



## Let's talk about sex! Why should healthcare professionals address sexual distress in breast cancer patients and survivors?

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### ABSTRACT

**Purpose:** Sexual distress impacts the quality of life (QoL) of breast cancer patients but is often overlooked in standard care pathways. This study evaluated the prevalence and factors of sexual distress among Dutch breast cancer patients, compared them to the general population, and explored how sexual distress is discussed in clinical settings from the perspectives of patients and healthcare professionals (HCPs).

**Methods:** Questionnaires containing the Female Sexual Distress Scale (FSDS) and demographic variables were distributed to women with breast cancer. The effect of breast cancer on sexual distress was assessed with a Mann-Whitney *U* test. Multivariable linear regression was used to analyze variables associated with FSDS. The Sexuality Attitudes and Beliefs Survey (SABS) was sent to HCPs.

**Results:** Breast cancer patients reported significantly higher sexual distress compared to a Dutch non-breast cancer cohort, respectively 16.38 (SD 11.81) and 23.35 (SD 11.39). Factors associated with higher sexual distress were psychological comorbidities, the body image scale, and being diagnosed >10 years ago. Sexual distress was not discussed as often as patients needed. Barriers to addressing sexual distress were time constraints, HCPs' confidence in their ability to address sexual distress, and uncertainty about who is responsible for initiation.

**Conclusions:** Breast cancer patients showed significantly higher sexual distress compared to the Dutch population. However, it was not frequently addressed in the consultation room. While some barriers have been identified, this study highlights the importance of further exploring obstacles to integrating discussions about sexual distress into routine care to improve QoL of breast cancer patients.

### 1. Introduction

Breast cancer patients face difficult challenges throughout and after their trajectory of disease which may negatively impact their overall quality of life (QoL) (Dennerstein et al., 2008; Michael et al., 2000; Stein et al., 2008). Sexual distress refers to different negative emotional responses (such as worries, frustration, or feelings of inadequacy) that people experience associated with their sexuality, sexual health, and sexual problems and has a significant impact on a person's QoL (Dennerstein et al., 2008; Hayes, 2008).

Sexual distress is known to be negatively impacted by breast cancer,

causing a decreased QoL (Ljungman et al., 2018; Marsh et al., 2020; Mokhatri-Hesari and Montazeri, 2020). Currently, it is estimated that most of the breast cancer survivors report sexual distress at some point after their diagnosis (Ljungman et al., 2018; Marsh et al., 2020; Qi et al., 2021). However, most literature predominantly assesses sexual problems rather than distress. While in literature the terms sexual problems and sexual distress are often used interchangeably, the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria, established a clear distinction between them (*The Diagnostic and Statistical, 2013 Manual of mental Disorders, Fifth Edition, Text Revision(DSM-5-TR)*, 2013). Sexual problems involve difficulties in the sexual response, but some

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individuals report these issues without significant sexual distress (Agustus et al., 2017; Dennerstein et al., 2008; Graham et al., 2020; Hatzichristou et al., 2016; Hayes, 2008). Furthermore, sexual problems and sexual distress are associated with different risk factors, emphasizing the importance of examining both domains (Christensen et al., 2011; Hayes, 2008; Hayes et al., 2007, 2008).

Moreover, research in different disease settings and countries has shown that discussing issues of sexual distress is not frequently embedded in the common care pathways for patients even though patients express the need for such information (Dyer and das Nair, 2013; Ussher et al., 2013). Studies across disciplines revealed that most healthcare professionals (HCPs) agreed that addressing changes in sexuality due to diseases or their treatment is an essential part of care. However, only a minority of them felt comfortable discussing and addressing sexual distress (Abdolrasulnia et al., 2010; Aguiar Frias et al., 2021; Dyer and das Nair, 2013; Fitch et al., 2013; Haboubi and Lincoln, 2003; Reese et al., 2017). This leads to an unmet need for addressing sexual concerns among breast cancer patients and survivors (Hill et al., 2011).

Unfortunately, most of the literature included patients from different countries with various types of cancer. Findings cannot be generalized to other populations as sexual distress is complex and is influenced by a range of factors such as social and cultural factors, relationship dynamics, sexual problems, and individual beliefs and attitudes towards sex and sexuality (De Graaf and Wijzen, 2017). Little is known about the prevalence of sexual distress among (Dutch) breast cancer patients, the occurrence of discussions on sexual distress in the consultation room, and the needs of patients and HCPs to address this.

Therefore, this study aimed to assess the prevalence of sexual distress in Dutch breast cancer patients and survivors by comparing the sexual distress of breast cancer patients to a sample of the non-breast cancer Dutch population (Anouk S. Huberts et al., 2023). Additionally, this study aimed to identify factors associated with sexual distress in patients with breast cancer and their lives thereafter. Lastly, this study aimed to explore the occurrence of discussions on sexual distress in the clinical setting and who is responsible for initiating these discussions, examining perspectives from both patients and HCPs. The findings of this study will provide crucial insights that could guide enhancements in healthcare protocols, ensuring that sexual distress is effectively addressed in the care of breast cancer patients, thereby improving their overall QoL in the future.

## 2. Methods

### 2.1. Questionnaires patients and HCPs

For patients, we combined the Female Sexual Distress Scale (FSDS), the Body Image Scale (BIS), and additional demographic questions in one questionnaire. To assess the impact of breast cancer on sexual distress the FSDS was used. The FSDS is a 12-item scale; each question is scored on a 4-point Likert scale with higher scores indicating a higher level of sexual distress (Derogatis et al., 2002). In a Dutch sample of females with and without sexual distress, the test-retest coefficients of all questions showed a Spearman's correlation between 0.72 and 0.97 and the internal consistency was high (Cronbach's  $\alpha$  of 0.93) (ter Kuile et al., 2006). The maximum score is 48 with a validated cut-off score of  $\geq 15$  which indicates the presence of sexually related personal distress.

The Body Image Scale (BIS) was used to assess body image in cancer patients (Hopwood et al., 2001). The BIS contains ten questions answered on a Likert scale, with higher scores indicating a higher body image concern. A score  $>10$  is a significant predictor of psychological distress (Chopra et al., 2021). In a Dutch sample of breast cancer patients, the test-retest coefficients of all questions showed a Spearman's correlation between 0.63 and 0.92 and the internal consistency of the BIS was high (Cronbach's  $\alpha$  of 0.91) (van Verschuer et al., 2015).

Further demographics such as gender (male, female non-binary,

other), age, educational level, relationship status (single, in a relationship, married/living together), the presence of children (having children or not), and psychological comorbidities were included in the questionnaire. Respondents' self-reported highest education levels were categorized as low (primary school and secondary school), medium (Vocational training, in Dutch: Middelbaar Beroepsopleiding), and high (Applied sciences or university bachelor's degree, master's degree or Doctorate). The presence of children was determined by the question, "Do you have children?". Psychological comorbidities were assessed through two questions: "Do you have other diseases, and do you use medication for depression?". If psychological comorbidity or the use of medication for depression was reported, it was recorded as "yes".

The study included the following disease-related variables; type of breast surgery (breast-conserving surgery, mastectomy, reconstruction, no surgery), metastasis (yes/no), time since diagnosis, active treatment (yes/no), hormonal therapy (yes/no), and chemotherapy (yes/no). Mastectomy and reconstruction were mutually exclusive in this study, as patients with mastectomy without a reconstruction were labeled as mastectomy, and patients who underwent mastectomy and reconstruction were labeled as reconstruction and were not included in the mastectomy group. The variable metastasis was included to provide insights into the severity of the disease, recognizing that patients might not be able to accurately report their exact tumor stage. Active treatment was defined as any therapeutic intervention for breast cancer at present, including hormonal treatment. Hormonal therapy and chemotherapy were included as they are both known to impact sexual function through their side effects such as vaginal dryness, atrophy, fatigue, decreased sexual desire, and premature menopause (Frechette et al., 2013; Kedde et al., 2013; Ljungman et al., 2018; Partridge et al., 2001; Zhou et al., 2015). All variables were self-reported.

To explore the occurrence of discussions on sexual distress in clinical settings, as well as patients' perspectives on their acceptability and comfort levels, the questionnaire included three questions and six statements on this topic, with one question specifically addressing who patients believed should initiate these discussions (Supplementary File 1).

The Sexuality Attitudes and Beliefs Survey (SABS), along with additional statements and demographic questions, was used to assess the perspective of the HCPs (Supplementary File 2) (Aguiar Frias et al., 2021; Reynolds and Magnan, 2005). The SABS consists of 12 items presented in a Likert-type format, with reversed items for 7 of the 12 items. Total SABS scores range from 6 to 72 with higher scores indicating more barriers to incorporating sexual distress into practice. As the SABS is not validated in Dutch, the English version was used. In an American sample of nurses, the test-retest coefficients of the overall scale showed a Spearman's correlation of 0.85 and the internal consistency of the BIS was high (Cronbach's  $\alpha$  of 0.75–0.82) (Reynolds and Magnan, 2005).

### 2.2. Distribution and population of breast cancer patients and HCPs

We distributed the FSDS, BIS, the demographic and disease-specific questions, and the additional questions concerning sexual distress in the clinical setting via "Limesurvey", an online survey tool. The questionnaire was disseminated through multiple channels. The open link was distributed via a Dutch breast cancer association (B-Force) and the website and social media of our local patient panel, Borst Vooruit. Patients were included if they reported a history of breast cancer, were  $\geq 18$  years old, were proficient in Dutch and could access the questionnaire on a digital device.

In addition to patients, HCPs were invited to participate via an e-mail with an open link. Invitations were sent to national Dutch breast cancer workgroups, comprising HCPs specializing in breast cancer care, such as medical specialists and specialized nurses. HCPs were included if they worked with breast cancer patients, were active members of the Dutch breast cancer workgroups, were proficient in Dutch and English, and

could access the questionnaire on a digital device.

### 2.3. Distribution and population of the non-breast cancer Dutch population

The collection of data and results of the reference group, a sample of the non-breast cancer Dutch population, have been published before (Huberts et al., 2023). This data was used as the reference group.

### 2.4. Ethical considerations

Informed consent was obtained after notification of study information. Participants were not compensated and had the opportunity to withdraw at any moment. Data was collected between 17-05-2022 and 08-08-2022. Ethical approval for the study was obtained from the METC Erasmus Medical Centre Rotterdam Medical Ethics Review Committee (MEC-2022-154).

### 2.5. Statistical analyses

Data are presented as counts and percentages for categorical variables, means and standard deviations (SD) for continuous normally distributed variables, and medians and interquartile ranges (IQR) for non-normally distributed variables. To assess the effect of the diagnosis and/or treatment of breast cancer on sexual distress we matched the non-breast cancer reference group to the breast cancer respondents 1:1 on age and gender. Subsequently, we conducted a Mann-Whitney *U* test to compare the sexual distress of breast cancer patients and survivors with the non-breast cancer reference group.

Multivariable linear regression was used to analyze variables associated with FSDS within the breast cancer population. Based on the literature we included age, educational level, relationship status, having children, psychological comorbidities, type of breast surgery, metastases, active treatment, time since diagnosis, hormonal therapy, and chemotherapy. To test the assumptions of a regression, the residuals were tested on normality and homoscedasticity with residual plots. The variables were tested for multicollinearity, with all factors showing low probability for multicollinearity (VIF <5). A positive  $\beta$  coefficient indicates a higher level of associated sexual distress.

For all statistical analyses, two-sided *p*-values <0.05 were considered statistically significant. Moreover, confidence intervals were reported for the multivariable linear regression to reflect the degree of variability.

The questions regarding discussing sexual distress in the consultation room are presented in Likert scales for both patients and HCPs. The SABS is presented as a mean with standard deviation and per question in percentages. Statistical analysis was performed using R statistical software (version 4.4.2) (Team, 2022).

## 3. Results

### 3.1. Demographic variables

The FSDS was completed by 319 respondents. Male (*n* = 4) and non-binary (*n* = 1) respondents were excluded. Fifty-seven percent of the respondents (*n* = 178) did still undergo treatment for their breast cancer at the time of completing the questionnaire. Of the patients without surgery, 96% (*n* = 24) reported metastasis. Further demographic variables of the patients are presented in Table 1.

The SABS was completed by 99 HCPs, of which 81.8% identified as female, and most were employed in the surgery department (43.4%). Further demographic variables of the HCPs are presented in Table 2.

#### 3.1.1. Association between breast cancer and sexual distress

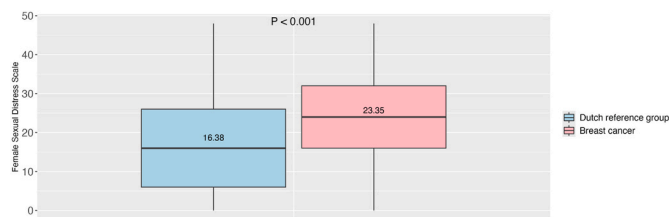
Two hundred forty-seven patients had an FSDS score above the threshold of  $\geq 15$  (78.7%). After matching the patient respondents to the

**Table 1**  
Demographic variables of the breast cancer patients.

	Overall (N = 314) N (%), mean (SD) or median (IQR)
<b>Age, Mean (SD)</b>	52.3 (8.99)
<b>Education</b>	69 (22.0%)
Low education level	94 (29.9%)
Middle education level	150 (47.8%)
High education level	1 (0.3%)
Missing	
<b>Relationship status</b>	40 (12.7%)
Single	20 (6.4%)
In a relationship	38 (12.1%)
Living together	216 (68.8%)
Married/Registered partnership	
<b>Children</b>	261 (83.1%)
<b>Psychological comorbidities</b>	40 (12.7%)
<b>Active treatment</b>	178 (56.7%)
<b>Type of surgery</b>	25 (8.0%)
No surgery	100 (31.8%)
Mastectomy	122 (38.9%)
Breast-conserving surgery	67 (21.3%)
Reconstruction	
<b>Metastasis</b>	70 (22.3%)
<b>Hormonal therapy</b>	232 (73.9%)
<b>Chemotherapy</b>	234 (74.5%)
<b>Time since diagnosis</b>	94 (29.9%)
0–2 years ago	84 (26.8%)
2–5 years ago	90 (28.7%)
5–10 years ago	46 (14.6%)
>10 years ago	
<b>FSDS score, Median [Min, Max]</b>	24.0 [0, 48.0]

**Table 2**  
Demographic variables of the healthcare professionals.

	Overall (N = 99)
<b>Age</b>	
Mean (SD)	47.9 (9.09)
Median [Min, Max]	48.0 [30.0, 67.0]
<b>Gender</b>	18 (18.2%)
Male	81 (81.8%)
Female	
<b>Occupation</b>	54 (54.5%)
Medical specialist	3 (3.0%)
Medical specialist in training	40 (40.4%)
Nurse (specialist)	2 (2.0%)
Physician assistant	
<b>Department</b>	43 (43.4%)
Surgery	34 (34.3%)
Oncology	14 (14.1%)
Radiotherapy	5 (5.1%)
Internal Medicine	2 (2.0%)
Genetics	1 (1.0%)
Plastic Surgery	
<b>Type of hospital</b>	80 (80.8%)
General	19 (19.2%)
Academic	



**Fig. 1.** Boxplot of Female Sexual Distress Scale of the Dutch reference group and cohort with breast cancer. Presented in boxplot: mean, interquartile range, and range.

Dutch reference cohort, the mean FSDS of respondents with a history of breast cancer was significantly higher ( $p < 0.001$ ), respectively 16.38 (SD 11.81) and 23.35 (SD 11.39) (Fig. 1).

Factors associated with significantly higher sexual distress, after correction for demographic- and disease-specific variables, were psychological comorbidities ( $\beta$ : 3.97, 95% CI: 0.23; 7.72), the body image scale ( $\beta$ : 0.68, 95% CI: 0.53; 0.83) and being diagnosed >10 years ago ( $\beta$ : 5.82, 95% CI: 1.40; 10.25) (Table 3). Not having undergone surgery was associated with lower FSDS scores, meaning lower sexual distress, compared to patients undergoing breast-conserving surgery.

### 3.2. Sexual distress in the clinical setting from the patients' perspective

Thirty-eight patients only completed the FSDS and were therefore excluded from the analyses for the clinical setting. Ninety-three patient respondents (29.6%) discussed sexual distress in the consultation room with their HCP, of which 53.7% ( $n = 50$ ) discussed it with their (specialized) nurse in the hospital. If sexual distress was discussed, most patients started the conversation themselves (Supplementary File 3: Table 1).

Sixty-four percent of the patients did at least partly agree with the statement that discussing sexual distress in the consultation room is valuable (Q1; 42.8% and 21%). Forty-five percent of the patients did at least partly agree to start the conversation themselves (Q4; 22.8% and 21.7%) and 47% did at least partly agree with the statement that their HCP must start the conversation (Q5; 26.1% and 21.0%). Sixty percent of the patients expected information or guidance on sexual distress whenever they experienced an increase in sexual distress (Q6; 31.2% and 28.6%) (Table 4 and Supplementary File 3, Fig. 1).

### 3.3. Sexual distress in the clinical setting from the HCPs' perspective

Of the HCPs, 51% (partly) agreed that discussing sexuality is essential to a patient's health outcomes. Ninety percent of the HCPs (partly or

**Table 3**  
Multivariable regression of the Female Sexual Distress Scale.

Adjusted R2 = 0.306	Beta	95% CI
<b>Age</b>	-0.05	-0.20; 0.10
<b>Education</b>	0.75	-2.76; 4.25
Low education level	RF	RF
Middle education level	-1.10	-3.94; 1.74
High education level		
<b>Relationship status</b>	RF	RF
Single	1.78	-4.05; 7.61
In a relationship	2.31	-2.60; 7.22
Living together	3.23	-0.57; 7.03
Married/Registered partnership		
<b>Children</b>	2.55	-0.77; 5.87
<b>Psychological comorbidities</b>	3.97	<b>0.23; 7.72*</b>
<b>Active treatment</b>	1.24	-1.93; 4.40
<b>Type of surgery</b>	-9.53	<b>-16.37; -1.86*</b>
No surgery	-1.59	-4.45; 1.27
Mastectomy	RF	RF
Breast-conserving surgery	-1.75	-5.08; 1.58
Reconstruction		
<b>Metastasis</b>	-2.25	-6.36; 1.86
<b>Hormonal therapy</b>	0.24	-2.67; 3.15
<b>Chemotherapy</b>	1.64	-1.24; 4.52
<b>Time since diagnosis</b>	RF	RF
0-2 years ago	2.06	-1.30; 5.42
2-5 years ago	3.01	-0.44; 6.46
5-10 years ago	5.82	<b>1.40; 10.25*</b>
>10 years ago		
<b>Body Image Scale</b>	0.68	<b>0.53; 0.83*</b>

Note: common side effects of hormonal therapy include vaginal dryness, atrophy, decreased sexual desire, and premature menopause (Frechette et al., 2013). Common side effects of chemotherapy include nausea, fatigue, premature menopause, and weight gain (Partridge et al., 2001). Bold indicates CIs are entirely above or below 0.

**Table 4**  
Answers of patients on statements regarding sexual distress in the consultation room.

	Strongly Agree % (n)	Partly Agree % (n)	Neutral % (n)	Partly disagree % (n)	Strongly disagree % (n)	No opinion % (n)
<b>Q1</b>	42.8% (118)	21% (58)	20.3% (56)	4.7% (13)	3.3% (9)	8.0% (22)
<b>Q2</b>	71.7% (98)	16.3% (45)	6.2% (17)	2.9% (8)	2.2% (6)	0.7% (2)
<b>Q3</b>	10.1% (28)	16.7% (46)	26.8% (74)	17.0% (47)	26.8% (74)	2.5% (7)
<b>Q4</b>	22.8% (63)	21.7% (60)	19.6% (54)	14.1% (39)	17.0% (47)	4.7% (13)
<b>Q5</b>	26.1% (72)	21.0% (58)	18.8% (52)	12.3% (34)	14.1% (39)	7.6% (21)
<b>Q6</b>	31.2% (86)	28.6% (79)	15.2% (42)	9.1% (25)	10.1% (28)	5.8% (16)

Percentages of the answers given by responders are presented per question.

Q1 = I find discussing sexual distress in the consultation room valuable.

Q2 = I know that my disease and treatment may influence sexual distress.

Q3 = Sexual distress is a private topic.

Q4 = I feel comfortable to start the conversation about sexual distress in the consultation room myself.

Q5 = I expect the nurse or doctor to start the conversation about sexual distress.

Q6 = If I experience increased sexual distress, I would like to receive information about and/or guidance on this.

strongly) disagreed with the statement "Sexuality is too private to discuss with patients" (Supplementary File 3: Table 2). Fifty-five HCPs (55.6%) discussed sexual distress with patients and 62.6% ( $n = 62$ ) thought that starting the conversation is a shared responsibility between the patient and the care team. Eighty-three HCPs (83.8%) thought that patient-reported outcome measures (PROMs) about sexual distress in regular care would help to discuss sexual distress (Supplementary File 3: Table 3).

## 4. Discussion

This study aimed to evaluate sexual distress among Dutch breast cancer patients, compare it with the general population, identify factors associated with sexual distress, and explore how it is discussed in clinical settings from the perspectives of patients and HCPs. The results demonstrated a significant increase in sexual distress among breast cancer patients compared to the general Dutch population without breast cancer. Factors associated with higher sexual distress were psychological comorbidities, body image concerns, and being diagnosed >10 years ago. Most breast cancer patients (88%) acknowledged the impact of breast cancer on sexual distress and more than 60% of the patients expressed the need to discuss sexual distress. Moreover, the results underscored the insufficient frequency of discussions on sexual distress, highlighting the crucial need to address this issue in the consultation room. Our findings are consistent with earlier research showing that breast cancer and its corresponding treatment can lead to sexual concerns and problems (Hayes et al., 2008; Ljungman et al., 2018; Marsh et al., 2020; Qi et al., 2021; Vrancken Peeters et al., 2024).

Notably, our study did not find an association between demographic factors, such as age, gender, and educational level, that are known to influence sexual distress in healthy populations (Dennerstein et al., 2008; Graham et al., 2020; Hayes et al., 2008; Anouk S. Huberts et al., 2023; Stein et al., 2008). The psychological impact of the disease itself may act as a moderator for these demographic factors. It is known that psychological well-being is an important factor for sexual distress in healthy populations and women with breast cancer (Dennerstein et al., 2008; A S Huberts et al., 2023; Stein et al., 2008). Moreover, in women with urological cancers the distress of the diagnoses and reduced body image, which is a psychological construct that captures people's perception of emotions and attitudes toward their bodies, are also

known to impact sexual distress (Hopwood et al., 2001; Vencill et al., 2022). In our study reduced body image was also associated with more sexual distress. Breast cancer often alters body image due to surgery, chemotherapy-related hair loss, and loss of breast sensation (Mokhatri-Hesari and Montazeri, 2020; Stein et al., 2008). These changes can impact how patients perceive intimate communication and disclosure to their partners hence impacting psychological well-being and sexual distress (Marsh et al., 2020; Reese et al., 2016). This is supported by a study in a healthy population which reported a significant association between the inability to express sexual needs and sexual distress (Hayes et al., 2008).

Our study did not find an association between chemotherapy, endocrine therapy, and sexual distress, in contrast to other research (Ljungman et al., 2018; Marsh et al., 2020). The inclusion of both actively treated patients and survivors may explain this absence. Forty-three percent of the patients did not undergo active treatment when questioned, potentially minimizing side effects. However, it could also be explained by the fact that most studies predominantly focused on sexual problems, which are often used interchangeably in literature with sexual distress. Women could adapt to sexual side effects of the treatment such as vaginal dryness, atrophy, and decreased sexual desire. For example, in a population of cervical cancer survivors, it was shown that sexual pain worry mediated the association between vaginal sexual symptoms and sexual distress (Bakker et al., 2017). Moreover, some studies stated that the use of endocrine therapy did not worsen sexual distress even though it increases vaginal symptoms (Frechette et al., 2013; Rosenberg et al., 2014).

Interestingly, although most HCPs reported that they discussed sexual distress, only 30% of patients recalled such conversations. Moreover, the acknowledgment among HCPs regarding the importance of addressing sexual distress for overall health outcomes contrasted with a failure to effectively meet patients' needs. This incongruity might be attributed to several factors, including potential selection bias among HCPs. HCPs with an interest in this topic could be more likely to respond to the invitation. Furthermore, the nationwide nature of the questionnaire introduced the possibility that the surveyed patients received treatment from different healthcare providers. Last, it could be that sexual distress was discussed at an inopportune time, such as immediately following a diagnosis when patients are coping with intense emotions, which can make it challenging for the patient to remember this. Hence, emphasizing the importance of discussing sexual distress at multiple moments during the disease trajectory.

#### 4.1. Clinical implications

Patients' responses were divided almost evenly between feeling comfortable discussing sexual distress during consultations and expecting HCPs to initiate the conversation. Clinicians are faced with the challenge of navigating this diversity. PROMs focusing on sexual distress before consultations could be instrumental in this process by helping to identify patients requiring additional guidance and discussions on this topic (Bober et al., 2016; Hungr et al., 2017). Moreover, it is crucial to establish a supportive and open environment where patients can freely express their concerns. Clinicians should actively encourage discussions about sexual issues and provide personalized information and support tailored to each patient's needs, such as consultations with a sexologist.

#### 4.2. Strengths and limitations

One of the major strengths of this study was the inclusion of perspectives of both HCPs and patients. By doing so, this study provided a holistic understanding of the needs, and potential facilitators and barriers, of both groups. Another important strength of this study was the focus on sexual distress rather than sexual problems, providing valuable insights into the broader emotional and psychological impacts that extend beyond clinical sexual dysfunction. Moreover, this study

included both women currently undergoing treatment and those who had completed treatment for breast cancer, whereas most studies predominantly focus on sexual problems during the active treatment phase.

Nonetheless, a few limitations should be noted. The use of an open-link questionnaire may introduce bias, as respondents with a higher interest in the topic might be more likely to participate. However, this approach allowed for nationwide participation, enhancing the generalizability of the results. Additionally, it did not assess whether patients suffered from sexual problems, which can be associated with distress. It was decided not to do so, as this may reduce the respondent numbers due to the sensitive topic. Moreover, sexual problems do not always correlate with sexual distress (Agustus et al., 2017; Dennerstein et al., 2008; Graham et al., 2020; Hatzichristou et al., 2016; Hayes, 2008). Last, only standardized questionnaires were used. While the researchers engaged in discussions with the patient organizations to ensure alignment with patients' experiences, a more nuanced understanding of patient's needs should be obtained through interviews or focus groups.

#### 4.3. Future research

The results of the SABS and extra questions revealed some possible barriers, such as time constraints, HCPs' confidence in their ability to address sexual distress, and uncertainty about who is responsible for initiating the conversation, hindering the incorporation of sexual distress discussion in clinical practice (Marsh et al., 2020; Reese et al., 2017; Saunamäki et al., 2010). These barriers need further exploration. Moreover, patients and HCPs were not conclusive about who should take the lead in initiating conversations on this topic. Conducting additional qualitative research could provide valuable insights into the preferences and perceptions of both patients and HCPs regarding the initiation of discussions on sexual distress.

Additionally, eighty-three percent of the HCPs in this study supported PROMs as a potential solution to bridge the gap between practice and patient's needs. This is strengthened by existing literature on the potential of PROs to facilitate conversations on QoL (Bober et al., 2016; Hungr et al., 2017). While the application of one or more simple questions may help break the taboo surrounding this topic, the effective use of PROs in addressing sexual distress necessitates further exploration (Galina et al., 2004; Kotronoulas et al., 2014; Reese et al., 2017).

Further research should also focus on the possible interplay between the psychological burden of the disease and sexual distress. While most side effects affecting sexual problems are known, little is known about the effect of breast cancer on sexual distress. This knowledge gap can also act as a significant barrier for HCPs in addressing sexual distress (Reese et al., 2017).

## 5. Conclusion

Breast cancer patients showed significantly higher sexual distress compared to the Dutch population. Factors associated with higher sexual distress were psychological comorbidities, the Body Image Scale, and being diagnosed >10 years ago. The majority of both the patients and HCPs thought it was important to discuss sexual distress to improve health outcomes, but HCPs did not discuss concerns as often as patients needed. Barriers to discussing sexual distress were time availability, HCP's confidence in their ability to address sexual distress, and uncertainty about who is responsible for the initiation of the conversation. Further research should explore these and other barriers to incorporate the discussion of sexual distress in daily care to improve the QoL of breast cancer patients.

#### CRediT authorship contribution statement

**Anouk S. Huberts:** Writing – review & editing, Writing – original draft, Visualization, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Noëlle J.M.C.**

**Vrancken Peeters:** Writing – review & editing, Visualization, Software, Formal analysis. **Hester Pastoor:** Writing – review & editing, Methodology, Conceptualization. **Cristina Guerrero Paez:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Linetta B. Koppert:** Writing – review & editing, Supervision, Methodology, Conceptualization.

## Declaration of competing interest

No conflicts of interest.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ejon.2024.102606>.

## References

- Abdolrasulnia, M., Shewchuk, R.M., Roepke, N., Granstaff, U.S., Dean, J., Foster, J.A., Goldstein, A.T., Casebeer, L., 2010. Management of female sexual problems: perceived barriers, practice patterns, and confidence among primary care physicians and gynecologists. *J. Sex. Med.* 7, 2499–2508.
- Aguarí, F., Soto-Fernández, I., Mota de Sousa, L.M., Gómez-Cantarino, S., Ferreira Barros, M.D.L., Bocos-Reglero, M.J., Aaberg, V., Caldeira, E., Sim-Sim, M., 2021. Sexuality attitudes and beliefs survey (SABS): Validation of the instrument for the Spanish nursing Students. *Healthc* 9.
- Agustus, P., Munivenkatappa, M., Prasad, P., 2017. Sexual functioning, beliefs about sexual functioning and quality of life of women with Infertility problems. *J. Hum. Reprod. Sci.* 10, 213–220.
- Bakker, R.M., Kenter, G.G., Creutzberg, C.L., Stiggelbout, A.M., Derks, M., Mingelen, W., Kroon, C.D., Vermeer, W.M., Ter Kuile, M.M., 2017. Sexual distress and associated factors among cervical cancer survivors: a cross-sectional multicenter observational study. *Psycho Oncol.* 26, 1470–1477.
- Bober, S.L., Reese, J.B., Barbera, L., Bradford, A., Carpenter, K.M., Goldfarb, S., Carter, J., 2016. How to ask and what to do: a guide for clinical inquiry and intervention regarding female sexual health after cancer. *Curr. Opin. Support. Palliat. Care* 10, 44–54.
- Chopra, D., De La Garza, R., Lacourt, T.E., 2021. Clinical relevance of a Body Image Scale cut point of 10 as an indicator of psychological distress in cancer patients: results from a psychiatric oncology clinic. *Support. Care Cancer* 29, 231–237.
- Christensen, B.S., Grønbaek, M., Osler, M., Pedersen, B.V., Graugaard, C., Frisch, M., 2011. Sexual dysfunctions and difficulties in Denmark: prevalence and associated Sociodemographic factors. *Arch. Sex. Beyond Behav.* 40, 121–132. <https://doi.org/10.1007/s10508-010-9599-y>.
- De Graaf, H., Wijzen, C., 2017. *Seksuele Gezondheid in Nederland 2017*. Uitgeverij Eburon.
- Dennerstein, L., Guthrie, J.R., Hayes, R.D., DeRogatis, L.R., Lehert, P., 2008. Sexual function, dysfunction, and sexual distress in a prospective, population-based sample of mid-aged, Australian-born women. *J. Sex. Med.* 5, 2291–2299.
- Derogatis, L.R., Rosen, R., Leiblum, S., Burnett, A., Heiman, J., 2002. The female sexual distress scale (FSDS): Initial validation of a standardized scale for Assessment of sexually related personal distress in women. *J. Sex Marital Ther.* 28, 317–330. <https://doi.org/10.1080/00926230290001448>.
- Dyer, K., das Nair, R., 2013. Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom. *J. Sex. Med.* 10, 2658–2670.
- Fitch, M.I., Beaudoin, G., Johnson, B., 2013. Challenges having conversations about sexuality in ambulatory settings: part II—health care provider perspectives. *Can. Oncol. Nurs.* 3, 182–196.
- Frechette, D., Paquet, L., Verma, S., Clemons, M., Wheatley-Price, P., Gertler, S.Z., Song, X., Graham, N., Dent, S., 2013. The impact of endocrine therapy on sexual dysfunction in postmenopausal women with early stage breast cancer: encouraging results from a prospective study. *Breast Cancer Res. Treat.* 141, 111–117.
- Galina, V., Laura, B., Adam, B.S., Paul, M.B., Pamela, L., Julia, M.B., Peter, J.S., 2004. Measuring quality of life in routine oncology practice improves communication and patient well-being: a Randomized controlled Trial. *J. Clin. Oncol.* 22, 714–724. <https://doi.org/10.1200/jco.2004.06.078>.
- Graham, C.A., Štulhofer, A., Lange, T., Hald, G.M., Carvalheira, A.A., Enzlin, P., Træen, B., 2020. Prevalence and predictors of sexual difficulties and associated distress among partnered, sexually active older women in Norway, Denmark, Belgium, and Portugal. *Arch. Sex. Behav.* 49, 2951–2961.
- Haboubi, N.H., Lincoln, N., 2003. Views of health professionals on discussing sexual issues with patients. *Disabil. Rehabil.* 25, 291–296.
- Hatzichristou, D., Kirana, P.S., Banner, L., Althof, S.E., Lonnee-Hoffmann, R.A., Dennerstein, L., Rosen, R.C., 2016. Diagnosing sexual dysfunction in men and women: sexual history taking and the Role of symptom scales and questionnaires. *J. Sex. Med.* 13, 1166–1182.
- Hayes, R.D., 2008. Assessing female sexual dysfunction in epidemiological studies: why is it necessary to measure both low sexual function and sexually-related distress? *Sex. Health* 5, 215–218. <https://doi.org/10.1071/SH08016>.
- Hayes, R.D., Dennerstein, L., Bennett, C.M., Koochaki, P.E., Leiblum, S.R., Graziottin, A., 2007. Relationship between hypoactive sexual desire disorder and aging. *Fertil. Steril.* 87, 107–112. <https://doi.org/10.1016/j.fertnstert.2006.05.071>.
- Hayes, R.D., Dennerstein, L., Bennett, C.M., Sidat, M., Gurrin, L.C., Fairley, C.K., 2008. Risk factors for female sexual dysfunction in the general population: exploring factors associated with low sexual function and sexual distress. *J. Sex. Med.* 5, 1681–1693. <https://doi.org/10.1111/j.1743-6109.2008.00838.x>.
- Hill, E.K., Sandbo, S., Abramo, S., Makelarski, J., Wroblewski, K., Wenrich, E.R., McCoy, S., Temkin, S.M., Yamada, S.D., Lindau, S.T., 2011. Assessing gynecologic and breast cancer survivors' sexual health care needs. *Cancer* 117, 2643–2651.
- Hopwood, P., Fletcher, L., Lee, A., Al Ghazal, S., 2001. A body image scale for use with cancer patients. *Eur. J. Cancer* 37, 189–197.
- Huberts, A.S., Clarijs, M.E., Pastoor, H., van Rosmalen, M., Koppert, L.B., 2023. Sexual well-being in patients with early-stage breast cancer at 1- and 2-year follow-up. *J. Sex. Med.* 20, 507–514.
- Huberts, A., Anouk, S., Peeters, N.J.M.C.V., Kaplan, Z.L.R., van Linschoten, R.C.A., Pastoor, H., van der Woude, C.J., Koppert, L.B., 2023. Dutch normative data of the sexual distress scale and the body image scale. *Qual. Life Res.* 32(10), 2829–2837. doi: 10.1007/s11136-023-03434-w.
- Hungr, C., Sanchez-Varela, V., Bober, S.L., 2017. Self-image and sexuality issues among young women with breast cancer: Practical Recommendations. *Rev. Invest. Clin.* 69, 114–122.
- Kedde, H., van de Wiel, H.B., Weijmar Schultz, W.C., Wijzen, C., 2013. Sexual dysfunction in young women with breast cancer. *Support. Care Cancer* 21, 271–280.
- Kotronoulas, G., Kearney, N., Maguire, R., Harrow, A., Di Domenico, D., Croy, S., MacGillivray, S., 2014. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J. Clin. Oncol.* 32, 1480–1510.
- Ljungman, L., Ahlgren, J., Petersson, L.-M., Flynn, K.E., Weinfurt, K., Gorman, J.R., Wettergren, L., Lampic, C., 2018. Sexual dysfunction and reproductive concerns in young women with breast cancer: type, prevalence, and predictors of problems. *Psycho Oncol.* 27, 2770–2777. <https://doi.org/10.1002/pon.4886>.
- Marsh, S., Borges, V.F., Coons, H.L., Afghahi, A., 2020. Sexual health after a breast cancer diagnosis in young women: clinical implications for patients and providers. *Breast Cancer Res. Treat.* 184, 655–663. <https://doi.org/10.1007/s10549-020-05880-3>.
- Michael, Y.L., Kawachi, I., Berkman, L.F., Holmes, M.D., Colditz, G.A., 2000. The persistent impact of breast carcinoma on functional health status: prospective evidence from the Nurses' Health Study. *Cancer* 89, 2176–2186.
- Mokhatri-Hesari, P., Montazeri, A., 2020. Health-related quality of life in breast cancer patients: review of reviews from 2008 to 2018. *Heal. Qual Life Outcomes* 18, 338.
- Partridge, A.H., Burstein, H.J., Winer, E.P., 2001. Side effects of chemotherapy and combined chemohormonal therapy in women with early-stage breast cancer. *J. Natl. Cancer Inst. Monogr.* 135–142.
- Qi, A., Li, Y., Sun, H., Jiao, H., Liu, Y., Chen, Y., 2021. Incidence and risk factors of sexual dysfunction in young breast cancer survivors. *Ann. Palliat. Med.* 10, 4428–4434. <https://doi.org/10.21037/apm-21-352>.
- Reese, J.B., Bober, S.L., Daly, M.B., 2017. Talking about women's sexual health after cancer: why is it so hard to move the needle? *Cancer* 123, 4757–4763.
- Reese, J.B., Porter, L.S., Casale, K.E., Bantug, E.T., Bober, S.L., Schwartz, S.C., Smith, K.C., 2016. Adapting a couple-based intimacy enhancement intervention to breast cancer: a developmental study. *Health Psychol.* 35, 1085–1096. <https://doi.org/10.1037/hea0000413>.
- Reynolds, K.E., Magnan, M.A., 2005. Nursing attitudes and beliefs toward Human sexuality: Collaborative research Promoting evidence-based practice. *Clin. Nurse Spec.* 19, 255–259.
- Rosenberg, S.M., Tamimi, R.M., Gelber, S., Ruddy, K.J., Bober, S.L., Kerekoglou, S., Borges, V.F., Come, S.E., Schapira, L., Partridge, A.H., 2014. Treatment-related amenorrhea and sexual functioning in young breast cancer survivors. *Cancer* 120, 2264–2271. <https://doi.org/10.1002/cncr.28738>.
- Saunamäki, N., Andersson, M., Engström, M., 2010. Discussing sexuality with patients: nurses' attitudes and beliefs. *J. Adv. Nurs.* 66, 1308–1316.
- Stein, K.D., Syrjala, K.L., Andrykowski, M.A., 2008. Physical and psychological long-term and late effects of cancer. *Cancer* 112, 2577–2592.
- Team, R.C., 2022. *R: A Language and Environment for Statistical Computing* [WWW Document]. URL <https://www.r-project.org/>.
- ter Kuile, M.M., Brauer, M., Laan, E., 2006. The female sexual function Index (FSFI) and the female sexual distress scale (FSDS): psychometric properties within a Dutch population. *J. Sex Marital Ther.* 32, 289–304. <https://doi.org/10.1080/00926230600666261>.
- Text Revision(DSM-5-TR) The Diagnostic and Statistical Manual of Mental Disorders, fifth ed., 2013. American Psychiatric Association, Washington DC.
- Ussher, J.M., Perz, J., Gilbert, E., 2013. Information needs associated with changes to sexual well-being after breast cancer. *J. Adv. Nurs.* 69, 327–337.

- van Verschuer, V.M., Vrijland, W.W., Mares-Engelberts, I., Klem, T.M., 2015. Reliability and validity of the Dutch-translated body image scale. *Qual. Life Res.* 24, 1629–1633.
- Vencill, J.A., Kacel, E.L., Avulova, S., Ehlers, S.L., 2022. Barriers to sexual recovery in women with urologic cancers. *Urol. Oncol. Semin. Orig. Investig.* 40, 372–378. <https://doi.org/10.1016/j.urolonc.2020.11.011>.
- Vrancken Peeters, N.J.M.C., Vlooswijk, C., Bijlsma, R.M., Kaal, S.E.J., Kerst, J.M., Tromp, J.M., Bos, M.E.M.M., van der Hulle, T., Lalisang, R.I., Nuver, J., Kouwenhoven, M.C.M., van der Ploeg, I.M.C., van der Graaf, W.T.A., Husson, O., 2024. Sexual quality of life of adolescents and young adult breast cancer survivors. *ESMO Open* 9, 102234. <https://doi.org/10.1016/j.esmoop.2024.102234>.
- Zhou, E.S., Falk, S.J., Bober, S.L., 2015. Managing premature menopause and sexual dysfunction. *Curr. Opin. Support. Palliat. Care* 9, 294–300.