Sexual Health Screening for Gynecologic and Breast Cancer Survivors: A Review and Critical Analysis of Validated Screening Tools
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ABSTRACT

Introduction: Studies have shown that the sexual health concerns of gynecologic and breast cancer survivors are not adequately being addressed by clinicians.

Aim: To provide a comprehensive narrative review of validated sexual health screening tools and aid clinicians in choosing a screening tool that will allow them to best address their patients’ sexual health concerns.

Methods: A review of PubMed and Google Scholar databases was conducted, using search terms “sexual health”, “screening”, “tools”, “cancer”, and “survivors” to identify sexual health screening tools meeting the following inclusion criteria: 1) published in a peer-reviewed journal, 2) were written in English, 3) included breast and/or gynecological cancer patient population, 4) included self-reported measure of sexual health and function, and 5) underwent psychometric validation.

Main Outcome Measure: Criteria used to evaluate identified screening tools included ability to assess desire, arousal, satisfaction, orgasm, dyspareunia, solo sexual expression, relationship with partner, body image, distress over changes in sexual function, and support systems. Pre and post-treatment comparisons, differentiation between lack of sexual desire and inability, heterosexual bias, diversity in patient population, and ease of scoring were also evaluated.

Results: Based upon the inclusion criteria, the following 10 sexual health screening tools were identified and reviewed: Female Sexual Function Index, European Organization for Research and Treatment of Cancer Quality of Life Questionnaires for both Cervical and Endometrial Cancer, Sexual Adjustment and Body Image Scale, Sexual Adjustment and Body Image Scale - Gynecologic Cancer, Sexual Function and Vaginal Changes Questionnaire, Gynaecologic Leiden Questionnaire, Information on Sexual Health: Your Needs after Cancer, Sexual Satisfaction Questionnaire, and Sexual Activity Questionnaire. Most tools assessed satisfaction (n=10), desire (n=9), and dyspareunia (n=8). Fewer addressed objective arousal (n=7), body image/femininity (n=7), partner relationship (n=7), orgasm (n=5), pre/post treatment considerations (n=5), distress (n=4), and solo-sexual expression (n=2). Heterosexual bias (n=3) and failure to differentiate between lack of desire and inability (n=2) were encountered.

Conclusion: Understanding the strengths and limitations of sexual health screening tools can help clinicians more effectively address cancer survivors’ sexual health concerns, which is essential in providing comprehensive care and improving quality of life. Screening tools have room for improvement, such as eliminating heterosexual bias and including cancer and treatment-specific questions. Clinicians can use this guide to select the most appropriate screening tool for their patients and begin bridging the gap in sexual healthcare.

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Key Words: Sexual Health; Screening; Cancer Survivors; Gynecology; Oncology
INTRODUCTION

Cancer care research has demonstrated that many patients with breast and gynecologic cancers have unmet needs related to their sexual health.1 Cancer treatments such as surgery, systemic chemotherapy, pelvic radiation, and endocrine therapies severely affect sexual health and body image.2 The consequences of negative sexual health and body image can be severe, including long-term emotional effects such as low-self-esteem, depression, and anxiety.3 Thus, it is important for patients who are diagnosed with breast and gynecological cancers to discuss and share information about their sexual needs with health care providers. Studies have shown that half of patients treated for cancer reported cancer-related sexual concerns, and yet, fewer than one-third of them reported receiving information about potential side effects of treatments.4 One of the major barriers to accessing treatment for sexual health was inadequate training for clinicians in how to hold such discussions.5 One way to address this problem is through the use of screening tools.

Screening tools are essential in identifying post-gynecologic and breast cancer treatment sexual concerns. They help medical professionals gather important patient information and allow patients to express sensitive concerns regarding their sexual health that may otherwise go unnoticed. Moreover, they can be used as a natural transition into the sensitive topic of sexual health and, therefore, help solve the aforementioned barrier of communication. In fact, a recent study on sexual health needs for patients with cancer found that over 65% of participants preferred written material on the topic of sexual health followed by discussion with their medical provider.6 If clinicians do not address a patient’s concerns regarding sexual health after cancer, patients may wrongly infer that little or nothing may be done to manage the negative side effects of their cancer treatment, and may suffer from those symptoms chronically.7 It is clear that the use of screening tools, particularly in the context of sexual health, is not only beneficial to both patient and provider, but bridges an important gap in follow-up care for cancer patients.

In order for these tools to be useful, clinicians must be aware of the scope of each tool, its objective, the ease of scoring, and most importantly, the usefulness to the patient in detecting their sexual health concerns. There is a myriad of screening tools available to evaluate sexual health, however, many of them are neither user-friendly nor comprehensive. There is also currently no guide for clinicians about the strengths and weaknesses of each screening tool. In this comprehensive narrative review, we analyze 10 validated screening tools that assess sexual health in gynecologic and breast cancer survivors. Our goal is to create an easy-to-use guide for practicing medical professionals to determine the most appropriate sexual health screening tool available for their patients’ needs.

METHODS

Search Strategy

The review was conducted using the databases PubMed and Google Scholar in May 2020. The terms used in the search included “sexual health”, “screening”, “tools”, “cancer”, and “survivors”.

Eligibility Criteria

Inclusion criteria for studies were the following: (i) published in a peer reviewed journal, (ii) included breast and/or gynecological cancer patient population, (iii) were available in English, (iv) included self-reported measure of sexual health and function, and (v) tools underwent psychometric validation. Studies that did not include breast and/or gynecological cancer patients and non-validated tools were excluded.

Outcome Criteria

The criteria used to evaluate their strengths and weaknesses included desire, arousal, satisfaction, orgasm, dyspareunia, solo sexual expression, relationship with partner, body image, distress over changes in sexual function, support systems, pre and posttreatment comparisons, differentiation between lack of sexual desire and physician inability, hetero-sexual bias, diversity in patient population, age range, ease of scoring, accessibility, and time needed to complete the tool (Tables 1, 2).

Table 3 describes mode of delivery, estimated time required for completion, and accessibility of each screening tool. The Consensus-based Standards for the Selection of Health Measurement Instruments was used to evaluate and describe the quality measures of each screening tool. Mechanisms to access the tools described in the analysis are presented in Appendix 1.

RESULTS

A total of 21 tools were initially reviewed of which 11 were excluded for not meeting inclusion criteria (Appendix 2). Thus, the following 10 screening tools were identified and reviewed: Female Sexual Function Index, European Organization for Research and Treatment of Cancer Quality of Life Questionnaires for both Cervical and Endometrial Cancer, Sexual Adjustment and Body Image Scale, Sexual Adjustment and Body Image Scale-Gynecologic Cancer, Sexual Function and Vaginal Changes Questionnaire, Gynaecologic Leiden Questionnaire, Information on Sexual Health: Your Needs after Cancer, Sexual Satisfaction Questionnaire, and Sexual Activity Questionnaire. Most tools assessed satisfaction (n = 10), desire (n = 9), and dyspareunia (n = 8).

Fewer addressed objective arousal (n = 7), body image/femininity (n = 7), relationship with partner (n = 7), ability to achieve orgasm (n = 5), pre/post treatment considerations (n = 5), psychological distress (n = 4), solo-sexual expression (n = 2), and support system (n = 0). Heterosexual bias (n = 3) and failure to differentiate between lack of desire and inability (n = 2) were encountered with some screening tools (Table 1).
Female Sexual Function Index

Background: The Female Sexual Function Index (FSFI) is a brief, albeit comprehensive, questionnaire commonly used by clinicians to measure sexual function in cancer patients, including gynecological, bone marrow, breast, and cervical cancer patients. It has been specifically validated and adapted for use in breast cancer patients. The FSFI has been validated in multiple other languages, including Italian, Urdu, Spanish, and Hungarian. It was developed to assess sexual desire, arousal, lubrication, orgasm, satisfaction, and dyspareunia within a 4-week time period in a sample composed of patients experiencing sexual dysfunction as determined by a clinical history. The FSFI scores 19 items on a scale of 0 (indicating no sexual activity) to 5. Higher scores on the FSFI indicate optimal sexual function while total scores below 26 represent a potential diagnosis of female sexual dysfunction.

Strengths: The FSFI is considered a gold standard due to its widespread use in clinical settings. One of the major strengths of the FSFI is its extensive psychometric validation via studies involving female gynecological, bone marrow, and cervical cancer patients with appropriately matched controls. The diverse patient populations seen in the validation studies prove the applicability of the FSFI for female cancer patients. This tool is available in 9 languages including English and only takes fifteen minutes to fill out, which underscores the ease with which clinicians may administer it to their patients. The FSFI is also available on MDApp, an online application, that immediately calculates the score once the questionnaire is filled out. The questionnaire includes multiple definitions of sexual experiences for the patient to clearly understand, articulate, and differentiate between their feelings regarding sexual activity, intercourse, desire, stimulation, and arousal.

Weaknesses: Limitations of the FSFI include a lack of differentiation between diminished desire and physical inability for patients who scored 0 on certain items. This could lead to a false sexual dysfunction diagnosis when in actuality the patient may have not been engaging in sexual activity at all. Additionally, the FSFI only pertains to a 4-week time period. This limits the applicability of this tool for patients who were not sexually active in the last 4 weeks, as they would obtain a score of “0” for this section. This may also detract from the FSFI’s validity if patients who had not engaged in sexual activity during the prior 4-week period were included in the original validation studies. The FSFI does not acknowledge or differentiate between the different types of cancer treatments received and how they may impact the validity of its scoring system. The FSFI is also targeted towards heterosexual sexual practices and intercourse (penile-vaginal intercourse), which further limits its utility to a specific patient population.

EUROPEAN ORGANIZATION FOR RESEARCH AND TREATMENT OF CANCER QUALITY OF LIFE QUESTIONNAIRES - CERVICAL CANCER (CX-24)

Background: The European Organization for Research and Treatment of Cancer (EORTC) is an independent, non-profit
| Measure                  | Year Validated | Study Population | Diversity of Participant Sample | Number of Items | Recall Period | Age Range as provided in the study | Number of Languages Available | Ease of Scoring* | Time required to complete in minutes (number of items) |
|-------------------------|----------------|------------------|----------------------------------|-----------------|---------------|-------------------------------------|-----------------------------|-----------------|---------------------------------------------------|
| FSFI                    | 2012           | 217 (female cancer survivors) | Not provided                     | 19              | 4 wk          | 18–50                               | 1 (English)                | Simple math    | 5–10 (19)                                          |
| SABIS                   | 2009           | 353 (breast cancer patients) | 89.5% Caucasian, 4.7% Native American, 2.9% Black, 2% Asian, 0.9% Hispanic | 14              | Posttreatment | Average age of 49                    | Simple math                | 0–5 (14)       |                                                   |
| SABIS-G                 | 2011           | 294 (gynecological cancer patients) | 81.6% Caucasian, 6.8% Asian, 3.4% Black, 8.2% Other | 7               | Posttreatment | 27–80                               | 1 (English)                | Statistical analysis | 0–5 (7)    |
| EORTC QLQ CX-24        | 2006           | 167              | 12 different countries represented | 24              | Past week     | Average age of 48.6                  | 12                          | Simple math    | 10–15 (24)                                         |
| EORTC QLQ EN-24        | 2010           | 286              | 10 different countries represented | 24              | Past week; past 4 wk | 35.8–87.8                          | 39                          | Simple math    | 10–15 (24)                                         |
| SVQ                     | 2004           | 257              | Denmark represented              | 27              | Past month    | 28–77                               | 2 (Danish, English)        | Simple math    | 10–15 (24)                                         |
| GLQ                     | 2007           | 198              | Not provided                     | 21              | None          | Not provided                        | 2 (Dutch, English)         | Qualitative analysis and simple math | 0–5 (11) |
| InSYNC                  | 2015           | 114 (56 breast cancer patients) | Both men and women represented: 88% Caucasian men, 93% Caucasian women, 10 Black men, 9% Black women | 12              | No time frame given                  | 18+                                 | 1 (English)                | Qualitative analysis | 0-5 (12)   |
| SEXSAT-Q                | 2019           | 148 (breast cancer patients) | Not provided                      | 17              | No time frame given                  | 18–65                              | 2 (English, Spanish) | Simple math | 5–10 (17)                                          |
| SAQ                     | 1996           | 528              | Not provided                     | 22              | Past month   | 35–65                               | 1 (English)                | Qualitative analysis only | 10–15 (23) |

EORTC = European organization for research and treatment of cancer quality of life; FSFI = female sexual function index; GLQ = gynaecologic Leiden questionnaire; InSYNC = information on sexual health: your needs after cancer; SABIS = sexual adjustment and body image scale; SABIS-G = sexual adjustment and body image scale-gynecologic cancer; SAQ = sexual activity questionnaire; SEXSAT-Q = sexual satisfaction questionnaire; SVQ = sexual function and vaginal changes questionnaire.

*Ease of scoring was assessed using 3 categories: statistical analysis required, simple math required, or qualitative analysis.

†Also validated in 58 prostate cancer patients

‡Pilot study included 20, and reduction sample included 152 breast cancer patients

§Recall bias is present
Table 3. Consensus-based standards for the selection of health measurement instruments

| Measure       | Internal Consistency* | Reliability | Validity of Content | Structural Validity | Cross cultural validity |
|---------------|-----------------------|-------------|---------------------|---------------------|-------------------------|
| FSFI          | Excellent             | Not reported| Excellent           | Excellent           | Not reported            |
| SABIS         | Excellent             | Good        | Not reported        | Not reported        | Not reported            |
| SABIS-G       | Excellent             | Fair        | Fair                | Excellent           | Not reported            |
| EORTC QLQ CX-24 | Poor                  | Not reported| Excellent           | Poor                | Excellent               |
| EORTC QLQ EN-24 | Poor                  | Fair        | Excellent           | Poor                | Excellent               |
| SVQ           | Fair                  | Poor        | Excellent           | Fair                | Not reported            |
| GLQ           | Good                  | Good        | Not reported        | Good                | Not reported            |
| InSYNC        | Not reported          | Not reported| Not reported        | Not reported        | Not reported            |
| SEXSAT-Q      | Excellent             | Good        | Good                | Not reported        | Not reported            |
| SAQ           | Not reported          | Not reported| Not reported        | Not reported        | Not reported            |

None of the included studies reported information on measurement error or responsiveness, and thus these columns are not displayed in the table.

EORTC = European organization for research and treatment of cancer quality of life; FSFI = female sexual function index; GLQ = gynaecologic Leiden questionnaire; InSYNC = information on sexual health: your needs after cancer; SABIS = sexual adjustment and body image scale; SABIS-G = sexual adjustment and body image scale-gynecologic cancer; SAQ = sexual activity questionnaire; SEXSAT-Q = sexual satisfaction questionnaire; SVQ = sexual function and vaginal changes questionnaire.

*Excellent = alpha > 0.8

Cancer research organization that aims to improve the standard of cancer treatment for patients. In addition to clinical and basic science research, EORTC develops questionnaires and research tools for academic use to assess quality of life of cancer patients.

The EORTC QLQ-C30 is the core quality of life questionnaire, composed of 30 items to assess the patient’s experiences over the past week. While the QLQ-C30 may be used as a screening tool on its own, it may also be supplemented by an additional questionnaire that asks patients specific questions related to their particular type of cancer, including physical, emotional, and sexual changes they may experience throughout their diagnosis and treatment course. The EORTC has developed 4 supplemental reproductive cancer-specific questionnaires: Cervical Cancer (EORTC QLQ CX-24), Endometrial Cancer (EORTC QLQ EN-24), Ovarian Cancer (EORTC QLQ OV-28), and Breast Cancer (EORTC QLQ BR45), however the latter 2 have yet to be validated.

The EORTC QLQ CX-24 evaluates the quality of life in cervical cancer patients who have undergone hysterectomies and received radio-and/or chemotherapy. It is composed of 24 items addressing cervical cancer specific questions in addition to questions about sexual health, including symptom experience, body image, and vaginal functioning. The time frame for questions is limited to the past 1–4 weeks. The responses are self-reported and scored on a scale of 1–4. The total score is then converted to a different scale in accordance with the questionnaire manuals. The questionnaire can be readily requested and received by email through the official EORTC website.

Strengths: The EORTC QLQ CX-24 underwent extensive validation in diverse patient populations from Europe, Australia, and Taiwan. The EORTC QLQ CX-24 was also validated in Brazil and Korea. Additionally, the questionnaire being specific to cervical cancer patients allows for a well-rounded and thorough assessment of quality-of-life issues, not limited to sexual function, that are pertinent to this patient population. This screening tool addresses body image, which is not always included in questionnaires on sexual health, such as the FSFI, but is an important consideration for optimal sexual function. The EORTC QLQ CX-24 is available in numerous languages (including English) and takes only fifteen minutes to complete; patients also reported that it is easy to complete.

Weaknesses: Despite providing a thorough overview of health issues specific to cervical cancer patients, the EORTC QLQ CX-24 omits sexual desire, orgasm achievable, and questions about relationships or partners. This omission makes this questionnaire less comprehensive in its assessment of sexual function. The EORTC QLQ CX-24 also fails to differentiate between lack of desire and physical inability in sexually inactive patients, which yields a less accurate assessment. Additionally, some of the items ask leading questions, such as “Have you felt less feminine as a result of your treatment?” or “Have you felt dissatisfied with your body?”. Furthermore, the score calculation requires a raw score calculation and linear transformation, which may be cumbersome for clinicians especially when administering the questionnaire to numerous patients.

EUROPEAN ORGANIZATION FOR RESEARCH AND TREATMENT OF CANCER QUALITY OF LIFE QUESTIONNAIRES - ENDOMETRIAL CANCER (EN-24)

Background: The Quality-of-Life Questionnaire-Endometrial Cancer (EORTC QLQ EN-24) evaluates the quality of life in endometrial cancer patients in different phases of treatment. It has the same format and scoring as the EORTC QLQ CX-24. It is composed of 24 items addressing endometrial cancer specific questions in addition to questions about sexual health, including symptom experience, body image, and vaginal functioning.
The time frame for questions is limited to the past 1–4 weeks. The responses are self-reported and scored on a scale of 1–4. The total score is then converted to a different scale in accordance with the questionnaire manuals. The questionnaire can be readily requested and received by email through the official EORTC website.

**Strengths:** The EORTC QLQ EN-24 also underwent extensive validation in diverse patient populations from Europe, Australia, and Taiwan.\(^9\) The EORTC QLQ EN-24 was also validated in Poland.\(^9\) Additionally, the questionnaire being specific to endometrial cancer patients allows for a well-rounded and thorough assessment of quality of life issues, not limited to physical arousal (lubrication) and orgasm. Additionally, the SABIS excludes gender specific terminology to eliminate heterosexual bias.

**Weaknesses:** Similar to the EORTC QLQ CX-24, the EORTC QLQ EN-24 omits sexual desire, orgasm achievable, and questions about relationships or partners. Additionally, it fails to differentiate between lack of desire and physical inability in sexually inactive patients and includes the same leading questions as the EORTC QLQ CX-24. The EORTC QLQ EN-24 also has the same complicated scoring system involving raw calculations and linear transformations as the EORTC QLQ CX-24.

**Sexual Adjustment and Body Image Scale**

**Background:** The Sexual Adjustment and Body Image Scale (SABIS) is a 14-item questionnaire designed to assess changes in sexuality and body image in female breast cancer patients who had undergone surgery and/or chemotherapy, hormone, and/or radiation treatments. The SABIS was validated in a randomized, multi-center trial. The questions were additionally validated by psychotherapists and clinicians treating breast cancer patients.\(^10\) The questionnaire is divided into 2 scales, with 6 questions on the body image scale and 8 questions on the sexual adjustment scale. The questions are scored on a scale of 1–5, and the average score is calculated for each subscale, with lower or negative scores indicating worse sexual adjustment and body image.\(^10\)

**Strengths:** The greatest strength of the SABIS is its focus on body image, which as previously discussed, is not thoroughly investigated with other screening tools. Body image has direct implications on sexual desire and function and its inclusion allows for a comprehensive assessment of sexual health. Additionally, the SABIS excludes gender specific words and instead includes words such as “other” and “partner”, which eliminates heterosexual bias.

**Weaknesses:** The SABIS underwent thorough validation; however, the patient population was predominantly Caucasian.\(^10\) This may limit the usefulness of this screening tool in more diverse patient populations. The SABIS does not provide a comprehensive assessment of sexual function because it lacks questions on physical arousal (lubrication) and orgasm. Additionally, it is not user-friendly due to only being available in English and its complex and time-consuming scoring algorithm. It also has recall bias because it contains questions pertaining to sexual health pretreatment despite its recall period being limited to posttreatment.

**Sexual Adjustment and Body Image Scale-Gynecologic Cancer**

**Background:** The Sexual Adjustment and Body Image Scale-Gynecologic Cancer (SABIS-G) is a modified version of SABIS intended to assess changes in sexuality and body image in patients with gynecologic cancer.\(^12\) The SABIS-G is a 7-item questionnaire with 3 of the 7 items composing the body image subscale and the remaining items composing the sexual adjustment subscale. This tool was validated in a cross-sectional observational study. The questions were additionally validated by psychotherapists and clinicians treating gynecologic cancer patients.\(^12\) Each SABIS-G item is scored on a scale from 1–5, with 5 being the best outcome. Higher scores correspond with better body image and sexual adjustment outcomes.

**Strengths:** Similar to the SABIS, the greatest strength of the SABIS-G is its focus on body image. The SABIS-G employs non-gender specific terminology to eliminate heterosexual bias. The brevity of this questionnaire makes it convenient for patients to quickly complete. It also encompasses multiple sexual factors, including confidence, desire, satisfaction, and initiation.

**Weaknesses:** Similar to the SABIS, the SABIS-G was also validated using a predominantly Caucasian patient population and excludes questions on lubrication and orgasm.\(^12\) The SABIS-G is also only available in English and has an even more complex scoring algorithm, involving linear transformations, making it less user-friendly for clinicians to use. Additionally, there is no published diagnostic cut off score.\(^9\)

**Sexual Function and Vaginal Changes Questionnaire**

**Background:** The Sexual Function and Vaginal Changes Questionnaire (SVQ) is a 27-item screening tool designed to assess sexual function in gynecological cancer patients. It was initially created as a supplement to the EORTC QLQ-C30.\(^13\) Twenty items evaluate sexual desire, lubrication, vaginal size, dyspareunia, intimacy, orgasm, sexual activity and satisfaction, issues with sexual partner, comfort level after sex, support systems, and body image within the past 4 weeks. The remaining 7 items assess pre- and posttreatment sexual and vaginal problems. The SVQ items have varying scale parameters for different questions to determine the overall score. The SVQ was validated by assessing both the comprehensibility and scale properties for each item.\(^13\)

**Strengths:** The major strength of the SVQ is its inclusion of vaginal changes, body image concerns, support systems, relationship with partner(s), and comparisons of pre- and posttreatment outcomes, which offers a well-rounded approach to addressing...
sexual health. The thorough, dual validation lends confidence in the reliability of the questionnaire.\textsuperscript{13} The questionnaire compiles all questions relating to sexual activity into select subsections, and the patient is only asked to fill them out if they are sexually active. This avoids confusion if the patient is not currently sexually active, something most of the other questionnaires omit.

Finally, unlike other questionnaires, the SVQ includes items to be answered about the partner, such as “has your partner’s interest changed since you were diagnosed with cancer?” This inclusion is significant, as it may help the clinician develop a more individualized treatment plan for the patient.

Weaknesses: The SVQ was validated in a sample composed of predominantly cervical cancer patients from Denmark.\textsuperscript{13} This may limit its utility to a specific patient population. Some items are also geared towards heterosexual practices or can only be answered if the patient is sexually active. There is no published diagnostic cut off score or scoring template for the questionnaire.\textsuperscript{9} Furthermore, the SVQ was developed to supplement the EORTC Quality of Life Questionnaire, which means it itself does not encompass general quality of life intake.

Gynecologic Leiden Questionnaire

\textbf{Background:} The Gynecologic Leiden Questionnaire (GLQ) is a 21-item questionnaire designed to evaluate sexual and vaginal problems specific to patients with gynecologic cancer. In addition to sexual function (11 items), the questionnaire items also address “weariness” (1-item), lymphedema (1-item), “voiding” (6 items), and “bowel problems” (2 items).\textsuperscript{14} The items specifically addressing sexual function are divided into 3 sections: female sexual complaints, female sexual function, and female orgasm. The GLQ was validated in a 2008 study with cervical patients who had undergone radical hysterectomy with pelvic lymphadenectomy as well as patients without cancer undergoing treatment for female sexual dysfunction.\textsuperscript{14} The GLQ has varying scale parameters for different items.

\textbf{Strengths:} The GLQ can be used as a brief screening tool as an introduction to a discussion of sexual function. It also includes an item on masturbation, which is not always addressed in other questionnaires, but is an important component of sexual health. Additionally, the GLQ employs non-gender specific terminology to eliminate heterosexual bias. The questionnaire prompts the patient to skip questions if not sexually active.

\textbf{Weaknesses:} The GLQ was only validated in a Dutch sample of cervical cancer patients, potentially limiting its utility in more diverse patient populations with other types of gynecological cancer.\textsuperscript{14} The GLQ has been translated and is available in English, however, there seems to be some errors in the translation. One question asks, “Do you experience numbness of your labia and/or the inner sides of your tights [sic]?” Similar to the FSFI, the GLQ also fails to differentiate between a lack of sexual desire and physical inability if a patient selects “No sexual activity” as a response.

Information on Sexual Health: Your Needs after Cancer

\textbf{Background:} The Information on Sexual Health: Your Needs after Cancer (InSYNC) is a 12-item questionnaire designed to assess sexual health concerns and needs for sexual after cancer treatment in breast and prostate cancer survivors.\textsuperscript{15} The validation study was completed in 2016 using a patient population of breast and prostate cancer survivors. This is one of the few tools that used both male and female patients to validate the tool, and the only one that may be used for different sexes. The items are scored on a scale of 1–5, and there is a “N/A” option. Patients can indicate if they would like more information on each item. The scale asks about the patient’s sexual health after cancer treatment, but gives no time frame beyond that.

\textbf{Strengths:} The InSYNC is a well-rounded questionnaire because it was developed with content experts in medicine, nursing, psychology, public health, and social work, with the intention of being used as a way for clinicians to best identify sexual health problems in their patients.\textsuperscript{15} The questionnaire assesses multiple dimensions of sexual health, including sexual function, self-perception, and sexual relationships with others. It includes important items on psychosocial aspects of sexual health including concerns about starting new relationships and losing confidence as a sexual partner. The InSYNC also employs non-gender specific terminology to eliminate heterosexual bias. The questionnaire is brief, user friendly, and an efficient way to assess if patients need more information on various sexual health concerns in a clinical setting. The option to request more information for each item is unique to the InSYNC.

\textbf{Weaknesses:} The validation study for the InSYNC was small and lacked diversity in relationship status, race, ethnicity, and sexual orientation.\textsuperscript{15} More validation studies are needed to evaluate the utility of this questionnaire in more diverse patient populations.

Additionally, it is currently only available in English. There are also a number of leading questions in the assessment. Question 4 asks, “Are you concerned about being physically attractive after cancer?” While the intent of this question is to capture a common side effect of cancer treatment, it may make the patient feel as if they should be concerned about their appearance, even when they may not be.

Sexual Satisfaction Questionnaire

\textbf{Background:} The Sexual Satisfaction Questionnaire (SEX-SAT-Q) is a 17-item questionnaire originally designed and validated to assess changes in sexual dysfunction and satisfaction in female breast cancer patients.\textsuperscript{16} The items in the questionnaire cover 5 dimensions including loss of sex drive, body image, discomfort during intercourse, sexual satisfaction, and satisfaction after breast reconstructive surgery. The first 14 items are scored on a scale of 0–4, with the remaining items only applying to patients who have undergone breast reconstruction surgery. The
questionnaire is intended to be administered to those patients who have received adjuvant chemotherapy treatment and could be receiving adjuvant hormonal treatment, and had a sex life at least 3 months prior to starting treatment. It may be administered periodically to assess changes in symptoms and sexual functioning.

Strengths: The SEXSAT-Q is the only one of its kind to thoroughly assess sexual function exclusively in breast cancer survivors. In contrast, older questionnaires which are similarly specific to breast cancer patients have limited questions on sexual function. This questionnaire applies a well-rounded approach to addressing sexual health issues through the inclusion of sexual satisfaction, body image, and satisfaction after reconstructive surgery. It allows patients to reflect and discuss how a myriad of sexual function aspects have changed posttreatment in comparison to pretreatment. All of these items are unique and frequently omitted in the other reviewed screening tools. Unlike other tools, some items in the tool are specific and address the patient’s feelings during sexual activity. For example, item 4 asks the patient about their comfort during caressing or embracing during foreplay. Other tools are limited to specifically asking about intercourse. The SEXSAT-Q is reported to be user-friendly, quick to complete, and well understood by the patient sample it was used with to be validated. The SEXSAT-Q also employs non-gender specific terminology to eliminate heterosexual bias.

Weaknesses: The validation study included a small patient sample from Spain, thereby limiting the generalizability of this tool’s effectiveness in more diverse populations. Additionally, sexual orientation and frequency of sexual intercourse were not addressed. Masturbation was not included as a measure of sexual health. To date, the study is also only available in English and Spanish.

Sexual Activity Questionnaire

Background: The Sexual Activity Questionnaire (SAQ) was originally designed to assess the long-term effects of Tamoxifen on sexual function in those at a high risk for developing breast cancer. Since then, it has been validated in studies with ovarian cancer patients and utilized in a variety of studies with other cancers, including breast cancer. The SAQ is now used to assess sexual function in patients with gynecological cancers, regardless of Tamoxifen use. It is a 23-item questionnaire with 3 sections: hormonal status (6 items), reasons for sexual inactivity (7 items), and sexual functioning of patients in terms of activity, pleasure, and discomfort (10 items). The first section determines hormonal status (premenopausal, postmenopausal with or without HRT), and whether or not the patient is sexually active through a series of yes-or-no questions. The second section is completed by those patients who are sexually inactive; it lists 7 potential reasons for sexual inactivity and allows patients to select those that apply to them or list other reasons, if necessary. The third section contains 10 items that focus on specific aspects of sexual functioning for those patients who are sexually active, such as desire, frequency, satisfaction, vaginal lubrication, and pain during penetration.

Nine of the 10 questions ask for a Likert-type response. Patient surveys were combined and scored on the basis of 3 factors (pleasure, discomfort, and habit) based on their responses in order to compare sexual function between different groups.

Strengths: The SAQ is a simple, short questionnaire that is considered easy to complete and analyze. This questionnaire considers areas such as body image, sexual functioning, and social wellbeing; it also uncovers reasons for sexual inactivity. The SAQ was validated in a small sample of 96 ovarian cancer patients and 447 patients considered high-risk for breast cancer & (Thirlway, et al. 1997). Although the SAQ has only been validated in patients with ovarian cancer, the questionnaire is not specific to one type of gynecological cancer. It has been used in studies that included patients with breast cancer and endometrial cancer, as well. It can also be used for patients who are at high risk of developing breast cancer, (due to the original validation studies), or for patients with other gynecological conditions such as endometriosis. This questionnaire takes an interesting approach to assessing sexual health. It first asks why the patient may not be sexually active at the moment. This is helpful in providing context for the remainder of the questionnaire. Also, it provides a space for the patient to provide further comments they wish to disclose to the physician.

Weaknesses: This questionnaire also takes a heteronormative approach to sex and does not address non-penile-vaginal intercourse, orgasm, or vaginal problems. The SAQ also does not address physiological changes associated with cancer treatment. While the SAQ may uncover reasons for not being sexually active, it is not designed to address or solve issues for patients who are not currently sexually active as it mainly focuses on frequency of sexual activity.

DISCUSSION

Summary of Screening Tools

The distinction between lack of sexual desire (ie, libido) and physical inability to engage in sexual activity (ie, due to pain or lack of physiological arousal) is particularly relevant in cancer survivors. Most of the tools measured both sexual desire and arousal, however, only 8 clearly differentiated between the lack of sexual desire and physical inability to respond to it (Table 1). This is an important part of a sexual health screening tool because it elucidates specifically what is causing the lack of sexual activity and if further treatment and counseling is required.

Seven tools assessed objective (physiological) sexual arousal (Table 1). However, only 2 out of these 7 tools assessed both objective and subjective (psychological) aspects of sexual arousal (Table 1). The lack of assessment of subjective sexual arousal hinders providers from getting a more nuanced understanding of what their patients may be going through. For example, the
patient may need further counseling or emotional support services in order to feel sexually aroused, but may not divulge that information if the screening tool does not specifically ask for it. While all of the tools ask about sexual satisfaction, only 5 tools asked about achieving orgasm (Table 1). Despite orgasm not being essential for sexual pleasure, it is considered one of the most important predictors of sexual satisfaction amongst women of all ages. Furthermore, only 4 tools ask if the patient is feeling distressed about their sexual health (Table 1). The psychological components of sexual health, including cancer patients’ distress about changes in their sexuality, may be related to the ability to achieve orgasm and subjective arousal. A comprehensive assessment is required in order to fully appreciate what the patient may be experiencing both physiologically and psychologically in order to provide appropriate care.

Eight tools screened for dyspareunia, an especially important criteria to evaluate for gynecological cancer patients (Table 1). 7 tools also assessed body image (Table 1), which may be an important consideration for breast cancer patients who have undergone a mastectomy. However, body image should be included in all screening tools, regardless of cancer patient population. This is important as physical side effects of chemotherapy and radiation (ie, hair loss) may impact body image, subjective sexual arousal, and overall mental health. This is particularly relevant for younger breast cancer patients who may experience more detrimental body image issues posttreatment.

Most of the tools were validated in a patient population with a wide age range (ie, 18−65) (Table 2). While having a screening tool available for patients of all ages is convenient, it may not be the most effective because sexual health needs may vary by age, with postmenopausal status being associated with changes in sexual function. Additionally, many of the validation studies did not indicate the race of their participants. However, those that did included a majority (ie, 80%−90%) Caucasian patient population. This lack of racial diversity also limits how effective the tools may be since racial disparities have a significant impact on health outcomes. A homogenous patient population also limits how the screening tool may have been perceived by patients with different cultural backgrounds.

It is important to note that many gynecologic and breast cancer patients identify as non-binary and/or part of the LGBTQ community. It is a disservice to these patients to not have a screening tool that is inclusive of them and their sexual health needs. Generally, the sexual health of same-sex partners has been understudied and overlooked as an important aspect of well-being. The lack of inclusion of this population in sexual health screenings. Three of the screening tools had heterosexual bias and most did not investigate solo-sexual expression or relationships with partners (Table 1). Masturbation is a critical component of female mental and sexual wellbeing. Failing to acknowledge and ask about these practices will lead to even more unrecognized struggles in a patient population that is already dealing with numerous adversities related to their cancer. According to Izyki et al, chemotherapy and radiotherapy can cause loss of libido and negatively affect the capacity to experience pleasure or orgasm. This is a particularly sensitive topic for many patients, so having a tool that can introduce orgasm and self-pleasure into the conversation with a patient would be extremely useful. Only 1 tool, the GLQ, addresses solo-sexual expression. However, it has its own limitations, as described above. This indicates a need for more inclusive and comprehensive screening tools in order to ensure that providers can address their patients’ sexual health concerns to the fullest.

Furthermore, only 5 screening tools addressed sexual health comparisons pre- and post-cancer treatment (Table 1). This indicates that the majority of the screening tools are not applicable to patients who have not undergone treatment. This limits the usefulness of the screening tool posttreatment, because clinicians will not have a good understanding of what their patients’ sexual health baseline was prior to treatment. It also limits further studies on how specific treatment modalities impact sexual health.

An important component of these screening tools is the recall period. Recall period refers to the time frame in which the screening questions are applicable. Many tools have 1 month recall periods, which may narrow how much information clinicians can elicit from their patients (Table 2). For example, a patient may not have been sexually active in the month filling out the questionnaire, but may have experienced sexual health issues prior to that. Four screening tools do not provide any time frame, which may be helpful for clinicians to establish a more comprehensive interpretation of their patients’ sexual health (Table 2). Another issue with recall periods is the potential for recall bias. For example, SABIS contains questions pertaining to sexual health pretreatment despite its recall period being limited to posttreatment.

### Important Logistic Considerations

In order for screening tools to be effective they must be user-friendly. This means that they should be easy to score and be
available in every language. Unfortunately, many of the screening tools evaluated in this study are only available in 1 or 2 languages and have no scoring template available (Table 2). In fact, only the EORTC and FSFI screening tools are available in multiple languages (Table 2). This makes it difficult for physicians to objectively assess their patients’ responses. However, clinicians can still use these tools as a starting point for a conversation about sexual health issues with their patients. The time it takes to complete a screening tool is also an important consideration. Tools such as the SABIS-G and GLQ, may take the least amount of time to complete, but it is important to balance this factor with the comprehensibility. It may be more beneficial to use a tool that may take slightly longer to complete, but will provide the practitioner with more information. The time for completion for all tools is listed in Table 2. There is considerable variability in how the responses to the screening tool questions are scored, with 7 tools requiring complex calculations, linear transformations, and statistical analysis (Table 2). One of the advantages of using screening tools is to have a way to screen patients’ health concerns thoroughly, but efficiently. A complicated and time-consuming scoring template will hinder how effective the screening tools are for both clinicians and patients to discuss important health issues.

It may also be possible to group screening tools together to receive the most comprehensive assessment of a patient’s sexual health and function. For example, it may be useful to administer the SexSAT-Q alongside the GLQ in order to assess self-pleasure, which is lacking in the SexSAT-Q, and to differentiate between level of sexual activity and level of sexual desire, which is lacking in the GLQ.

The SAQ is unique in that it provides a space for the patient to provide further comments they wish to disclose to the patients, however, it does not directly ask questions about orgasm or vaginal problems. The SAQ may be combined with the SVQ, which does cover these important aspects of sexual health, but does not provide an opportunity for patients to write in comments.

The FSFI, which does not distinguish between sexual desire and physical ability, may be combined with the EORTC QLQ CX-24 or EN-24, which addresses body image, while the FSFI does not. Ideally, the use of 1 tool would be sufficient; however, combining tools may provide a temporary solution to assessing sexual health while a new comprehensive screening tool may be developed.

Additional Tools to Consider

This review was specifically meant to focus on the tools that were designed for and validated in breast and gynecologic cancer patients. Thus, in order to meet the inclusion criteria, certain useful tools had to be excluded from the overall analysis. However, some are worth mentioning because of their strength in assessing various aspects of sexual health, as the goal of this paper is to provide clinicians with the most effective and comprehensive methods specific to their patients. The following section pertains to tools that were outside of the eligibility criteria defined in this review. These tools may be particularly useful, especially when combined with other tools mentioned previously, to ensure a holistic view of a person’s sexual and mental wellbeing Appendix 3 contains internet links to access additional tools that were excluded.

The NIH Patient-Reported Outcomes Measurement Information System Sexual Function and Satisfaction (PROMIS SexFS) was specifically validated in general population of cancer patients, which included both males and females. Because the validation study was not specific to breast or gynecologic cancer patients, it was excluded from the above analysis. Though originally validated in this patient population, a more recent initial validation study pertains to a newer, improved version of the questionnaire (PROMIS SexFS v2.0) that is applicable to a more broad and diverse population, including individuals with diabetes, heart disease, anxiety, depression, or specific sexual problems unrelated to cancer. The tool also seeks to include lesbian, gay, and bisexual populations, making it particularly useful. The scored domains it addresses included interest in sexual activity, lubrication, vaginal discomfort, clitoral discomfort, labial discomfort, erectile function, orgasm ability, orgasm pleasure, oral dryness, oral discomfort, and satisfaction.

The Arizona Sexual Experience Scale (ASEX) is a 5-item tool that was originally validated in females with sexual dysfunction disorder, but it has also been used to evaluate breast cancer patients. This tool has been reviewed extensively and deemed a particularly strong resource for assessing sexual health in a variety of clinical settings, including patients with substance abuse disorders, hepatitis, IBS, renal disease, dermatological conditions, laryngeal cancer, Parkinson’s disease, and patients on antidepressants. It is also easy to score compared to some of the other tools, with individual items summed to reach a total score. The tool is easily accessed online, and it addresses common sexual experiences in both men and women such as sex drive, arousal, lubrication, and ability to reach orgasm, as well as personal satisfaction with orgasms. However, ASEX does not have any items that address pain, and also does not ask about sexual distress. Although the ASEX has been validated in the general population as well as in psychiatric populations, it has not been validated in any breast or gynecologic cancer patient populations and thus could not be included in this review.

The Female Sexual Distress Scale (FSDS) is another tool that is meant to assess female sexual health in those with female sexual dysfunction. This scale did not fit our inclusion criteria as it is not developed specifically for cancer patients, however it may be useful for practitioners to consider using scales such as these in conjunction with other tools specific to cancer patient populations. The FSDS does not specifically address lubrication or other physiological issues as some of the more cancer-specific tools, but unlike many aforementioned tools, it takes care to
evaluate the mental toll that sexual dysfunction can take on a person by focusing on various feelings including stress, anger, embarrassment, inadequacy, worry, and guilt. By combining these more psychologically oriented tools with the cancer tools presented in this review, clinicians can more comprehensively address the sexual and mental wellbeing of their patients, as these 2 entities are strongly interrelated.32

The Brief Sexual Symptom Checklist for Women (BSSC) is a 4-item questionnaire developed by the International Consultation in Sexual Medicine and.33 While not designed specifically for patients undergoing cancer treatment, this tool may be useful in identifying particular concerns of sexual functioning (ie, dryness vs pain during sex). It also asks about the inability to achieve orgasm, and includes an item where patients can write in their own specific concern(s). It is a very short tool and is less comprehensive than some of the other questionnaires as a result. For example, it fails to ask about the psychological components of sexual health, such as distress or feelings of embarrassment. There are also no validation studies available for this tool.

In addition to the tools assessed in this study, the EORTC has developed other questionnaires that may have met the inclusion criteria, but had not been validated at the time of publication. These tools include the QLQ-OV28 for ovarian cancer, the QLQ-BR45 for breast cancer, the QLQ-VU34 for vulvar cancer, the QLQ-SHQ for sexual health, and the MBC for metastatic breast cancer. These tools are currently in various stages of development, but certainly will have applicability for use in this patient population. One of the advantages of the EORTC questionnaires is that they tailor the items to possible symptoms and side effects of specific cancers. This in turn may help highlight more nuanced sexual health experiences in these patient populations.

Further research must be done on these tools in order to identify whether or not they are fit to use as a singular assessment method for sexual health in female cancer patients. However, there are opportunities for practitioners to use these in conjunction with other, more appropriately validated questionnaires specific to breast and/or gynecological cancer patients. For the complete list of tools that were excluded from the study, please refer to Appendix 2.

Recommendations for Practitioners

In summation, there are many aspects to consider when choosing a sexual health screening tool. Not all tools are created equal and it is important to note that this is not an exhaustive list of available tools. Despite the Female Sexual Function Index (FSFI) being widely used, The Information on Sexual Health: Your Needs after Cancer (InSYNC), stands out as one of the better options due to its comprehensive and inclusive questions (ie, it is one of the few tools that does not have heterosexual bias) as well as its user-friendly scoring format. Consequently, the InSYNC would also be recommended as the best tool for use with patients in same sex relationships, due to its lack of gender-specific terminology. The GLQ is the best available tool for use with solo sexual individuals, as it is the only tool to ask about masturbation.

However, all of the tools have significant need for improvement. For example, all of the tools need to address support systems. Sexual health is dependent on psychosocial determinants of well-being, including emotional and interpersonal support systems.22

Another important consideration is the inclusion of cancer-specific questions since treatments for breast cancer may cause different sexual health concerns (ie, body image issues post-mastectomy) in comparison to gynecologic cancer treatments (ie, menopausal effects post-hysterectomy). Additionally, treatment-specific questions will further elucidate concerns about specific side effects, such as chemotherapy induced hair loss vs radiation induced vaginal stenosis. Other areas of improvement include removing heterosexual bias and leading questions, improving ease of scoring, diversifying the patient population in validation studies (ie, the inclusion of transgender females), and making the tool available in all languages.

CONCLUSIONS

There are many considerations when choosing the appropriate tool for use with a particular patient, including that patient’s preferences. A recent study found that preferences for receiving sexual health information vary by age,1 with 70% of patients preferring the topic of sexual health was raised by the medical team as opposed to having to raise it themselves. Assessment of sexual well-being is essential in providing comprehensive care for breast and gynecologic cancer patients, however, there is much room for improvement in this field. An ideal screening tool should identify a patient’s physical, emotional, and interpersonal concerns pertaining to sexual health, ranging from intercourse and self-pleasure to support systems and self-esteem. It should be applicable to patients of all sexual orientations and ask about all possible symptoms of cancer treatment related to sexual health. Furthermore, it should help clinicians facilitate conversations with their patients about sexual health concerns.

Widespread use of a comprehensive sexual health screening tool would substantially improve the quality of life for gynecologic and breast cancer survivors.

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**APPENDIX 1: QUESTIONNAIRES**

1. Female Sexual Function Index (FSFI)
   a. Link to assessment tool: https://www.fsi questionnaire.com/FSFI%20questionnaire2000.pdf

2. European Organization for Research and Treatment of Cancer Quality of Life Questionnaires; Cervical Cancer (EORTC QLQ CX-24)
   a. Link to assessment tool: https://www.eortc.be/qol/CX24/CX24%20English.pdf

3. European Organization for Research and Treatment of Cancer Quality of Life Questionnaires; Endometrial Cancer (EORTC QLQ EN-24)
   a. Link to assessment tool: https://www.eortc.be/qol/EN24/EN24%20English.pdf

4. Sexual Adjustment and Body Image Scale (SABIS)
   a. Access via Reference 5

5. Sexual Adjustment and Body Image Scale- Gynecologic Cancer (SABIS-G)
   a. Access via Reference 9

6. Sexual Function and Vaginal Changes Questionnaire (SVQ)
   a. Access via Reference 16

7. Gynaeologic Leiden Questionnaire (GLQ)
   a. Access via Reference 20

8. Information on Sexual Health: Your Needs after Cancer (InSYNC)
   a. Access via Reference 4

9. Sexual Satisfaction Questionnaire
   a. Access via Reference 12

10. Sexual Activity Questionnaire (SAQ)
    a. Access via reference 27

**APPENDIX 2: TABLE OF EXCLUDED TOOLS**

| Assessment Tool | Reason for exclusion |
|-----------------|----------------------|
| Arizona Sexual Experience Scale (ASEX) | Not validated specifically in breast and/or gynecologic patients |
| Brief Sexual Symptom Checklist for Women (BSSC) | Not validated specifically in breast and/or gynecologic patients |
| Cancer Rehabilitation Evaluation System - Short Form (CARES-Short Form) | Not validated specifically in breast and/or gynecologic patients |
| European Organisation for Research and Treatment of Cancer - Breast Cancer (EORTC QLQ-BR45) | Not validated at time of publication |
| European Organisation for Research and Treatment of Cancer - Metastatic Breast Cancer (EORTC MBC) | Not validated at time of publication |
| European Organisation for Research and Treatment of Cancer - Ovarian Cancer (EORTC QLQ-OV28) | Not validated at time of publication |
| European Organisation for Research and Treatment of Cancer - Vulvar Cancer (EORTC QLQ-VUL) | Not validated at time of publication |
| Female Sexual Distress Scale (FSDS) | Not validated specifically in breast and/or gynecologic patients |
| Patient Reported Outcomes Measurement Information System (PROMIS) | Not validated specifically in breast and/or gynecologic patients |
| The Functional Assessment of Chronic Illness Therapy (FACIT) | Not validated specifically in breast and/or gynecologic patients |

**APPENDIX 3: ACCESS TO EXCLUDED TOOLS**

1. Arizona Sexual Experience Scale (ASEX)
   a. Link to assessment tool: https://www.mirecc.va.gov/visn22/Aizona_Sexual_Experience_Scale.pdf

2. Brief Sexual Symptom Checklist for Women (BSSC)
   a. Link to assessment tool: https://balancewomenshealth.com/wp-content/uploads/2020/03/Brief-Sexual-Symptom-Checklist.pdf

3. Cancer Rehabilitation Evaluation System - Short Form (CARES-Short Form)
   a. Link to assessment tool: https://cancer.ucla.edu/home/showdocument?id=723

4. European Organization for Research and Treatment of Cancer - Breast Cancer (EORTC QLQ-BR45)
   a. Link to assessment tool: https://www.eortc.org/app/uploads/sites/2/2018/08/Specimen-BR45-English.pdf

5. European Organization for research and Treatment of Cancer - Metastatic Breast Cancer (EORTC MBC)
   a. Access upon request via EORTC website: https://www.eortc.org

6. European Organization for Research and Treatment of Cancer - Ovarian Cancer (EORTC QLQ-OV28)
a. Link to assessment tool: https://www.eortc.org/app/uploads/sites/2/2018/08/Specimen-OV28-English.pdf

7. European Organization for Research and Treatment of Cancer - Sexual Health Questionnaire (EORTC QLQ-SHQ-22)
   a. Link to assessment tool: https://www.eortc.org/app/uploads/sites/2/2018/08/Specimen-SHQ-C22-English.pdf

8. European Organization for Research and Treatment of Cancer - Vulvar Cancer (EORTC QLQ-VU34)
   a. Link to assessment tool: https://www.eortc.org/app/uploads/sites/2/2018/08/Specimen-VU34-English.pdf

9. Female Sexual Distress Scale (FSDS)
   a. Access via Reference 6

10. Patient Reported Outcomes Measurement Information System (PROMIS)
    a. Access via Reference 31

11. The Functional Assessment of Chronic Illness Therapy (FACIT)
    a. Access via FACIT Tool Library: https://wizard.facit.org/