.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of the data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of accountable for all aspects of the work.

Disclosure

The authors declare that they have no conflicts of interest.

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